



LEND Brief

ASD and Culture • Spring 2015

Introduction

Amy Hewitt*, PhD, Anab Gulaid, MPA

There is a growing body of research in the United States that identifies differences between children from diverse cultural, ethnic and linguistic backgrounds who have neurodevelopmental disabilities regarding estimated prevalence, access to early identification, assessment and diagnosis as well as access to various forms of intervention and treatment. The MN LEND program trains practitioners, researchers and advocates about how to identify and implement strategies to reduce health disparities as well as to provide culturally and linguistically competent services and supports to individuals and families. Being culturally and linguistically competent is a process that evolves over time for both individual practitioners and the organizations in which they work. It requires individuals and organizations to purposefully have: values and principles, attitudes,

actions and practices that encourage and promote working cross-culturally (Cross, Bazron, Dennis and Isaacs, 1989).

This edition of *LEND Brief* provides information about how diverse communities view, understand and experience Autism Spectrum Disorders (ASD) and other neurodevelopmental disabilities (NDD). It showcases projects and programs that recognize dimensions of culture, socio-economics, and language through the services and supports they deliver to children with neurodevelopmental disabilities and families. Articles covered in this issue are varied and include information on a range of topics, from a variety of states (and the country of Zambia) as well as a variety of perspectives related to culture and the delivery of intervention programs within culturally and linguistically diverse communities.

Many of the articles are written by or have involved LEND trainees in program development, implementation or evaluation (indicated by an “*” following their name).

In this issue, **Bronheim** discusses the role of culture in the provision of services for children with ASD and their families. In particular, the article focuses on how culture informs a family's expectations of a typical child development; perceptions about the causes of disability, choices about diagnosis and about options for family social support. It also offers suggestions on culturally competent supports and services.

Esler, Hall-Lande* and Stronach examine current ASD diagnostic assessment processes and the importance of considering the culture of a child and family when making diagnoses. Cultural factors that might account for the discrepancy

MN LEND Program | Leadership Education in Neurodevelopmental & Related Disabilities

in prevalence across racial, ethnic, and socioeconomic groups both in the US and across the world are discussed.

Watkins and Tapias-Heinrich provide an article on the important role played by skilled and trained interpreters in strengthening communication between providers and families. This article describes interpreter certification and training processes and includes helpful strategies designed to improve the outcome of services and supports to culturally and linguistically diverse populations. In their article, **Owens, Hess and Fisher** provide an overview of a program that exemplifies the power of collaborative approach in working together across multiple organizations and agencies to better support individuals with ASD across the lifespan.

McAlpine, Egal*, Pergament, Novillo and Yang share the findings of their recent study that utilized community-based participatory research (CBPR) to document key barriers to early identification and access to early intervention services for children with autism spectrum disorder in the Latino, Hmong and Somali Communities in Minnesota. They include policy recommendations for improvement. **Hamre* and Gulaid** share the results of the Minneapolis Somali autism spectrum disorder prevalence project.

Haworth* shares her article, *Family Perspectives: Experiences of a LEND Family Trainee*, which describes a parent's perspective on the journey of a mother of a child with ASD from enrolling in the Virginia LEND program to becoming a faculty member of the program at Virginia Commonwealth University.

These issues are not unique to the United States. The growing presence of ASD in Zambia, Africa and the current challenges facing Zambian families, advocates, and educators



of children with ASD is explored in the article by **Mukongolwa and Nye-Lengerman**.

Ovalle and Davila* describe innovative and culturally responsive programs that support Chicago's Latino children with ASD and their families. These programs include advocacy, support, recreational and community engagement opportunities and skill development. **Fagen and Berdahl** describe how they developed an early intervention program designed specifically for cultural diverse communities in Minneapolis, MN.

In addition to a rich set of articles, this issue also includes numerous resources (e.g. materials, websites, articles) and suggestions for improving services to be responsive across cultures.

Conclusion

The MN LEND program hopes that you enjoy this issue of *MN LEND Brief*. Each article represents the opinion of the author and does not necessarily reflect the position of the MN LEND program. To ensure broad

representation of the issue in this edition of *MN LEND Brief* authors from various perspectives and disciplines were sought to highlight the breadth of the topic.

Learn more about our program and follow our activities on our website lend.umn.edu. Watch for future issues of the *MN LEND Brief* that might be of interest to you. The Summer 2015 issue will be on transition to adult life. If you have any comments regarding this publication please direct them to Rebecca Dosch Brown at dosch018@umn.edu.

Considering culture in autism spectrum disorders

Suzanne M. Bronheim, PhD

Introduction

Having an understanding of the cultural values, beliefs, and practices related to disability is essential for professionals and agencies/organizations that provide services and supports for individuals with autism spectrum disorders (ASD) and their families. The importance of culture should be emphasized in addressing the needs of children. There is not yet a consensus on the causes of ASD or on how best to treat it. Families may feel a need to fill this vacuum. Many families may create their theories of causation and treatment based, in part, on their own cultural beliefs and values. Thus, practitioners need to be prepared to partner with families who bring a range of cultural beliefs, including those who embrace medical explanations, follow social media theories about ASD, embrace New Age beliefs, or rely on beliefs rooted in their own religion, ethnicity or national origin to inform their understanding of ASD.

There are culturally-defined beliefs about disability, ASD, and its treatment that span many racial, ethnic, and cultural groups. It is important to take into consideration that not every member of a particular cultural group shares or acts on the normative beliefs and values of that group. Thus, in order to discourage stereotyping of the views of any particular cultural group, this article will discuss the array of cultural beliefs and values related to ASD.

Several reviews suggest a range of issues that should be considered when addressing culture in the provision of services for children with ASD and their families. An understanding of how culture informs each of the following is important (Bernier, Mao, & Yen, 2010; Mandell & Novak,



2005; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004) —

- Family expectations of typical child development;
- General beliefs about disability causes, including ASD;
- Choices about diagnosis and intervention for ASD; and
- Social support for families of children with ASD.

This article will address each of these issues and offer suggestions for professionals and programs on the provision of culturally competent care, services, and supports to children with ASD and their families.

Family expectations of typical child development

There are a range of cultural views related to the concepts of typical vs. atypical child development. While in Western culture there is a delineation between “typical” and “pathological” that is applied to behaviors and abilities, that is not the case in all cultures. For some, behavior and ability

are seen on a spectrum. Each child is a valued member of the community and their functional abilities are appreciated (McCubbin, McCubbin, Thompson, & Thompson, 1998; Connors & Donnellan, 1998). Rather than using labels that designate a diagnosis, descriptive statements about an individual child’s behaviors are used. As a result, families whose culture embraces this continuum world view may not be motivated to seek early diagnosis and intervention or may even resist such efforts because they do not perceive a problem or disorder (Glascoe & Dworkin, 1993; Glascoe F. 1997; Lau, Garland, Yeh, McCabe, Wood, & Hough, 2004).

Seeking diagnosis and treatment for ASD may also be impacted by cultural expectations for young children. For example, in cultures where direct eye contact with elders and authority figures is considered a sign of disrespect, lack of eye contact in interactions might not raise concerns (Sue & Sue, 2008; Lian, 1996). Similarly, families in cultures where children who are quiet and keep to them-

selves are seen as “good” children or those that believe that boys in their culture speak late may not seek or even accept evaluation for ASD (Daley & Sigman, 2002). The type of atypical behavior that may motivate families to seek help can also be impacted by cultural beliefs. In cultures that value social interaction and conformity, it may be those aspects of ASD that create concern, while in other cultures it is delays in language that are first noted (Mandell, Zubritsky, Novak, 2004; Coonrod & Stone, 2004; Daley & Sigman, 2002). Finally, culturally-based attributions about atypical behavior can impact whether or where families seek help. In some circumstances atypical behavior may be attributed to a health condition in Western culture, but in other cultural perspectives it may be attributed to other factors such as willfulness (Mandell, Listerud, Levy, & Pinto-Martin, 2002).

Beliefs about the causes of ASD

Literature highlights two types of explanations for ASD across cultural groups—physical or naturalistic causes and metaphysical or spiritual and religious causes (Shaked & Bilu, 2006). Within Western medicine, the search for causes of ASD has a physical focus and seeks that knowledge through a scientific method in which evidence from carefully designed studies provides authority. For many families, who also believe in a physical cause for ASD, there are different sources for authority, including testimonials from other families or those who promote quasi-scientific theories that validate a family’s lived experience. Thus, while the causes are seen as physically based, such as vaccines, the culturally-based sources of authority are actually different from those of Western science. Additionally, theories of environmental causes for ASD such as early life experiences or inadequate socializing or learning

experiences are within the naturalistic realm.

Across a range of cultures, ASD may be attributed to metaphysical causes. In some cases the causes are seen as negative, such as punishment for previous family wrongdoing, or sin, punishment for mother’s neglect of the child, ghosts, a curse, or evil eye cast by others in the community (Shaked & Bilu, 2006; Rogers-Adkinson, Ochoa, & Delgado, 2003; Groce, & Zola, 1993; Kleinman, 1986; Hwang, & Charnley, 2010; Grinker, 2007). As a result, ASD may be seen by some families as a stigma and source of shame for the family.

In other cultures the metaphysical source of ASD is seen as a positive. For example, a child with ASD is viewed as having been sent with a message for the community to unravel and Western medical treatment is seen as interfering with the transmission of that lesson (Medina, Jones, & Miller, 1998). In some religions there is a belief that God causes ASD and that the individual with ASD has a special pure soul and that soul may even have come back to carry out an important religious mission (Shaked & Bilu, 2006; Jegatheesan, Miller, & Fowler, 2010). In cultures with these positive views, the individual with ASD actually may have an elevated social standing and the family is seen as having a sacred role in the child’s care.

Choices about diagnosis and intervention for ASD

A family’s cultural beliefs about the causes of ASD may naturally affect if and how they seek diagnosis and intervention. The field’s current emphasis on early screening and diagnosis may be at odds with some cultural perspectives. Beliefs that create a negative reaction to screening may include: talking about bad things can make them happen; not knowing about a problem makes it more likely that God will intervene than knowing

about it and praying for intervention; screening is a way for the government or medical system to take control over private and family matters; or since the child’s ASD is God’s will, it is not in the power of humans to predict the outcomes (Abrums, 2000; Streefland, 2001; Gross, & Shuval, 2008). In addition, in cultures where there is stigma attached to having a child with a disability, a family may avoid diagnosis of ASD out of fear of discrimination toward their child and their family.

Family cultural beliefs about the causes of ASD can also inform the types of intervention sought. Families who believe that vaccines are the cause may seek chelation therapies or those who see ASD as a sensory-based disorder may seek auditory integration therapy. If there is a cultural belief about a physical basis for ASD that is rooted in a non-Western system of understanding disease, such as imbalance of factors like hot and cold, families may seek intervention from traditional healers (Ortiz, Shields, Clauson, & Clay, 2007).

For families who hold to metaphysical explanations, spiritual healers and religious leaders may be sought. Technology based interventions may also be used in response to metaphysical explanations, such as the use of facilitated communication as a way for children with ASD to impart special messages from the divine realm (Shaked & Bilu, 2006). These things may seem appealing to families with metaphysical beliefs. Finally, there may be a belief that since ASD is God’s will, the disability just needs to be accepted and there is no reason to attempt intervention (Mirza, Tareen, Davidson, & Rahman, 2009).

The goal of intervention may also be defined by cultural beliefs and values. Where cultural beliefs place high value on individualism and independence, families may seek interventions that focus on skills and

behaviors that support autonomy such as self-help skills, independent thinking (Bernier, Mao, & Yen, 2010) and ultimately independent living. Where culture values a collectivist orientation the preferred focus of intervention may be on social integration, politeness, and obeying authorities (Rodriguez, & Olswang, 2003).

Social support for families of children with ASD

Cultural beliefs about the causes of ASD and the role of people with disability in the community impact the types and levels of social support families receive. When cultural norms require conformity and allow for little acceptance of individual differences, families may worry they will be blamed and ostracized due to their ASD. This can result in families keeping their child with ASD at home and limiting overall family engagement in the community. Even siblings may avoid talking about their sibling with ASD to prevent negative community reactions (Hwang, & Charnley, 2010).

On the other hand, cultures with strong beliefs about a collective responsibility for all members of the family, clan, or extended family bring the possibility of many hands to support the nuclear family in meeting the needs of a child with ASD (McCubbin, McCubbin, Thompson, & Thompson, 1998; Pruchno, Patrick, & Burant, 1997). Families from these collectivist cultures are thus more likely to seek support from networks of family and friends than to reach out to professionals or people beyond those in their close circles (Dyches et al., 2004).

In contrast, families from more individualistic Western cultures, have been reported to be more likely to rank other parents of a child with ASD as their source of support over other family members (Mackintosh, Goin-Kochel, & Myers, 2006). Thus, while all families need support in raising their children with ASD,

cultural factors strongly influence how and from whom they prefer to receive that support.

Ensuring cultural and linguistic competence: Implications for professionals and programs

For professionals

Culturally and linguistically competent professionals serving children with ASD and their families should be able to acknowledge cultural differences, understand their own cultures, engage in self-assessment related to cultural and linguistic competence and acquire cultural knowledge and these skills. These factors can play out within the provision of services as described below.

Screening

The concepts of screening and early intervention are culturally-bound. Culturally and linguistically competent professionals and programs address cross-cultural and language differences when presenting screenings to families. Professionals need to acquire knowledge about cultural expectations, norms and world views of families they serve to inform the screening process. They will also need to be attuned to their cultural perspectives on screening and early intervention and the culturally based values and beliefs that are implicit in screening tools and processes.

Effective screening involves accurate communication among the screener, the child and family, or other adult informants. The appropriate use of trained interpreters and translation of information relating to results and recommendations is vital for families who need or prefer those services.

A significant challenge in screening is identifying and using ASD

screening tools that: 1) have been normed on the cultural population of the child being screened; 2) are available in the preferred language of the informants through a quality translator; and 3) have included cultural adaptations to make them relevant (Gokiert, Chow, Parsa, Rajani, Bisanz, Vandenberghe, & Chui, 2010).

Identifying culturally and linguistically appropriate screening tools for ASD is challenging. Soto et al. (2014) reviewed translated tools and found that differences between the psychometric properties of the original and adapted versions were common and that not all translations adhered to the rigor of addressing cultural adaptations in the process. *Considering Culture in Autism Screening* from Massachusetts Act Early Coalition is a useful resource for professionals who are interested in screening across cultures (MA Act Early Coalition, 2014).

Creating family-professional partnerships that acknowledge and respect culture

A key to successfully partnering with families of children with ASD requires a thorough understanding of their culturally-based perspectives on ASD. This is true of each family as human behavior is informed by culture and is not limited to those who represent a different racial, ethnic, or immigration status. Recognizing cultural differences and examining one's own culture are part of cultural competence. The family-professional partnership provides the opportunity to engage in explicit discussion of culture and how it will inform the joint decisions about assessment, diagnosis, and intervention. Such discussions can help the professional recognize his or her own cultural beliefs (including the beliefs that come from Western medicine), if the professional is open to respectfully learning from the family and avoids dispelling their beliefs and cultural

frameworks as myths or superstitions. Levy et al. (2003) suggested a set of questions adapted from Kleinman (1980) to open these discussions including —

- What did you call your child's problem before it was diagnosed?
- What do you think caused it?
- Why do you think it started when it did?
- What do you think autism does? How does it work?
- How severe is it? Will it have a short or long course?
- What are the chief problems your child's autism has caused?
- What do you fear most about it?
- What kind of treatment do you think your child should receive?
- What do you expect from this treatment?

This conversation is not a one-time event. The issues addressed in these questions comprise an ongoing part of the partnership. Over time families may adopt more beliefs and values reflective of Western medicine as they interface with professionals and providers from that world. These shifts in beliefs and perspectives may put families at odds with their extended families and communities who may not have made the shift in perspective. Supporting families to deal with those potential conflicts is an important role for professionals and family-support providers.

In addition, professionals who partner with families will need to have knowledge of Complementary and Alternative Medicine (CAM) and an openness to discussing it respectfully with families. *The American Academy of Pediatrics* (AAP) provides extensive guidance on this issue in its 2008 report on the use of complementary and alternative medicine in pediatrics (Kempton Vohra, & Walls, 2008). AAP recommends developing a knowledge of CAM used by patients and approaches to respectful communication about the

topic (Kempton et al., 2008). Such respectful communication requires professionals to identify and acknowledge the cultural perspectives that inform Western medicine.

Self-assessment and acquisition of cultural knowledge

Culturally and linguistically competent professionals take opportunities for self-assessment. This can be done through the use of checklists for self-reflection, completion of questionnaires, and participation in reflective peer supervision and feedback from families and through formalized service evaluation processes. Continuing to learn about culture, its impact on provision of services and ways to adapt practice is important. This learning may occur in informal ways such as peer sharing, engaging in communities served, or reading academic or popular literature that addresses culture. Formal learning is also an important approach and many states have incorporated requirements for continuing professional education on cultural and linguistic competence into relicensing procedures.

For programs and organizations

Policy, structures and resources to support culturally and linguistically competent practice

It is difficult for individual professionals to provide culturally and linguistically competent services without organizational support. This support includes policies, structures and resources to assure quality language support services as required by the *Title VI of the Civil Rights Act of 1964* and described in the *The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care* and addressing communication needs of family members with disabilities. This includes sign language

interpretation, large print or Braille materials and adapting communication to address the needs of those with intellectual disabilities; training, mentoring and sharing of cultural knowledge among staff of the organization. Finally, engaging families and members of communities served in planning, implementing and evaluating services and supports provided by the organization and to serve as knowledge resources to professionals will support the development of culturally and linguistically competent services.

Adapting service delivery

Given the array of cultural beliefs about stigma, family preference related to support, desired intervention outcomes, and expectations for the future functioning of a child with ASD, programs and services offered will need to be adapted to fit the needs of all families. For example, while support groups with families of children with ASD may be a common practice, this model may not work for families who prefer natural networks of support within their communities. Models that increase the capacity of those networks to support the family may be more appropriate. In addition, for families who may choose to work with traditional healers or spiritual or religious leaders, it is important for programs to be knowledgeable about those resources and establish partnerships with them to create an integrated approach to intervention and support.

Suzanne M. Bronheim, PhD, is Associate Professor in the Department of Pediatrics and a senior policy analyst within the Center for Child Health and Mental Health Policy of the Georgetown University Center for Child and Human Development. Dr. Bronheim provides training and technical assistance to state Title V programs, health and mental health care systems, non-profit organizations, health care providers, family advocacy, and support organizations. She has written and produced effective products for the field about the role

of cultural and linguistic competence in infant mortality disparities, approaches to implementing cultural and linguistic competence in health promotion, and providing culturally and linguistically competent services and supports to families.

References

- Abrams, M. (2000). Jesus will fix it after a while: meanings and health. *Social Science and Medicine*, 50(1), 89–115.
- Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: Autism. *Child and adolescent psychiatric clinics of North America*, 19(4), 855–867.
- Connors, J.L., Donnellan, A.M., (1998). Walk in beauty: Western perspectives on disability and Navajo family/cultural resilience. In H.I. McCubbin, E.A. Thompson, A.I. Thompson, & J.E. Fromer (Eds.), *Resiliency in Native American and immigrant families*, (p. 159). Thousand Oaks, CA: Sage Publications, Inc.
- Coonrod, E.E., & Stone, W.L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children*, 17(3), 258–268.
- Daley, T.C., & Sigman, M.D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32(1), 12–23.
- Dyches, T.T., Wilder, L.K., Sudweeks, R.R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34(2), 211–222.
- Glascoe F., (1997). Parent's concerns about children's development: Prescreening technique or screening test? *Pediatrics*, 99(4), 522–528.
- Glascoe, F.P. and Dworkin P.H. (1993). Obstacles to effective developmental surveillance: errors in clinical reasoning. *Journal of Developmental & Behavioral Pediatrics*, 14(5), 344–349.
- Gokiart, R.J., Chow, W., Parsa, B., Rajani, N., Bisanz, J., Vandenbergh, C., & Chui, Y. (2010). *Early childhood screening in immigrant and refugee populations*. Edmonton, Alberta, Canada: Community-University Partnership for the Study of Children, Youth, and Families.
- Goode, T.D., Harris-Haywood, S.H., Wells, N., and Rhee, K. (2009). Family-centered, culturally, and linguistically competent care: Essential components of the medical home. *Pediatric Annals*, 38(9), 505–512.
- Grinker, R.R. (2007). *Unstrange minds: Remapping the world of autism*. Philadelphia, PA: Basic Books.
- Groce, N.E., & Zola, I. K. (1993). Multiculturalism, chronic illness, and disability. *Pediatrics*, 91(5), 1048–1055.
- Gross, S.E., & Shuval, J.T. (2008). On knowing and believing: prenatal genetic screening and resistance to 'risk-medicine'. *Health, Risk & Society*, 10(6), 549–564.
- Hwang, S.K., & Charnley, H. (2010). Making the familiar strange and making the strange familiar: Understanding Korean children's experiences of living with an autistic sibling. *Disability & Society*, 25(5), 579–592.
- Jegatheesan, B., Miller, P. J., & Fowler, S.A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities*, 25(2), 98–109.
- Kemper, K.J., Vohra, S., & Walls, R. (2008). The use of complementary and alternative medicine in pediatrics. *Pediatrics*, 122(6), 1374–1386. <http://pediatrics.aappublications.org/content/122/6/1374.full.pdf+html>
- Kleinman A. (1980). *Patients and healers in the context of culture*. Berkeley, CA: University of California Press.
- Kleinman, A. (1986). Concepts and a model of the comparison of medical systems as cultural systems. In C. Curren & M. Stacey (Eds.), *Concepts of health, illness and disease: A comparative perspective*, (pp. 27–47). Leamington Spa, UK: Berg.
- Lau, A.S., Garland, A.F., Yeh, M., McCabe, K.M., Wood, P.A., & Hough, R.L. (2004). Race/ethnicity and inter-informant agreement in assessing adolescent psychopathology. *Journal of Emotional and Behavioral Disorders*, 12(3), 145–156.
- Levy, S.E., Mandell, D.S., Merhar, S., Ittenbach, R.F., & Pinto-Martin, J.A. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental & Behavioral Pediatrics*, 24(6), 418–423.
- Lian, M-G.J. (1996). Teaching Asian American children. In: E. Durán (Ed.), *Teaching students with moderate/severe disabilities, including autism: Strategies for second language learners in inclusive settings*, (2nd ed., p. 239). Springfield, IL: Charles C Thomas.
- Massachusetts Act Early (2014). Considering culture in Autism screening kit. Retrieved from <http://www.maactearly.org/considering-culture-screening-kit.html>
- Mackintosh, V.H., Goin-Kochel, R.P., & Myers, B.J. (2006). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, 12(1), 41–51.
- Mandell, D.S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110–115.
- Mandell, D., Zubritsky, C., Novak, M. (2004). *A services research perspective on autism*. Paper presented at the American Public Health Association 132nd Annual Meeting and Exposition, Washington, DC.
- Mandell, D.S., Listerud, J., Levy, S.E., & Pinto-Martin, J.A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(12), 1447–1453.
- McCubbin, H.I., McCubbin, M.A., Thompson, A.I., & Thompson, E. A. (1998). Resiliency in ethnic families: A conceptual model for predicting family adjustment and adaptation. In H.I. McCubbin, E.A. Thompson, A.I. Thompson, & J.E. Fromer (Eds.), *Resiliency in Native American and immigrant families*. Thousand Oaks, CA: Sage Publications, Inc.
- Medina, C., Jones, D., & Miller, S. (1998). Traditional versus contemporary Navajo views of special education. In *Coming together: Preparing for rural special education in the 21st century*, (pp. 179–185). Conference proceedings of the American council of rural special education, Charleston, SC.
- Mirza, I., Tareen, A., Davidson, L. & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: A mixed methods study. *Journal of Intellectual Disability Research*, 53(6), 559–570.
- Ortiz, B.I., Shields, K.M., Clauson, K.A., & Clay, P.G. (2007). Complementary and alternative medicine use among Hispanics in the United States. *Annals of Pharmacotherapy*, 41(6), 994–1004.
- Pruchno, R., Patrick, J.H., & Burant, C.J. (1997). African American and White mothers of adults with chronic disabilities: Caregiving burden and satisfaction. *Family Relations*, 46(4), 335–346.
- Rodriguez, B.L., & Olswang, L.B. (2003). Mexican-American and Anglo-American mothers' beliefs and values about child rearing, education, and language impairment. *American Journal of Speech-Language Pathology*, 12(4), 452–462.
- Rogers-Adkinson, D.L., Ochoa, T.A., & Delgado, B. (2003). Developing cross-cultural competence: Serving families of children with significant developmental needs. *Focus on Autism and Other Developmental Disabilities*, 18(1), 4–8.
- Shaked, M., & Bilu, Y. (2006). Grappling with affliction: Autism in the Jewish ultraorthodox community in Israel. *Culture, Medicine and Psychiatry*, 30(1), 1–27.
- Soto, S., Linas, K., Jacobstein, D., Biel, M., Migdal, T., & Anthony, B. J. (2014). A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism*, 1362361314541012.
- Streifel, P.H. (2001). Public doubts about vaccination safety and resistance against vaccination. *Health Policy*, 55(3), 159–172.
- Sue, D.W., & Sue, D. (2008) *Counseling the culturally diverse: Theory and practice* (5th ed.). Hoboken, NJ: John Wiley & Sons, Inc.

Family perspectives: Experiences of a LEND family trainee

Shannon Marie Haworth*, MA

"I am a leader." I remember having to say those words during my first VA LEND Leadership class. I was so uncomfortable, because the word leader was not in my vocabulary. I applied for VA LEND because I lacked confidence, advocacy skills, and knowledge about neurodevelopmental disabilities and children.

I am the parent of a child with ASD, and a co-occurring mental health disorder. I had a very hard time getting a diagnosis for him. When I lived in Nebraska, I noticed when he was about 16 months that his speech did not progress from about 2-3 words. I talked to his pediatrician. I was told it was just a speech delay and that I should go the local elementary school and inquire about speech therapy. After a few months I still didn't feel he was where he needed to be developmentally. The pediatrician never mentioned early intervention, and I knew nothing about it. I took my son to a diagnostic clinic two hours away when he was 22 months for an ASD evaluation. I was again told it was a speech delay.



he is just a little delayed. When I moved to Virginia, the week I got off the plane, I made an appointment for a child development clinic. We received a diagnosis when he was four. I felt it was late, but in actuality it is earlier than most minority children. I was very frustrated with the entire process, and when I finally got the diagnosis I felt that I had nowhere

this there are health disparities, and disparities in the diagnosis and treatment of ASD for culturally diverse families.

My research on disparities

While in the LEND program, I began to learn about cultural competency, interdisciplinary teamwork, and children with neurodevelopmental disabilities. I began researching health disparities in diagnosis and treatment of ASD for minority families. Culture plays a large part in the disparity. Culture is a set of beliefs, customs, values, and actions shared within a community, ethnicity, race, or organization of people. Culture can influence how the family perceives treatment options. Families may base the choice of treatment for a child on the belief of the cause of the diagnosis, and this can vary across cultures. Expectations of the role of the parent and provider may vary across cultures. In some cultures parents do not expect, or may not want to have

I was told to wait and see, and he will be fine, he is just a little delayed.

Finally my sister-in-law told me about early intervention. Why wasn't I told about this service? I called the Early Intervention Agency, and they were quite upset that my pediatrician never told me about them. We had in-home services and therapies. I moved to a larger town, with the same concerns as when he was two. The pediatrician never mentioned the "A" word, nor did he provide a developmental screening. I was told to wait and see, and he will be fine,

to turn. I applied for every program, workshop, anything. I found the VA LEND program, and that is where my true advocacy began.

Many families that are minorities, live in rural areas, or are poor, have very similar experiences to what we had. It is difficult to find culturally competent providers who are trained, non-bias, and able to take into consideration the many cultural and environmental factors that make families different. Because of

a role in the treatment of the child. They may expect therapists, doctors, and schools to be the primary providers of the treatment plan, and therefore lessen their involvement. As a LEND student I created a poster on disparities in ASD diagnosis and treatment for African American families. I presented that poster at several national conferences, and feel that I am giving a voice to families.

LEND clinics

The VA LEND Interdisciplinary clinics address the problem of health disparities, and cultural competency. The interdisciplinary clinics are student led clinics. Our students come from a variety of backgrounds, and disciplines. In the program they are learning how to be culturally competent providers and advocates for families.

Cultural and linguistic competence is “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations” (Office of Minority Health, 2013). It is a skill that has to be taught and embraced by professionals. Cultural competency shines brightly in the VA LEND interdisciplinary clinics!

Our team meets at three different clinic locations during the semester. We often get referrals from providers who have families with children with ASD and other developmental disabilities that are minorities, or linguistically diverse. The clinic has an interdisciplinary team that is comprised of family members, psychologists, pediatricians, social workers, occupational and physical therapists, speech language pathologists, audiologists, as well as special education and behavioral experts. Our clinic is free, and allows families to have a team observe their child, provide recommendations, and provide family resources and supports.

I am certain that a lot of these

families would not be able to have this experience because of transportation issues, cost, and lack of awareness of such services. At our

ties and how to implement cultural competency into their practice, and meet families where they are. All families deserve that level of family

Families may base the choice of treatment for a child on the belief of the cause of the diagnosis, and this can vary across cultures.

clinics we have provided interpreters for our Spanish speaking families, and arranged transportation for others. We also visit the family with the report of recommendations, and can help the family to coordinate with other providers and organizations. I have an extreme sense of pride in the work that we do, and family centered care we provide families in our communities.

Conclusion

After LEND I became a much stronger advocate for my child and other families. I went to graduate school and earned master's degree in applied behavior analysis. Before my family traineeship was over I told the assistant director that if anything ever becomes available, please think of me. This is a special program, an important program, and I wanted to continue to support it. Well, they thought of me. I am now VA LEND faculty, the interdisciplinary clinic coordinator, and an adjunct professor co-teaching interdisciplinary teamwork. I was also hired as the project manager for Virginia's Autism State Implementation Grant awarded by HRSA and MCHB. I am currently pursuing a doctoral degree in public health (DrPH). I have had the privilege of speaking to local agencies, and even medical students about cultural and linguistic competency, and the disparity of diagnosis and treatment for ASD.

The LEND program trains these students and parents which enables them to recognize professional bias and self-correct as needed. They learn about children with disabili-

ties and how to implement cultural competency into their practice, and meet families where they are. All families deserve that level of family

centered care, understanding and support. I often wished I had that level of support from providers who served my son, but now I know how to advocate for it.

My son is now eight years old, very verbal, and high functioning. I have learned how to be his greatest advocate, and to set the bar high for him. He is in a private school for ASD, and on track for a standard or even advanced diploma, and has even been identified as gifted! Culture can be a barrier in receiving a diagnosis and treatment of ASD, but LEND programs and interdisciplinary clinics help to break down those barriers. I now have no problem saying “I am a leader,” and it is my hope that many other families will realize their leadership potential.

References

Office of Minority Health. (2013). *What is cultural competency?* Retrieved from: <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=11>

Shannon Haworth, MA is Senior Project Specialist at the Association of University Centers on Disability (AUCD) and faculty of LEND program at Virginia Commonwealth University where she teaches interdisciplinary teamwork. She is a former trainee of Virginia LEND program. She recently worked at the Partnership for People with Disabilities (UCEDD) as the project manager for the Virginia state ASD implementation grant. Ms. Haworth has a young child with ASD, and has extensive knowledge of ASD and other developmental disabilities, cultural competency, health disparities in minority populations, and children's mental health. In addition to her Masters degree in Applied Behavior Analysis, she has a Post Baccalaureate Graduate Certificate in Disability Leadership, and is completing a doctoral program in Public Health.

Assessment of autism spectrum disorder in children from diverse cultural, ethnic and linguistic backgrounds

Amy N. Esler, PhD, Jennifer Hall-Lande*, PhD, and Sheri T. Stronach, PhD

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by deficits in social interaction and communication and the presence of restricted and repetitive behaviors and interests. ASD is a complex disorder, with significant variability in characteristics across individuals. Although social communication deficits and restricted, repetitive behaviors are its hallmarks; ASD affects all aspects of development and often co-occurs with intellectual disability, speech-language impairment, and behavioral and psychological conditions (e.g., ADHD, anxiety). This difference is one of the reasons that specific causes of ASD remain largely unknown (State & Levitt, 2011). It is well established that genetics play a role (see Geschwind, 2011), and work is underway to identify possible environmental factors that may increase risk for ASD (Shelton et al., 2014). Despite these efforts, there is no reliable biological marker to identify ASD, and diagnoses are determined based on evaluation and analysis of behavior. As such, it is important to consider the culture of the child and family when determining and diagnosing ASD.

A culture consists of social practices, beliefs, values, and behaviors that members of a group use to communicate and interact (see Table 1). Due to the reliance on the behavioral characteristics of ASD—in particular, behaviors of social interaction and communication—the potential for culture to impact ASD diagnosis cannot be underestimated. Yet to date, little research has explored differences in behavioral characteristics across

Table 1. Definitions of race, ethnicity, and culture

Race: Historical classification system based on biological features, e.g. skin color

Ethnicity: A group of individuals who share a common language, heritage, religion, or geography/nationality

Culture: Social practices, beliefs, values, and behaviors that members of a group use to communicate and interact

cultures within the US or from other countries. The focus on identifying biological causes of ASD presumes that its symptoms and course are consistent across cultures (Berry, Poortinga, Segall, & Dasen, 2002). A more nuanced approach accepts the evidence of biological roots of ASD while acknowledging that culture may influence its expression, course, and families' interpretation of its characteristics (Daley 2002; Dyches et al., 2004). Culture can be defined as a dynamic but stable set of goals, beliefs and attitudes shared by a group of people (Matsumoto, 2001). These goals, beliefs, and attitudes influ-

diagnostic measures across cultural groups. Thus, the focus of this article is on cultural influences on assessment and diagnosis of children with ASD, particularly differences related to ethnic/racial background and/or socioeconomic status.

Research on culture and ASD

Leo Kanner (1943) was the first to define autism as a disorder. His original paper on 11 children he identified with autism described a specific culture he believed to be consistent across the families: "There is one other very interesting common

A more nuanced approach accepts the evidence of biological roots of ASD while acknowledging that culture may influence its expression, course, and families' interpretation of its characteristics

ence the type and level of behaviors that are identified as concerning, when parents choose to seek help, resources available for diagnosis and treatment, selection and efficacy of treatments, the relationship between families and professionals, and, in general, how families experience ASD (Grinker et al., 2012; Mandell & Novak, 2005; Ravindran & Myers, 2012). This information is critical to the accuracy of screening and

denominator in the background of these children. They all come from highly intelligent families" (p. 248). He further described the culture of family relationships: "In the whole group, there are very few really warmhearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genu-



ine interest in people” (p. 250). This initial description paved the way to even more damaging characterizations of “refrigerator mothers” and recommendations that children with ASD be removed from their homes and treated in residential settings (Bettelheim, 1967). These characterizations have been discredited, and it can be argued that Kanner’s identified family patterns had more to do with who had the resources to access specialized treatment at Johns Hopkins Hospital, where Kanner practiced, than a true connection between parent intelligence/education level and ASD risk.

More recently, studies on culture and ASD have been inspired by prevalence research showing discrepancies in ASD rates across racial, ethnic, and socioeconomic groups (e.g., Centers for Disease Control and Prevention [CDC], 2014; Mandell et al., 2009; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Morrier, Hess, & Heflin, 2008; Shattuck et al., 2009). Furthermore, children born outside of the US and children born

to foreign mothers are more likely to be diagnosed with ASD at later ages (Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). Members of the University of Minnesota’s Institute on Community Integration (ICI) and LEND program recently completed a study of ASD prevalence in Minneapolis and found statistically equivalent rates of ASD in White and Somali children; however, rates were much lower for non-Somali Black children and Hispanic children, and so few Asian and Native American children were identified with ASD that they could not be included in analyses (Hewitt et al., 2013).

Several hypotheses result from findings on differences in prevalence across race/ethnicity, including (a) differences in genetic liability; (b) immigration history as a risk factor for stress and/or environmental exposures in developing countries; (c) professional bias in referral, screening, and evaluation practices; (d) differences in parent report of concerns that may influence timing of referral

and accuracy of diagnosis; and (e) differences in social behaviors across culture may be picked up less well by existing diagnostic criteria and diagnostic instruments for ASD. The remainder of this article will focus on the last three points, as they are the most relevant to the diagnostic assessment process.

Referral and evaluation practices

Several studies have documented racial/ethnic and income disparities in referral and diagnostic practices in the US. Most notably, children from non-White or low-income backgrounds are diagnosed later, on average, than White children. In a study of Medicaid-eligible children with ASD, the average age Black children received an ASD diagnosis (7.9 years) was approximately a year and a half later than the average age of ASD diagnosis for White children (6.3 years). Further, before receiving a diagnosis, Black children required

three times the number of visits to specialty clinics over a longer period of time than White children (Mandell et al., 2002). In CDC studies, which estimate ASD prevalence via a multi-step process of reviewing medical and educational records (see CDC, 2014), Black, Hispanic, and children in an “other ethnicity” category are significantly less likely to have a diagnosis of ASD from an education or clinical health professional documented in their records compared to White children (Mandell et al., 2009). Regarding income level, children in moderate poverty receive a diagnosis almost a year later than children above the poverty level (Mandell, Novak, & Zubritsky, 2005).

Access to healthcare

Access to consistent, high-quality health care also appears to be a factor in the relationship between race/ethnicity, socioeconomic status, and diagnosis of ASD in the US. Data from the National Survey of Children’s Health reveals that Hispanic and Black children with ASD in the US typically have less reliable access to clinical healthcare than White children (Liptak et al., 2008). Mandell and colleagues (2005) found several factors that delay an ASD diagnosis, including less stability in a child’s primary care physician (i.e., four or more different primary care physicians), not being referred to a specialist, and living in rural areas, which often have limited access to specialist services.

Practitioner bias?

Bias on the part of professionals may result from lack of knowledge or experience with diverse cultures, which can affect professionals’ interpretation of parental reports of concerns (Bernier, Mao, & Yen, 2010). This bias also may reflect negative stereotypes regarding certain racial/ethnic groups. An interesting

finding resulted from a study of Medicaid-eligible families exploring diagnoses children were given, often inaccurately, prior to receiving a diagnosis of ASD. While most children who did not receive a diagnosis of ASD on their first specialty care visit were given a diagnosis of ADHD, Black children were 5.1 times more likely than White children to receive a diagnosis of Adjustment Disorder and 2.4 times more likely to receive a diagnosis of Conduct Disorder rather than ADHD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). A diagnosis of Conduct Disorder is distinguished by serious aggression, deceitfulness, and rule-breaking behavior; Adjustment Disorder focuses on an identifiable stressor that impacts functioning (American Psychiatric Association [APA], 2013).

Culture and parent report of concerns

Developmental expectations, timing of developmental milestones, and subsequent developmental concerns exist within a broader cultural context. Screening and evaluation for developmental delays often rely

literature from researchers studying Indian children with ASD, Daley (2004) found that urban Indian parents’ first concerns tended to center on problems with social interaction, due to the emphasis within that culture on conformity to social norms. Furthermore, Indian parents noted developmental concerns on average six to 10 months later than parents in the US. In the US and Europe, delays in language milestones are most often reported as the first concern (e.g., Howlin & Moore, 1997).

Differences in parent knowledge and expectations for typical child development also may impact the behaviors they identify as concerns. Observations of adult social interactions have revealed cultural differences with regards to personal space, use of eye contact, smiling, touch, silence and discourse (Gonzalez-Mena, 2008). In young children, evidence has shown cultural influences on communication and play. For example, Italian children are more likely to use gestures that represent something (for example, drinking from a cup), while US children are more likely to use gestures

Access to consistent, high-quality health care also appears to be a factor in the relationship between race/ethnicity, socioeconomic status, and diagnosis of ASD

on a parent or caregiver’s ability to recognize developmental issues and concerns. Expectations for typical child development impact when or if concerns are reported. Both expectations and recognition of concerns are shaped by cultural norms, (Bernier et al., 2010; Daley, 2002) as well as environmental and socioeconomic variables (Daley, 2004).

A handful of studies have examined developmental concerns for ASD that are typically reported across cultures, often within different countries. In a review of the Indian

to indicate something (for example, pointing; Iverson, Capirci, Volterra, & Goldin-Meadow, 2008); South Korean preschoolers engage in less pretend play and have fewer social interactions than preschoolers from the US (Farver, Kim, & Lee, 1995); and 2-year-old US children use more symbolic play than French children of the same age (Suiizzo & Bornstein, 2006). In many cultures, use of direct eye contact with an adult is considered a sign of disrespect (Grinker et al., 2012; Sue & Sue, 2008).

Expectations for and knowledge about child development also

can affect *timing* of concerns. For example, in South Africa, childcare workers expressed the belief that few differences in intellectual or social development are detectable prior to age 2 (Grinker et al., 2012). In India, many parents delayed seeking help for their children for over 2 years after first symptoms emerged due to cultural expectations, for example, that Indian boys talk later, and that children who are quiet and keep to themselves simply are well-behaved (Daley, 2004; Daley & Sigman, 2002). Investigators in Saudi Arabia found that girls are diagnosed later than boys and attributed this to the cultural expectation that boys are more outgoing than girls; thus, their social deficits are recognized earlier (Al-Salehi, Al-Hifthy, & Ghazziudin, 2009). If parents expect a different level of an aspect of social communication because of different cultural norms, they may be less likely to report concerns.

Stigma

Stigma about ASD and developmental disorders affects timing of diagnosis, and whether parents report developmental concerns at all. In some Asian cultures, there is a belief that mental illness and developmental disabilities are punishment for a parent's, often a mother's, behavior (Grinker, 2007; Raghavan, Weisner, & Patel, 1999). Grinker and colleagues (2012) documented the ways in which stigma led South Korean parents to mask or normalize their children's ASD symptoms, which led to undiagnosed cases or to parent rejection of an ASD diagnosis. Among Somali families in Minneapolis, shame and discrimination were identified as a concern impacting families' report of concerns to professionals, acceptance of the diagnosis, and seeking of services (Hewitt, Gulaid, Hamre, Esler, Punyko, Reichle, and Reiff, 2013).



Cultural appropriateness of diagnostic measures

Differences in how symptoms of ASD manifest across cultures has clear implications for accuracy of diagnostic instruments. A few studies have examined features of ASD across race, ethnicity, or culture. One study of 5- to 9-year-olds with ASD found that White children displayed more restricted, repetitive behaviors than Black children, but there were no differences in social communication skills (Sell et al., 2012). In other studies, core symptoms of ASD did not

groups (Hewitt et al., 2013).

We do not know whether findings for a few differences in symptom presentation across racial/ethnic groups result from possible test biases or a lack of actual differences in symptoms. Perhaps there are important symptoms of ASD that differ across cultures that are not being detected by existing instruments. Harris, Barton, and Albert (2014) reviewed research on four currently used diagnostic and six screening measures regarding their inclusion of cultural considerations. Most mea-

Much of the cultural adaptation process of an instrument's translation resulted in minor adjustments to colloquialisms and toys/materials referenced.

differ across groups, but differences were found in structural language skills, such that Black, Hispanic, and Asian children performed lower than White children on various measures of language understanding and production (Chaidez, Hansen, & Hertz-Picciotto, 2012; Cuccaro et al., 2007; Stronach, 2013; Tek & Landa, 2012). In the Minneapolis prevalence study, Somali children had much higher rates of ASD with intellectual disability than other racial/ethnic

groups include culturally diverse groups in the norming samples; however, only two screeners include limited English proficient samples. None of the measures include *standardized* methods for modifying or adapting test administration for culturally diverse families, although a couple offer suggestions for modifications. Finally, assessment of family acculturation is not included in any of the measures, nor is there a discussion of how acculturation may impact

parent report or child performance of behaviors related to ASD.

A number of diagnostic instruments for ASD have been translated into other languages for use in other countries. However, there is variability in how and whether field testing was performed to adapt the measures for cultural appropriateness, as well (Harris et al., 2014). Furthermore, much of the cultural adaptation process of an instrument's translation resulted in minor adjustments to colloquialisms and toys/materials referenced (e.g., Grinker et al., 2012; Canal-Bedia et al., 2011). Focus groups held in a Zulu community in South Africa evaluated the cultural appropriateness of 193 statements and questions culled from standardized instruments for ASD developed in the US, which included the Autism Diagnostic Observation Schedule (Lord et al., 2000) and the Communication and Symbolic Behavior Scales (Wetherby & Prizant, 2002). As a result of this process, 36% of the 193 items were revised to improve

Future directions

Although cultural influences on ASD are receiving increased attention, we still lack consensus on how best to define and categorize culturally relevant groups for research (Pierce et al., 2014). Most of the studies presented in this article use race/ethnicity as a proxy for culture, which is problematic, as there is likely to be more within-group variability than between-group. Factors such as socioeconomic and geographic status may have independent influences or interact with race/ethnicity to predict ASD diagnosis and access to services.

Questions about relative accuracy of diagnostic practices across cultures cannot be answered until we have improved understanding of how symptoms manifest across cultural groups. There is a need to examine the relationship between culture, environment, and early social communication and play skills in typical development to better understand potential differences in when and how development goes awry. Studies

samples of middle- to upper-income White children and adults (see Pierce et al., 2014). Further, traditionally underserved populations, such as children in poverty and non-White children, are under-represented in national registries (e.g., Autism Genetic Resource Exchange and Interactive Autism Network) (Valicenti-McDermott et al., 2012) and in genetic studies of ASD (Hilton et al., 2010). In their review of how race/ethnicity is reported and included in ASD research, Pierce et al. concluded that the challenge of recruitment and enrollment of diverse families requires specific attention and a tailored approach.

These findings highlight a need for increased access to developmental screening, culturally sensitive assessment, and high quality intervention services for children from culturally and linguistically diverse backgrounds. Further, more culturally sensitive screening and assessment practices are needed, with a special focus on outreach to families and caregivers from culturally and linguistically diverse communities. Working to understand family perceptions and cultural beliefs about their child's development as well as meaningfully incorporating family perspectives into the screening and evaluation process may empower families to address developmental concerns within their own cultural framework and further reduce disparities in age of ASD identification (Mandell et al., 2007; Mandell et al., 2002).

As researchers and practitioners devoted to the field of autism spectrum and other neurodevelopmental disorders, it is our ethical responsibility to partner with diverse individuals, families, and communities to improve screening and diagnostic practices. Otherwise, we will continue to under-identify, misidentify, or identify too late children from diverse cultures, leading to delays in or denial of efficacious treatments and supports.

Working to understand family perceptions and cultural beliefs about their child's development...may empower families to address developmental concerns within their own cultural framework.

clarity and simplicity of wording, replace English idiomatic expressions, and eliminate or replace content that was not culturally relevant (Grinker et al., 2012). These translation and adaptation processes are idiosyncratic and may not generalize easily. For example, colloquialisms and toys used in Spain likely differ from those of Spanish-speaking immigrant families in the US, such that utilizing the Spanish language M-CHAT developed by Canal-Bedia et al. (2011) may not be culturally appropriate.

have shown differences in child preverbal communication skills based on socioeconomic status and culture, although findings are not consistent (Hart & Risley, 1995; Iverson et al., 2008; Jackson-Maldonado & Acosta, 2006; Rowe & Goldin-Meadow, 2009; Tamis LeMonda, Song, Leavell, Kahana Kalman, & Yoshikawa, 2012; Watt, Wetherby, & Shumway, 2006). Regarding timing of diagnosis, we also need to understand the unfolding of ASD red flags across cultures.

Cultural barriers affect research participation for diverse families, which also impact development of culturally appropriate diagnostic practices. The large majority of ASD research has used non-diverse

Amy Esler, PhD, LP is an assistant professor of pediatrics at the University of Minnesota. Her research interests include screening and diagnostic practices for autism spectrum and other developmental disorders across cultures, as well as early intervention for children at-risk for autism spectrum disorder. Dr. Esler is a psychologist in the Autism Spectrum and Neurodevelopmental Disorders Clinic, directs training on diagnostic measures for autism spectrum disorder, and is the director of the Fragile X Clinic.

Jennifer Hall-Lande, PhD, is a psychologist and research associate at the Institute on Community Integration at the University of Minnesota. Dr. Hall-Lande is also a post-doctoral LEND (Leadership in Neurodevelopmental Disabilities) fellow and is currently CDC's Act Early Ambassador for Minnesota. She has served as a co-lead on state Act Early activities in which a statewide team of Act Early delegates was developed as well as many outreach activities with Act Early materials to culturally and linguistically diverse communities. Dr. Hall-Lande's principal research and community outreach activities have been focused on screening, assessment, and interventions for children at risk for neurodevelopmental disabilities.

Sheri Tracy Stronach, PhD, CCC-SLP is an assistant professor of Speech-Language-Hearing Sciences at the University of Minnesota-Twin Cities. Her research interests include early social communication development across cultures as well as early identification and intervention for children with autism spectrum disorder. In addition to research and teaching, Dr. Stronach also directs the Bilingual and Multicultural Emphasis Program for speech-language pathology and audiology students.

References

- Al-Salehi, S. M., Al-Hifthy, E. H., & Gha-ziuddin, M. (2009). Autism in Saudi Arabia: Presentation, clinical correlates and comorbidity. *Transcultural Psychiatry*, 46(2), 340–347. doi: 46/2/340 [pii]10.1177/1363461509105823
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, 5th Edition*. Arlington, VA: American Psychiatric Publishing.
- Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: Autism. *Child and Adolescent Psychiatric Clinics of North America*, 19(4), 855–+. doi: 10.1016/j.chc.2010.07.005
- Berry, J. W., Poortinga, Y. H., Segall, H. H., & Dasen, P. R. (2002). *Cross-cultural psychology: Research and applications*. Cambridge, UK: Cambridge University Press.
- Bettelheim, B. (1967). *Empty fortress: Infantine autism and the birth of the self*. New York, NY: Simon and Schuster.
- Canal-Bedia, R., Garcia-Primo, P., Martin-Cilleros, M. V., Santos-Borbujo, J., Guisuraga-Fernandez, Z., Herraez-Garcia, L., . . . Posada-de la Paz, M. (2011). Modified Checklist for Autism in Toddlers: Cross-Cultural Adaptation and Validation in Spain. *Journal of Autism and Developmental Disorders*, 41(10), 1342–1351. doi: 10.1007/s10803-010-1163-z
- Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorder among children aged 8 years: Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries*, 63(2), 22.
- Chaidez, V., Hansen, R. L., & Hertz-Picciotto, I. (2012). Autism spectrum disorders in Hispanics and non-Hispanics. *Autism: The International Journal of Research and Practice*, 16(4), 381–97. doi:10.1177/1362361311434787
- Cuccaro, M.L., Brinkley, J., Abramson, R.K., Hall, A., Wright, H.H., Hussman, J.P., . . . Pericak-Vance, M. A. (2007). Autism in African American families: Clinical-phenotypic findings. *American Journal of Medical Genetics. Part B, Neuropsychiatric Genetics: The Official Publication of the International Society of Psychiatric Genetics*, 144B(8), 1022–6. doi:10.1002/ajmg.b.30535
- Daley, T. (2002). The need for cross-cultural research on pervasive developmental disorders. *Transcultural Psychiatry*, 39, 532–551.
- Daley, T.C., & Sigman, M.D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32(1), 13–23.
- Daley, T. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science and Medicine*, 58, 1323–1335.
- Dyches, T. T., Wilder, L.K., Sudweeks, R.R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34(2), 211–222.
- Farver, J. A. M., Kim, Y. K., & Lee, Y. (1995). Cultural differences in Korean- and Anglo-American preschoolers' social interaction and play behaviors. *Child Development*, 66(4), 1088–1099. doi:10.1111/j.1467-8624.1995.tb00924.x
- Geschwind, D. H. (2011). Genetics of autism spectrum disorders. *Trends in Cognitive Sciences*, 15(9), 409–416.
- Gonzalez-Mena, J. (2008). *Diversity in early care and education: Honoring differences*. Boston, MA: McGraw-Hill.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. New York, NY: Basic Books.
- Grinker, R.R., Chambers, N., Njongwe, N., Lagman, A.E., Guthrie, W., Stronach, S., . . . Wetherby, A.M. (2012). "Communities" in community engagement: Lessons learned from autism research in South Korea and South Africa. *Autism Research: Official Journal of the International Society for Autism Research*, 5(3), 201–10. doi:10.1002/aur.1229
- Harris, B., Barton, E.E., & Albert, C. (2014). Evaluating autism diagnostic and screening tools for cultural and linguistic responsiveness. *Journal of Autism and Developmental Disorders*, 44(6), 1275–87. doi:10.1007/s10803-013-1991-8



- Hart, B., & Risley, T.R. (1995). *Meaningful differences in the everyday experience of young American children*. Baltimore, MD: Paul H. Brookes Publishing Co., Inc.
- Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J., & Reiff, M. (2013). *Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Hilton, C., Fitzgerald, R., Jackson, K., Maxim, R., Bosworth, C., Shattuck, P., et al. (2010). Brief report: Under-representation of African Americans in autism genetic research: A rationale for inclusion of subjects representing diverse family structures. *Journal of Autism and Developmental Disorders*, 40, 633–639. doi:10.1007/s10803-009-0905-2.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism*, 1(2), 135–162.
- Iverson, J.M., Capirci, O., Volterra, V., & Goldin-Meadow, S. (2008). Learning to talk in a gesture-rich world: Early communication in Italian vs. American children. *First Language*, 28(2), 164–181. doi:10.1177/0142723707087736
- Jackson-Maldonado, D., & Acosta, R. P. B. (2006). Assessing early communicative abilities in Spanish-speaking children from low-SES families. *Zero to Three* (1), 27(1), 22–27.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2(3), 217–250.
- Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., et al., (2008). Disparities in diagnosis and access to health services for children with autism: Data from the national survey of children's health. *Journal of Developmental Behavioral Pediatrics*, 29, 152–160.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr, Leventhal, B. L., DiLavore, P. C., . . . Rutter, M. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205–223.
- Mandell, D., Ittenbach, R., Levy, S., Pinto-Martin, J. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism Developmental Disorders*, 37(9), 1795–1802.
- Mandell, D., Listerud J., Levy, S., Pinto-Martin, J. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of American Academy of Child and Adolescent Psychiatry*, 41(12), 1447–1453.
- Mandell, D., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110–115.
- Mandell, D.S., Novak, M.M., & Zubrisky, C.D. (2005). Factors associated with the age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116, 1480–1486.
- Mandell, D.S., Wiggins, L.D., Carpenter, L.A., Daniels, J., DiGiuseppi, C., Durkin, M.S., et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493–498.
- Matsumoto, D. (2001). *The handbook of culture and psychology*. London, UK: Oxford University Press.
- Morrier, M.J., Hess, K.L., & Heflin, L.J. (2008). Ethnic disproportionality in students with autism spectrum disorders. *Multicultural Education*, 16(1), 31–38.
- Pierce, N.P., O'Reilly, M.F., Sorrells, A.M., Fragle, C.L., White, P.J., Aguilar, J.M., & Cole, H.A. (2014). Ethnicity reporting practices for empirical research in three autism-related journals. *Journal of Autism and Developmental Disorders*, 44(7), 1507–1519. doi: 10.1007/s10803-014-2041-x
- Raghavan, C., Weisner, T.S., & Patel, D. (1999). The adaptive project of parenting: South Asian families with children with developmental delays. *Education and Training in Mental Retardation and Developmental Disabilities*, 34(3), 281–92.
- Ravindran, N., & Myers, B.J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21(2), 311–319. doi: 10.1007/s10826-011-9477-9
- Rowe, M.L., & Goldin-Meadow, S. (2009). Differences in early gesture explain SES disparities in child vocabulary size at school entry. *Science*, 323(5916), 951–953.
- Sell, N.K., Giarelli, E., Blum, N., Hanlon, A.L., & Levy, S.E. (2012). A comparison of autism spectrum disorder DSM-IV criteria and associated features among African American and white children in Philadelphia County. *Disability and Health Journal*, 5(1), 9–17. doi:10.1016/j.dhjo.2011.08.00
- Shattuck, P.T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D.S., Wiggins, L., . . . Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48(5), 474–483. doi: 10.1097/CHI.0b013e31819b3848
- Shelton, J.F., Geraghty, E. M., Tancredi, D.J., Delwiche, L.D., Schmidt, R.J., Ritz, B., . . . & Hertz-Picciotto, I. (2014). Neurodevelopmental disorders and prenatal residential proximity to agricultural pesticides: The CHARGE study. *Environmental Health Perspectives* (122)10, 1103–1110.
- State, M.W., & Levitt, P. (2011). The conundrums of understanding genetic risks for autism spectrum disorders. *Nature Neuroscience*, 14(12), 1499–1506. doi: 10.1038/nn.2924
- Stronach, S. (2013). Social communication profiles of toddlers with and without autism spectrum disorder from three racial/ethnic groups. *Electronic Theses, Treatises and Dissertations*. Retrieved from <http://diginole.lib.fsu.edu/etd/7617>
- Sue, D.W., & Sue, D. (2003). *Counseling the culturally diverse: Theory and practice* (4th ed.). New York, NY: John Wiley & Sons, Inc.
- Suizzo, M.A., & Bornstein, M.H. (2006). French and European American child-mother play: Culture and gender considerations. *International Journal of Behavioral Development*, 30(6), 498–508. doi:10.1177/0165025406071912
- Tamis LeMonda, C.S., Song, L., Leavell, A.S., Kahana Kalman, R., & Yoshikawa, H. (2012). Ethnic differences in mother-infant language and gestural communications are associated with specific skills in infants. *Developmental Science*, 15(3), 384–397.
- Tek, S., & Landa R.J. (2012). Differences in autism symptoms between minority and non-minority toddlers. *Journal of Autism and Developmental Disorders*, 42(9), 1967–1973.
- Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012). Age at diagnosis of autism spectrum disorders. *Journal of Pediatrics*, 161(3), 554–556.
- Watt, N., Wetherby, A., & Shumway, S. (2006). Prelinguistic predictors of language outcome at 3 years of age. *Journal of Speech, Language, and Hearing Research*, 49(6), 1224–1237.
- Wetherby, A.M., & Prizant, B.M. (2002). *Communication and symbolic behavior scales: Developmental profile*. Baltimore, MD: Paul H. Brookes Publishing Co.

Interpreting autism: Lost in translation

Elizabeth Watkins, MA and Betty Tapias-Heinrich, MA

lb qho kev tsis taus uas yog puas rau phab kev nrog lwmm tus tham thiab koom nrog lwmm tus...Kev tsis taus no yuav tshwm sim tawm rau thaum muaj hnub nyoog 3 xyoo thiab yuav muaj mus tas lub neej. Hom uas tshwm sim tsis loj yog hom hu ua Asperger (MDE, 2012). (Hmong)

Cilladaha ootiisamku waxaay saameyn karaan maskaxda. Waxa dhacda in carruuraha qaba cilladaha ootiisamku sida ay bulshada ula dhaqmaan, hadlaan, ama u fakiraan ay ka duwan tahay carruuraha kale. Marxalado aad u adagna yeelan karaan (RTC, 2013). (Somali)

Autismo (Spanish)

Introduction

What do the words and phrases above in italics have in common? Both convey the concept of autism in the Hmong and Somali languages respectively. The Spanish language has a single word that captures the technical and emotional weight of the disability. In Hmong, the full glossary entry uses 161 words to describe the characteristics of a disability that falls outside the world-view of the traditional culture (MN Department of Education, 2012). The Somali language requires a sentence but these are still not adequate to bridge the divide between Somali families, the medical system and the educational system (Minnesota Department of Education, 2005). Words have power and the lack of a common language can form a tremendous barrier between English-speaking professionals and clients who speak other languages.

Hundreds of languages are spoken by students enrolled in public schools in the United States, but the majority of these languages lack even a single Autism Spectrum Disorder (ASD) professional who is bilingual. Both medical clinics and schools rely heavily upon interpreters to communicate with immigrant and refugee families as a result.

The field of interpreting is changing rapidly throughout the United States. It is moving in the direction of greater professionalism, but is still very loosely regulated.

Standards

Efforts have been made in the last twenty years to develop consistent standards for interpreters working in medical settings, but certification in these standards is still largely voluntary. The National Council on Interpreting in Health Care (NCIHC) was formed in 1998 and adopted its code of ethics and standards of practice in 2004 and 2005. The Code of Ethics addresses topics such as confidentiality, accuracy, impartiality, boundaries, patient advocacy and

ongoing professional development. The Standards of Practice provide more in-depth guidance on the application of ethics to daily, professional practices. At the national level, two organizations certify medical interpreters that have passed both written and oral language examinations and other competency areas: 1). Certification Commission for Healthcare Interpreters (CCHI), and 2). National Board of Certification of Medical Interpreters (NBCMI).

The CCHI certifies interpreters in the Spanish, Arabic and Mandarin Chinese languages while the NBCMI has examinations and certifies interpreters in Spanish, Russian, Mandarin, Cantonese, Korean and Vietnamese. These organizations have no options for certifying interpreters of other languages. Information regarding the Code of Ethics, Standards of Practice and the two certification organizations can be found at <http://www.ncihc.org>.

Minnesota is moving toward adoption of standards for medical interpreters. Currently a roster of medical interpreters is maintained by the Minnesota Department of Health. Employers are not required



to use interpreters from the Health Department roster unless the interpreting services will be billed to Medical Assistance or a state-funded insurance program for low-income residents. There are no training requirements in order to be listed on the roster, but the Minnesota Department of Health recently published a legislative report with recommendations for interpreting qualifications, professional training, language competency testing, professional standards, and oversight. These standards, if adopted, will apply to many services related to autism that are provided through medical clinics. It should be noted that health care standards for interpreting also apply when school districts are reimbursed by insurers for health-related services that are delivered in schools. Information regarding the medical roster and legislative report can be found at <http://www.health.state.mn.us/divs/pqcl/hcilindex.html>.

As noted on the NCIHC website, interpreting requires more than the ability to speak a language. NCIHC (2010) indicates that interpreting is the process of understanding and analyzing a spoken or signed message, and re-expressing that message faithfully, accurately and objectively in another language, taking the cultural and social context into account. An interpreter must have an excellent memory, good vocabulary and be attuned to the nuances of complex communication. Interpreters rarely use a “word-for-word” approach in which they attempt to translate each word spoken in English to a native language. This can result in misleading and unclear communication. Interpreters need to be able to listen to the source message, comprehend the meaning, let go of the actual words, and then restructure the message into the target language. Doing so ensures that the message will make sense and be accurate.

What people often do not know or readily realize is that accurate in-

terpreting is a difficult cognitive task and is not a skill that comes naturally. Comprehensive professional training programs provide instruction in the needed skills and allow sufficient time to practice and internalize these skills. Training programs must also have the capacity to assess proficiency in numerous language pairs and have access to bilingual instructors. In our experience, they often develop their own curricula because there are few published textbooks, and instructors and students compile their own glossaries in part because there are no published dictionaries or because dictionaries do not include technical terminology. Glossaries are also individually developed because they are personal tools depending on the needs of each interpreter.

At the present time, there are two university-level professional training programs in the state of Minnesota: 1) the Program in Translation and Interpreting (PTI) at the University of Minnesota, and 2) the Translating and Interpreting (TRIN) program at Century College. The PTI has been in existence for many years. It offers certificates of program completion in legal and medical interpreting. The PTI also recently developed equivalent courses in Special Education. More information about the PTI program can be found at <http://lce.umn.edu/CCE-Main/Program-in-Translation-and-Interpreting/index.html>. The Century College TRIN program was created in 2009 and also has coursework in health care, legal and educational interpreting. TRIN students may earn an associate in applied science degree once they have completed department coursework and fulfilled other core requirements. Additional information regarding TRIN may be found at http://www.century.edu/future_students/programs/pnd.aspx?id=58.

Cross Cultural Communications is a Maryland based organization that offers a community interpreting

training program; many Minnesota interpreters have completed this program. Community interpreting is defined as interpreting performed for the purpose of providing access to social services, health care or education. Individuals who provide community interpreting may have a dual role as an enrollment clerk or outreach worker. Cross-Cultural Communications has licensed trainers to deliver their curriculum throughout the United States. Additional information can be found at <http://www.thecommunityinterpreter.com>

In Minnesota, professional development workshops for interpreters working in public school special education programs are provided through the Minnesota Department of Education. These workshops emphasize the history and cultural context that are the basis of current special education laws and procedures.

Professional training programs help individuals define their role and build skills in simultaneous and consecutive interpreting. Simultaneous interpreting occurs when the interpreter begins interpreting shortly after the speaker, maintaining a slight lag to be able to process and convert the message, listening and speaking at the same time. This is ideal for meetings when a speaker cannot or should not be interrupted.

Consecutive interpreting takes place when the interpreter waits until the speaker has spoken a few sentences and then pauses to allow time for interpretation. The speaker and interpreter take turns speaking. This method is ideal when there are just two or three people for which to interpret and the exchanges are short. Group meetings may involve both simultaneous and consecutive interpreting. For example, in a meeting with one or two Somali speakers, simultaneous interpreting might be used for English to Somali, but it is more appropriate to use the consecutive style to interpret comments

made by each of the Somali participants into English.

Another task that is frequently undertaken is “sight translation” which is the oral interpretation of a document. It is best to prepare written documents in the language that the family reads. If this is not feasible, then the documents should be given to the interpreter ahead of time so that he/she has time to read and fully comprehend the material. For lengthy materials, another strategy is for the provider to provide a verbal summary which is interpreted. Interpreters should never be asked to summarize a document, as they are ethically bound to sight translate it in its entirety.

Interpreting services for children with Autism Spectrum Disorder (ASD)

Children with ASD and speech disorders may receive services in medical environments, school environments, or both. Service providers should be aware of how differences in settings can affect communication and thus affect interpreting practices. Communication in medical settings often involves one patient and one medical provider. In schools, communication often can be with a larger group in the context of an Individual Education Plan (IEP) meeting. The interpreter needs to know how to prepare for the meeting, arrange the seating, determine whether simultaneous and/or consecutive interpreting will be provided, determine how to handle sight translation, and effectively explain the communication process so that everyone involved knows how to proceed. During the meeting, the interpreter may need to —

- Request a repetition or clarification.
- Manage the flow and speed of conversation without interfering.
- Know when an interpretation

error is made and make corrections in a professional manner.

- Take notes to aid memory and avoid needless interruptions of the speaker.
- Be transparent in all that is said.
- Skillfully work so it appears that everyone is speaking the same language.

The purpose of the interaction should also be considered. Different interpreting modes may be needed for a meeting with several participants, an interview conducted as part of an evaluation, or a one-on-one assessment with a child.

Working with interpreters

It is helpful for monolingual staff to have training and practice in working with interpreters. Experts frequently recommend a three-step process when working with an interpreter which includes —

- 1. Briefing** — Have a conversation with the interpreter prior to the appointment or meeting to go over the purpose of the interaction, any technical terminology that will be used, the mode of interpreting (consecutive, simultaneous or both).
- 2. Interaction or encounter** — Is what occurs between the interpreter, client, and speaker. Content is determined by the nature of meeting or interaction.
- 3. Debriefing** — Conduct a

review of how things went and provide an opportunity for either party to ask questions or share impressions.

There are a number of things that English-speaking staff can do to make an interpreted meeting or evaluation go smoothly —

- Speak in a concise, succinct manner. Sentences that start and stop before finishing the thought or rambling speech are difficult to interpret and can sound very confusing.
- Pause every 3-4 sentences, particularly when consecutive interpreting is being provided.
- Make sure that only one person speaks at a time.
- Avoid side conversations and remember that everything said in the room will be interpreted.
- Avoid excessive use of jargon and ambiguous language.
- Pause frequently during the meeting to ask the family if they have questions. A good strategy to check for comprehension is to ask them to share what they understand.
- Use first person language (say “I evaluated Maryam on March 3” instead of “tell the mom that I evaluated Maryam...”).
- Address family members by names and titles (Mr. or Mrs.) and not as “mom and dad.”
- Be patient and realize that

New guidelines for EL services

On January 7, 2015, the U.S. Department of Justice and the Office for Civil Rights at the U.S. Department of Education issued joint guidelines regarding school services for English Learners. The guidelines address services for ELs who also have disabilities and also recommend practices for school districts to follow when communicating with parents who are not fluent in English. The guidance states that all interpreters and translators working in public schools should receive training in specialized terminology, ethics and data privacy. The full text can be viewed at: <http://www2.ed.gov/about/offices/list/ocr/letters/colleague-el-201501.pdf>

interpreted appointments will take longer. Plan to double the time needed for encounters requiring interpreting services.

- Keep in mind that at times the speech of the person with autism may not follow a normal speech pattern. This information should be shared with the interpreter so he /she can be prepared.
- Speak loudly enough for the interpreter to hear you.
- Do not speak too quickly.

Consider cultural barriers

Many professionals working in the field of autism know cultural barriers to communication may continue even with the assistance of a skilled and trained interpreter. In many situations, both the service provider and the client need help to navigate cultural differences. People who serve in this capacity may be called “cultural liaisons” or “cultural brokers” and are called upon to help explain a baffling system to clients or to provide information about cultural and linguistic differences to providers. Some interpreters are comfortable providing this assistance, but some are not.

It is important to have very clear boundaries between roles of a liaison and an interpreter and to remember that a single person cannot serve in both roles at the same time. For example, an interpreter should never be asked to provide cultural information during meetings with families. Explanations of cultural differences need to be given in another setting. Similarly, an interpreter cannot give advice to families in a meeting. It is most appropriate to refer families to an advocate if they need to discuss their options before making a decision. Some disability organizations have bilingual advocates. If a clinic or school is fortunate enough to have several bilingual staff members, administrators should review job descriptions and clarify roles.

Access to information

Access to information in an understandable language is considered a civil right and is protected by Title IV of the Civil Rights Act of 1964. This applies to any services that are provided through health care systems, human services, and schools that receive federal funding. Other federal laws have specific provisions for language access. For example, the Individuals with Disabilities Education Act (IDEA) requires that students be evaluated in the language or languages that best shows what the student can do “academically, developmentally and functionally.” This provision also applies to collection of evaluation information through family interviews, questionnaires or rating scales. In addition, IDEA requires that parents be informed of their legal rights in their native language and directs schools to take whatever steps are needed to assure that parents can participate in special education meetings and understand written documents.

Schools may utilize special education funding to cover part of the costs of interpreters for meetings and student evaluations. Costs for interpreting in medical settings are often covered by health insurance. Some public schools as well as large clinics and hospitals have their own staff of interpreters in common languages. One of the advantages of hiring in-house interpreters is that both the interpreter and the licensed staff can develop a rhythm of working together as a team. Schools and clinics also rely upon interpreting agencies or set up individual contracts with freelance interpreters. Interpreting agencies hire individuals as independent contractors and may have procedures to screen and maintain quality.

Conclusion

Beyond meeting legal obligations, having a skilled interpreter ensures that all parties have a voice. Even with the best intentions, communication cannot occur if families and providers do not have a common language. Autism is a life-long condition, but positive outcomes are possible when families, clients and providers develop good relationships rooted in good communication.

References

- MN Department of Education (2012). *Holding Individualized Education Program (IEP) Meetings with English Language Learner (ELL) Families and Interpreters*. Retrieved from <http://education.state.mn.us/MDE/SchSup/SpecEdComp/EngLearnDisabiRes/index.html>
- MN Department of Education (2005). *English-Somali Special Education Glossary*. Retrieved from <http://education.state.mn.us/MDE/SchSup/SpecEdComp/EngLearnDisabiRes/index.html>
- National Council on Interpreting in Health Care (2010). *What's in a word?* Retrieved from http://www.ncihc.org/assets/documents/publications/Whats_in_a_Word_Overview.pdf
- Research and Training Center on Community Living (RRTC-CL). (2013). There are many Somali and non-Somali children with autism spectrum disorder: Make sure your child and family get the help they need. Retrieved from http://rtc.umn.edu/autism/doc/Somali_parent_handout.pdf

Elizabeth Watkins is a cultural and linguistic diversity consultant with the Division of Special Education at the Minnesota Department of Education. She has led the development of training programs for interpreters working in special education as well as creation of glossaries in the Hmong and Somali languages. Ms. Watkins also develops materials and provides training on culturally fair special education assessment practices. She can be reached at Elizabeth.Watkins@state.mn.us.

Betty Tapias-Heinrich is a Spanish interpreter with over 15 years of experience and currently works as the Language Services and Welcome Center Coordinator for the Robbinsdale Area Schools. Ms. Tapias-Heinrich has completed both the legal and medical specializations of the Certificate in Interpreting and developed the equivalent courses for the Special Education certificate track at the U of MN. She is actively involved in teaching and developing interpreter courses in the Twin Cities and greater Minnesota. She holds a master's degree in educational leadership from Concordia University in St. Paul, MN.

Barriers to early identification and access to services for children with autism: Experiences of Somali, Hmong, and Latino families in Minnesota

Donna D. McAlpine, PhD, Mariam Egal*, MPH, Shannon Pergament, MSW, MPH, Walter Novillo, JD, MA, and Mai Khou Yang, MSW

Introduction

For children with autism spectrum disorders (ASD), early detection and access to timely, quality services are critical for positive outcomes (Vismara & Rogers, 2010; Handelman & Harris, 2008). Yet, many children are not identified as having ASD until quite late — in Minneapolis the average age at first diagnosis of ASD is about 5 years (Hewitt, Gulaid, Hamre, Esler, Punyko, Reichle, & Reiff, 2013). Moreover, even when identified as having ASD, many families struggle with getting their child access to appropriate services.

Challenges to early identification and getting connected to effective services may be particularly difficult for families from diverse cultural backgrounds. Challenges include: English language difficulties, isolation from extended families, discrimination, stigmatization, mistrust of providers, lack of health insurance



A recent study conducted by the Minnesota Department of Health examined the experiences of families from three major cultural groups: Somali, Latino, and Hmong commu-

The specific objectives of the study included —

1. Describing challenges in early identification of autism;
2. Identifying the challenges families experienced when accessing services; and
3. Developing recommendations to address the challenges faced by families.

Although these populations have diverse cultures and immigration histories, they share the experience of being relatively new to the United States, and face many similar structural disadvantages that are not faced by the majority of the European- an-American community.

and knowledge about resources, and unfamiliarity with the school and medical systems. Each of these alone or combined make the process from diagnosis through seeking treatment for a child with ASD extraordinarily difficult for new immigrant populations. Yet there has been little research specifically focused on families from minority cultural groups.

nities (MDH, 2014). Although these populations have diverse cultures and immigration histories, they share the experience of being relatively new to the United States, and face many similar structural disadvantages that are not faced by the majority of the European-American community.

Method of the study

Through community—based participatory research (CBPR) methods (Israel, Schulz, Parker, & Becker, 1998) we drew on the expertise and experience of community researchers in all stages of the research from design through dissemination. The team included researchers who were

bilingual in the either Hmong, Spanish, or Somali and English (Vismara & Rogers, 2010).

During the first stage of the research, 33 key informants including autism service providers, spiritual leaders, and staff from relevant government organizations were interviewed.

trying to get services, services most needed, and recommendations for improving access to services.

Interviews were audio-taped and then transcribed into English. Two members of the research team independently coded the transcripts based on pre-existing themes. The team members met to reconcile any

like ...if you do not know what is out there...that there are resources...but we do not know and we do not know how to ask for."
(Latino Parent)

In each community, respondents often talked about the tendency of parents to initially normalize their child's behaviors. Parents described that with the onset of what appeared to be subtle developmental concerns or peculiar behaviors it was easy to feel the behaviors were part of "normal" children's development and that the child would "grow out" of the behaviors —

"...we as parents tend to resist, to acknowledge and to accept ...because we see them as normal...we see them with paternal love ...we do not see them as children with disabilities." (Latino Parent)

A third common family-related reason for delays in identification was shame or stigma. Within the Somali community, one respondent explained —

"You either crazy or you're sane. There's no gray area. So, you're schizophrenic and that's it, and people always shun you. Well, you're an embarrassment to the family, so they, they hide you away. So they're afraid of that stigma, they don't want people to look at them different. Oh, especially women in our culture, most people would say, 'oh, it's because of the mother'." (Somali Parent)

Equally important, was that many parents also described the attitudes and behaviors of providers as responsible for late identification. Challenges included doctors normalizing the behavior(s) and dismissing the concerns of the parents, being shifted around among professionals, doctors not screening for the disorder, and racial discrimination —

"We took him back to the pediatrician, and the pediatrician said 'there is nothing wrong with the

Many parents also described the attitudes and behaviors of providers as responsible for late identification.

In the second stage of the research, parents were primarily recruited through canvassing places where members of each community were likely to be such as places of worship, libraries, health fairs, and through meetings with parents, local businesses, and providers. Flyers were distributed in Hmong, Somali, Spanish and English and potential participants contacted the researchers. We interviewed 70 parents¹ (38 Somali, 15 Hmong, and 17 Latino). Most families had one child with ASD, but almost one-fifth of Somali families had two or more children with the disorder. The age of the oldest child with autism in these families ranged from 2 to 30 years, with the average age ranging between 9 to 10 years. Thus, we were able to capture the experiences of families with young children and those whose child with autism was now an adult.

Interviews with Latino, Somali and Hmong families were conducted with participants in their native language as needed. The majority of Latino and Somali interviews and about half of Hmong interviews were conducted with participants in their native language. Respondents chose whether to participate in focus groups or individual interviews. Questions focused on perceptions of ASD, delays in getting a child with ASD properly identified or diagnosed, challenges

discrepancies in coding. Key problems or challenges identified were categorized according to whether they were related to 1) family or individual issues; 2) providers; or 3) system-level problems. The full report also covers results from the key informant interviews, how parents perceived ASD, and the gaps in services they experienced (Autism Research Team, 2014); here we focus on the main themes related to late identification and challenges receiving services.

Results

Late identification of autism

For the most part, parents were the first to notice something was different about their child and many attempted to seek help early. The delay between noting a problem and obtaining a diagnosis and treatment was a source of frustration. A common family-related reason given for delays was lack knowledge about the disorder, who to go to and available resources —

"First, they don't know the services and where to get information, Somalis that is. They also lack knowledge. The disease is a disease that we never saw before. We only saw it when we came here." (Somali Parent)

"I think that the most important thing is lack of information ... we do not know what to ask for... it is

1 While we use the term parent throughout, a small number of respondents were other types of caregivers such as grandparent.

child.' Check him from here, check him from there, his growth was very normal. When he was 3.5 years and you can see that the child is not normal... I mean, crying a lot, complaining about something, and not his normal usual self. That is when he referred us to a neurologist or a psychiatrist. Then the psychiatrist sent me to a neurologist. The neurologist was the first one who diagnosed him, and told me that he is autistic.... His pediatrician couldn't accept, he said 'that is not logical.' 'This child is normal and I think they are making a mistake.' Anyways while going through this period of doctor conflicts, he turned 4 years." (Somali Parent)

Similarly, a Latino and a Hmong parent recounted their stories of when they first went to the doctor with concerns about their child —

"...always went to the doctor and they always told me that he was just fine...they did some tests and they told me that he was just fine. Then later, a doctor who was a specialist told us that he had to speak because he was going to be three years old and he had to speak and he needed to know more than 15 words...then it was when we started to look for more help." (Latino Parent)

"...when I started it, there was nobody. The doctor, our doctors didn't talk to us about autism. You know, and I don't blame her because you know, you just don't think that 'Hey, this child is going to be born with autism'..." (Hmong Parent)

Despite trying to be proactive in their child's care, many parents experienced system level barriers including long wait lists and delays before services started. One parent's story of going from specialist to specialist illustrates the frustration of the process —

"I was able to get in...an appointment with the specialist, you know...cause you-I just went directly to our-my older son's specialist and said 'You know, You know I think my son has ASD and the school...this is evidence that the school has provided with' and ...they gave us some paperwork to fill out but that was during the summer and the teacher has to fill out paperwork too as well and so they weren't...in session so... the teacher still has to, you know, complete the paperwork, submit it in and then do another schedule, another appointment. And accord-

Waiting lists were an important system-related barrier common to all communities.

ing to the specialist, you know, we're on the waitlist to be seen because they're all booked...And so we're just...we just have to wait until the teacher completes the paperwork and when I last spoke with the specialist you know, she said that it's ...it's going to be a couple months because she's all booked up." (Hmong Parent)

Parents also identified a lack of cultural competency as an additional system-related barrier to early identification. They cited a lack of culturally competent service staff, a lack of cultural diversity among staff, and a general lack of culturally appropriate resources —

"We have a culture issue. It, we cannot express and tell people, oh, I need this and this. It, we get shy about that. We don't talk about it. Things, uh, hurt." (Somali Parent)

Challenges accessing services

Parents were asked about times they may have had difficulty accessing services that they felt were important for their child. It was clear from their answers that parents were under enormous stress trying to care for their child and navigate a complex system. Parents described never-ending stress associated with always being on the lookout for their child not to hurt oneself, damage property, run away in the middle of the night, or disturb the neighbors. They talked about the stress of getting rejected for services, enduring long

waiting lists, facing discrimination and other related issues and the toll of stress on their own physical and mental health.

Physical stress

"I would rather take care of ten normal children then taking care of an autistic child. It is a big challenge and it is not easy at all when it comes to those autistic children. I am so stressed and it causes me a lot of depression. So, when we have problems and he made me so stressed... I honestly went to the mental hospital twice because he stressed me out. I was so stressed out..." (Hmong Parent)

We were affected financially, physically, psychologically in every way, once you have that diagnosis. It is like a death sentence." (Somali Parent)

Stress was compounded for families from Somalia who have already experienced considerable trauma as refugees from a prolonged civil war.

Social stress

...yeah, the services are out there. They are available for everybody who you know, has car, can speak English, who can seek, who has knowledge of them. But here's the dilemma, we're dealing with a community that is immigrant, you know, refugee - who went through mental trauma who themselves, you know, haven't been treated for that. The parents themselves, of the trauma that they went through." (Somali Parent)

Many parents were frustrated about not knowing what types of resources were available, how or where to access resources or who to get support and assistance from —

"We don't know the system....My issue is how I can look and how can you look for something that you don't know? I don't know what she is eligible for. How I can look?" (Somali Parent)

Finally, parents described the stress associated juggling finding services for their child with competing demands such as work and tending to the needs of other children —

"I am a single mother with five children. Three of them attend schools and are healthy. They don't have time to learn. They (the two with autism) cut their books and tear their clothes. ...We don't have a home of our own and we live with other people. ...Even we ourselves don't get sleep; I am on the lookout for all night... Even my other children those who are in high school don't have time to learn or do their homework." (Somali Parent)

Parents also talked about challenges to accessing services that were associated with their provider. Communication problems went beyond the fact that providers often did not speak the same language as the parent or were from a different

culture. Indeed, many parents felt that their provider was not honest, did not call them back or follow up, held back important information, or treated them harshly. A Somali parent explains the frustration.

Communication challenges

"In my experience, I knew what services I needed. But the problem was [the] caseworker, who was not willing to tell me what my rights, the right that I have for my son. For example...there are a lot things that the county pays, like... respite care. There is something called respite care for the mother, not only for the child. And I knew that one. If I did not asked her, she will not tell me. So, the caseworkers and the nurses that come to your house, and then evaluate the child, they are not going to tell everything... they are withholding every information that you need it. So, if you do not know and you do not ask, you will never know, you will never find out. Plus the waiting list. The waiting list is too long even if you know." (Somali Parent)

Others spoke of direct discrimination —

"Our Hispanic children are discriminated against. We see reports that indicate that our children are not doing well. Our children are part of this country and they were born here. I was born here and I demand that our children should have the right to have education and therapies that other children are receiving." (Latino Parent)

"Every door I knock is slammed in my face with harsh language and false remarks, 'How can I help you?' 'Sit or there.' Finally I get discouraged and leave. I cannot take a step forward not to mention I have the kids waiting for me." (Somali Parent)

Finally, waiting-lists were an important system-related barrier common to all communities. Even when services were available, accessing care within a reasonable period was difficult —

"They could only operate on a small level. They can only in-intake about 30 clients. So it took a... another year ...took a year from the diagnosis to get him into...intensive therapy." (Hmong Parent)

Parents talked about being placed on waiting lists even though their child had been identified with autism years before —

"Yes, now like waiver, I applied and did not get. I am waiting 2011 up to now and we are at 2013. Two years waiting list. I was waiting [for Autism Center] for a long time, even though I finally got it. Transportation problems always exist... My child has MA which has a limitation and not many providers are accepting. All of those things." (Somali Parent)

Moreover, many parents were never able to connect to necessary resources.

Behavior analysis and other therapeutic services

Some parents felt that having access to staff who knew the specific language and culture would help parents navigate the system and connect to services and providers. For example, a Somali parent talked about what she needed —

"...first for me to get informed about what my child has rights for. After I get informed about the services my child has rights for, then to get informed about where I can get those services. Once I get the information on where to get the services, show me the way to get it and that way could be a Somali person who knows my language and can bridge the gap. For

instance that person can say, 'You are eligible for that service, your son is eligible for those 5 services, that is where you can find it.'" (Somali Parent)²

Access to insurance coverage and the costs of services were also common problems. Some parents mentioned that although they had private insurance the services they needed for their child were not covered or were only covered for a limited time. Others explained that, although they had public insurance, many of the best autism providers in the state did not accept Medical Assistance (MA). Parents often had a hard time figuring out the source of funding to pay for the services needed.

"We cannot get ABA because my child has MA [Medical Assistance]. The centers that we went to only 2 of them accept MA and those 2 centers are overwhelmed with people and they put us on a waiting list." (Somali Parent)

Parents from the Latino community shared many of the same frustrations with coverage issues, but cited concerns about immigrant status as an additional burden —

"For me, I want a PCA and they have not given it to us. The social worker has not helped us too much. I called the agency and I was told that if we do not have SSI we cannot get a PCA. I was told that I need to ask my social worker to see if we qualify. I was told that we can qualify for a family grant

but I do not see any help. I do not know information of any programs." (Latino Parent)

Housing emerged as a particularly important system-related problem in the Somali community. Space, safety, compromised rental history, financial issues associated with property damage and repairs, and alienating the neighbors were some of the issues discussed by parents talked about. They discussed their fear of landlords who refused to fix property and of inspectors who might find that their property did not meet standards. Problems with housing compounded the level of stress parents were already experiencing with raising a child with autism.

Finally, lack of support services for parents and families were commonly discussed by parents from all communities. Parents felt isolated and described how having a child with autism affected the entire family, taking a toll on their marriage and other children in the family. Parents talked about the value of networking with families who had a child with autism and being able to exchange ideas and just share frustrations:

"You know, there's ...Hmong advocates out there for parents and family who have disability needs, but there is no specifically Hmong or cultural...parent support group, you know, and I was talking more about you know, my emotions, my frustrations and when I was , you know, really heading down that emotional path. There was really no moral support to guide me back to focus on the bigger picture." (Hmong Parent)

Discussion

The results of our interviews with parents point to the strength of families. Parents have a tremendous amount of love, devotion and resiliency despite the stress and barriers faced in caring for a child

with autism. Also the results highlight parents' willingness to reach out and support others - a potential untapped resource in the community.

During the course of the study, the Somali participants formed a support group. That group created a formal organization — The Somali Parents Autism Network — that meets monthly and whose mission is "to unite and empower Somali families of children with autism in Minnesota, via outreach and education." The monthly meetings provide a venue for parents to support, learn from, and inspire each other, as well as help come up with solutions that address their needs. The support group also provides a forum for parents to enhance their self-advocacy and leadership skills. Experts in the field of autism are frequently invited to speak at meetings about ASD and other relevant issues, thereby increasing knowledge.

While parents persevere and are engaged, the current system is not meeting the needs of families who participated in this study. The obstacles to getting quality services are significant. The Somali community has been actively engaged in advocating for autism related services for over a decade now, yet still faces complex barriers to getting support for their children. The problems faced by families in the Latino and Hmong communities have not received as much attention, but should also highlight that there are significant barriers for families from culturally and linguistically diverse backgrounds. Collaboration between families and policy makers is critical to be able to build a service system that adequately meets the needs of children with ASD and their families. Participant researchers in this study worked together to identify recommendations that will make needed improvements.

2 In 2013, the Minnesota state legislature passed a law to create a new Medical Assistance Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit for children with ASD including parent/caregiver education and training, to reduce stress and improve long-term outcomes and quality of life for individuals with ASD and their families. The state of Minnesota is currently working with the Centers for Medicare and Medicaid on approval of their Medicaid waiver application.

Recommendations

The policy recommendations presented in Table 1 are built on suggestions of the families we interviewed and are designed to be a framework for action.

Table 1. Policy recommendations for improving early identification and access to services for children with autism spectrum disorders in the Latino, Hmong and Somali communities in Minnesota (MN Department of Health, 2014).

Policy recommendation	Key components
Build on the existing capacity of parents to help each other	<ul style="list-style-type: none"> Establish a program of community workers (Community Autism Workers) modeled after Community Health Workers program; Parent-leaders funded to educate peers, provide information about resources, advocate, help with health system navigation and connect families to resources; Ensure community workers are linguistically and culturally competent; Include members of each community as partners in decision-making on all task forces, grant opportunities and policy-making bodies on matters related to ASD.
Develop resource centers housed in the community	<ul style="list-style-type: none"> Fund one-stop resource centers in the community; Support the development of a center specifically for Somali community, providing culturally appropriate services to children with the most severe disabilities; Staff centers with linguistically and culturally competent staff who are knowledgeable about ASD and resources.
Provide resources to form support groups for families	<ul style="list-style-type: none"> Fund community agencies to hold support groups for families within these communities Identify culturally and linguistically appropriate respite providers.
Build capacity in the system to provide culturally sensitive services and decrease waiting times	<ul style="list-style-type: none"> Support workforce development for ASD service providers including community workers; Implement a surveillance system that tracks wait times by cultural community; Dedicate staff at the county level who are specialists in ASD, reflecting the linguistic and cultural backgrounds of the population they serve; Set targets for wait times; monitor and evaluate progress; Education of physicians about proper screening and evaluation of autism; Develop and pilot an intervention to improve communication between professionals and parents; Bring mobile screening services to the community, including staff that are culturally and linguistically competent; Monitor disparities in services, include waivers provided to publicly insured children; Ensure that schools have the capacity to provide quality, evidence-based services to children with ASD; More frequent meetings between parent and school where interpreters are available; and Greater accountability of school system for quality and adequacy of autism services provided.
Continue to address problems with insurance coverage and costs	<ul style="list-style-type: none"> Monitor the impact of autism insurance reform on use of services by children from different cultural communities; Ensure that comprehensive autism services are specified as “Essential Health Benefits” in health exchanges; Include non-documented children in Medicaid coverage; Provide help with enrollment and benefit information that may be viewed as trustworthy and non-threatening, for example reimbursing the support of Community Autism Workers.

References

- Handelman, J.S., & Harris, S.L. (eds.). (2008). *Preschool education programs for children with autism, 3rd edition*. Austin, TX: Pro-Ed.
- Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J., & Reiff, M. (2013). *Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013*. Minneapolis MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Israel B.A., Schulz A.J., Parker E.A., & Becker A.B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19: 173–202.
- Minnesota Department of Health. (2014). *A qualitative study of families of children with autism in the Somali community: Comparing the experiences of immigrant groups*. Minnesota Department of Health: Report to the Minnesota Legislature. Available at: <http://larchive.leg.state.mn.us/docs/2014/mandated/140404.pdf>
- Vismara, L.A., & Rogers, S.J. (2010). Behavioral treatments in autism spectrum disorder: What do we know? *Annual Review of Clinical Psychology*, 6: 447–468
- Donna D. McAlpine**, PhD, is an associate professor with the School of Public Health, University of Minnesota and the Director of the MPH program in Public Health Administration and Policy. She is a medical sociologist whose research focuses on alcohol, drug, and mental health care, and racial and ethnic disparities in health outcomes and treatment.
- Mariam Egal**, MPH, is with MN DHS- Disability Services Division-ASD operational team as a multicultural training & outreach coordinator. She is a MN LEND fellow with an MPH in International Health from Morehouse School of Medicine in Atlanta, GA. Ms. Egal has experience in community based research in area of health focusing on multicultural communities, Somalis in particular. She has been engaged in working with Somali families of children with autism at different capacities including but not limited to education, capacity building, and research. In her current position at DHS, she continues this work with a new lens. The goal still remains the same, closing the gap in understanding of ASD and access to services and resources for multicultural families of children with ASD.
- Shannon Pergament**, MSW, MPH, works with the Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo), a community driven translational research program of West Side Community Health Services, Inc., where she is co-director of Community Based Research. Previously Ms. Pergament served as program director of the Minnesota Migrant Health Promoter Program from 1996–1999 at the University of Minnesota, where she developed a background in popular education, Community Based Participatory Action Research (CBPAR), curriculum development and program evaluation. Ms. Pergament holds Master's degrees in Public Health and Social Work from the University of Minnesota.
- Walter Novillo**, JD, MA, is a community researcher with the SoLaHmo Partnership for Health and Wellness. SoLaHmo works in tandem with community members, researchers, and health care providers to make a positive difference in community health. Mr. Novillo has extensive research and program development experience and has served as program director of TRiO programs, charter schools, and postsecondary institutions. In addition to his J.D. degree and Master of Public Affairs degree, Mr. Novillo is completing his PhD from the University of Minnesota.
- Mai Khou Yang**, MSW, is a social work specialist with MN DHS-Community Support Services and is also a community researcher with SoLaHmo Partnership for Health and Wellness. Ms. Yang has prior research experience as a Project Assistant at the University of Wisconsin-Madison Waisman Center. She also worked as a Dialysis Social Worker in the Twin Cities for two years. Ms. Yang completed her MSW degree at the University of Wisconsin-Madison and is currently working towards becoming a Licensed Clinical Social Worker.

MN LEND webinar

If you are interested in learning more about effective strategies to work with Hmong families, you might want to access this webinar. It was developed by MN LEND staff and fellows. Click on the link below.

Building connections with Hmong families Culturally competent approaches to child development

<http://lend.umn.edu/forums/hmongconnections.asp>

This webinar is designed for professionals interested in learning more about culturally specific and relevant strategies working with Hmong families with young children. Cultural views of disability and child development are discussed. Resources and materials from “Learn the Signs. Act Early.” (LTSAE) are highlighted. Newly translated LTSAE materials are now available in Hmong on the website.



Autism in Africa: A Zambian perspective

Mikala Mukongolwa, BA and Kelly Nye-Lengerman, MSW

Zambia is a land locked country in Africa with a population of almost 15 million. Approximately 980,000 Zambians are living with HIV/AIDS making it one of the nation's most pressing health issues. Zambia's Ministry of Education is responsible for providing public education to Zambian children offers special education services to children with disabilities who are visually or hearing impaired. The Ministry has also provided special education to children with intellectual disabilities. While the central Ministry is charged with providing public education, a lack of resources and infrastructure makes universal education services difficult, and special education services are even more fragmented. Despite a lack of a strong centralized special education system, interest in Autism is growing from teachers, families, and communities.

Growing interest in Zambia

Autism is becoming a more commonly known disability in Zambia as new information is shared with parents, educators, families, and the public. Reports from the Centre of Excellence pediatric wing at the University of Zambia Teaching Hospital (2010), and the Zambia Home Based Education Program (2013) indicate the number of children with an autism spectrum disorder (ASD) growing in both rural and urban settings.

However, in Zambia children with ASD and other disabilities are mostly neglected by the society due to the challenges they have with communication and behavior. In many cases these children and adults are labeled as "mentally sick." There is a great deal of fear in Zambia about people with disabilities because disability is not well understood.



Building partnerships

In an attempt to build connections between Zambia and disability providers in Minnesota, the Twin Cities Zambia Disability Connection was formed in 2008. Through this partnership and information exchange, families and professionals from Zambia have traveled to the United States, and in return Minnesota advocates, researchers, and educators have traveled to Zambia. This interactive exchange has fostered new growth and learning in each of the respective countries. In 2011, a group from the University of Minnesota's Institute on Community Integration (ICI) provided specific information to families and educators on Autism. Since that time, parents and teachers have asked for more information on autism as they are finding that this group of children present unique and different challenges (e.g. behavior, limited communication, and challenges with skills of daily living).

Teachers and professional teaching groups have reported challenges in teaching children with Autism because most of these children struggle using verbal language. The Zambian education system relies heavily on

spoken and written language skills. Without special education opportunities or modified curriculum, teachers find it challenging to engage the children with ASD. There is currently no mechanism to identify children with ASD in Zambia before the age of 7 when they enter school. This leads to missed opportunities to provide critical early intervention services.

In 2011, visit both formal and informal sessions were set up with families, teachers, and government liaisons to discuss the challenges and opportunities in working with children with ASD. In conjunction with Zambian partners, the University team provided onsite training for special education teachers in the Zambian capital of Lusaka. The training focused on positive behavior supports, characteristics of children with Autism, and the promotion of community integration and disability rights. In addition the University team worked with individual families, teachers, and schools to provide on site training in working with their specific students with Autism. Although the University team came prepared to provide additional training on early screening and assessment it quickly became apparent that

these were not the types of services that were needed. It was irrelevant if a child had a formal diagnosis in Zambia, rather it was critical that a child's family and teachers felt like they had the knowledge to provide social and educational opportunities to improve the child and family's life.

Home based education program (HBEP)

To date, there are no coordinated services for children or adults with ASD in Zambia. Presently the Bauleni Special School located in Lusaka is the only school attempting to teach children with ASD in a classroom setting. Much of the support for children with autism is being provided by the Zambia Home Based Education Program (HBEP), which was developed by staff at the Bauleni School. Teachers through the HBEP travel to villages and family homes to meet with children and their families to provide basic education and skill development services. Currently staff from the HBEP are attempting to utilize screening tools as a way of promoting early identification and intervention. However, the challenges are still great. Despite the desire of a small team of educators to support children and families, the lack of infrastructure and resources provide a significant barrier to service access. Zambian professionals report that adults with Autism receive no services and are left at home with little to no interaction.

Family supports

In rural villages families of children with ASD receive virtually no supports or services. Thus, the HBEP is essential. Many of these families and small communities build their own informal infrastructure to meet the needs of children with ASD. Rather than waiting for government or NGO support, these families banded together, although not always in visible ways, to provide support for

each other and movement towards a common vision of education for their children. Many families also had developed natural supports within the family or community to help care for their children. These relationships are a source of strength and great resource and provide opportunities for integration and education for children with disabilities. Providing basic information in these informal settings on learning strategies, positive behavior support, and inclusion were some of the most powerful exchanges.

Currently other Non-governmental organizations are attempting to reach out to members of the Zambian community to build knowledge and infrastructure, and resources for families of children and adults with disabilities. A Special Hope Foundation and *CLASP International* (Connective Link Among Special needs Programs) are developing services for children with Autism along with specialist services. Zambian graduates of CLASP training programs will be charged with providing Speech and Language services to children across Zambia, but it is unclear if this program will meet its intended targets due to lack of infrastructure and well trained teachers.

The University of Zambia and the Zambia Institute of Special Education have begun to conduct screenings of children with various special needs including ASD. However, many professionals are left frustrated because screening is only a portion of the need. Currently, teachers are not trained on how to provide interventions to students with disabilities. Consequently, there is poor educational support and training.

A local study on the effectiveness of using the picture exchange strategy (PECS) in helping children with Autism to communicate (Mukongolwa, 2014). This study demonstrated that children with autism can be helped to address both behavior and communication skills through the use

of the picture exchange strategy by working with parents/caregivers as well as family members in the introduction of the strategy so that the strategy becomes part of the child's daily life. Despite the use of PECS producing positive findings Zambian professionals and other educated citizens found this work confusing and did not understand the nature of Autism, still choosing to label individuals with Autism as "mentally sick."

Zambian parents, teachers, advocates, and leaders can be a source of knowledge and strength as the country moves forward in developing infrastructure and services for children with ASD. From the University of Minnesota team's perspective Zambia's greatest resource lies in families and advocates themselves. They provide the key knowledge and vision to build more accessible and inclusive communities. With additional knowledge and supports provided by key Zambian professionals many families continue to become empowered and proud to support their children with disabilities. Many Zambians invite collaboration with international partners in an attempt to work together to improve the quality of life and services for Zambians with Autism.

Read more about the Twin Cities Zambia Disability Connection at: <http://twincitieszambiadisability-connection.blogspot.com/2008/01/twin-cities-zambia-disability.html>

Mikala Mukongolwa, Head teacher of Bauleni Special Education School, and one of the founders Zambia Home Based Education Program; a program that serves children with significant disabilities in their home and empowers parents to teach their own children. Ms. Mukongolwa conducted the first research on Autism in Zambia. She is currently pursuing a master's degree in Special Education from the University of Zambia.

Kelly Nye-Lengerman, MSW, LGSW, is a project coordinator at the University of Minnesota's Institute on Community Integration. She traveled with other University staff to Zambia in 2011 to provide and exchange disability related information with families, advocates, and professionals.

A Latino focus within autism: Moving forward with Grupo SALTO

Matie M. Ovalle, UIC LEND Family Faculty and Angelica Davila, 2013-14 UIC LEND Fellow*

In an effort to meet the void that many Latino families experienced Grupo SALTO (Sociedad Autista Latina Trabajando con Optimismo) was founded by Latino parents of children with autism spectrum disorders (ASDs) and Hispanic program staff from the UIC Developmental Disabilities Family Clinics (DDFC) in 2003. Over the years Grupo SALTO has continued to grow to meet the interchanging needs and interests of families and children with Autism Spectrum Disorder (ASD). Grupo SALTO aims to provide support for Latino families that have children with ASD by providing culturally and linguistically appropriate training, education, and services.

In 2007, The University of Illinois at Chicago (UIC) conducted a formal family needs assessment of Latino parents of children with ASD. The results produced an overwhelming concern regarding the therapy and services that Latino children with ASD received, as they were limited to school hours within a school setting. Barriers toward participating in out of school therapy and services included language, finances, transportation, ASD awareness, and cultural comfort. Latino children with an ASD were missing the much needed recreational and community opportunities that would help them develop skills and interests of importance to develop a future of independence. Consequently, Grupo SALTO and Latino Autism Society Working with Optimism with the support of the DD Family Clinics' Hispanic team developed a comprehensive arts, dance, music, and sibling support group called "SALTO al ARTE" ("Jump into the ARTS") where children and adults rotated between the different



arts disciplines while parents attended monthly meetings related to ASD needs and services. This became one of the varied programs offered by Grupo SALTO.

To encourage more participation from prospective group parents, the organization also offers childcare in conjunction with its "SALTO al ARTE" program. Currently the dance class transitioned to the Chicago Park District in collaboration with The Mexican Folkloric Dance Company of Chicago.

In 2013, 450 registered families were a part of Grupo SALTO which had become the largest organization for Latino families with ASD in Illinois. An average of 50 families attend each monthly session; as well as 35-45 children, adolescents, and adults participate in the artistic programs, social group for individuals with ASD, sessions for persons with ASD, siblings' group, and child-care. Each monthly session is still conducted with the DDFC Hispanic Team staff. The Autism Program of Illinois (TAP), current and former Illinois LEND trainees, parents, and volunteers also participate. Grupo SALTO has no employees and relies

on annual fundraising activities, such as a banquet, donations, grants, and membership fees to sustain its programming.

Since the development of Grupo SALTO, various collaborations and success stories have occurred. These resulting projects align with the mission of the organization.

Empowering the ASD community

A Former IL LEND trainee worked with Grupo SALTO in coordinating and facilitating a group composed of five young adults with ASD using the Child-to-Child concept and methodology. The Child-to-Child concept is that children can act as mentors to other children on issues that are important to them. There are four steps in the Child-to-Child method, which are to observe, study, act, and evaluate. Using this approach participants that engaged in Child-to-Child programs showed a growth in the personal, physical, social, moral, and intellectual development (Khamis, 2006; Kangwa & Bonati, 2003; Hawes, 2003; Hanbury, 2007). Grupo SALTO wanted to use the Child-to-Child concept and methodology to



voice the concerns of children with ASD, as it had not yet been used with this population.

"Tu y Yo: A Child-to-Child approach to promoting social integration in the classroom" was implemented thanks to a grant from The Autism Program (TAP). The young adults in the group focused on the issue of bullying toward children with ASD using the Child-to-Child approach. The group concluded that a key root in bullying stemmed from the lack of knowledge and myths surrounding ASD. In order to act on this issue, the group created an English and Spanish Power Point titled, "Myths and Facts about Autism".

The group presented these results at a Grupo SALTO benefit banquet and at a local YMCA. They also presented a more age appropriate presentation, "Fez and Elwood", to local schools. The message was still the same: to embrace people's differences.

The success of *"Tu y Yo"* is reflected in the support that they received from their audiences. The young adults that participated in *"Tu y Yo"* have planned to continue the program and conduct more activities with children during Grupo SALTO sessions. They have also expressed an interest in continuing to promote

the Child-to-Child approach at local schools.

Lending a hand for ASD awareness

IL LEND trainees have continued to support the mission of Grupo SALTO by coordinating several projects with them. A former trainee organized community screenings for ASD for Grupo SALTO's registered families at the monthly sessions. She also coordinated a LEND team for 2014's Walk Now for Autism Speaks in Chicago. She worked hard not only to assemble the screenings, but also in rallying up her fellow LEND trainees to assist in the screenings. This was familiar work for many of the trainees, as they had previously helped out with another Grupo SALTO sponsored screening events.

Bridging opportunities for young adults with ASD

A prominent worry that Grupo SALTO members have is what will happen to their child once they finish high school. It is a concern that is expressed at several of the monthly sessions. In order to address this concern and need in the community, Grupo SALTO has promoted its Sum-

mer Transition Program for the last four years. The program focuses on helping young adults with ASD enter college or other vocational endeavors by reinforcing college-essential skills, as well as providing them with ideas of how college will be different than high school.

The program consists of eight sessions within four weeks, and includes of both a young adult and parent group. DDFC Hispanic Program, and TAP staff help facilitate the parent group, while another team leader coordinates and facilitates the young adult group. DDFC staff mirror the topics discussed among the young adults during the parent sessions. The team leaders for the young adult group have mainly been former LEND trainees. The program also gives two young adults with autism the opportunity to work as classroom assistants, providing them with employment and leadership experience.

The success of the Summer Transition Program can be seen in the participants' responses. Since there is communication between the parent group and the young adult's group team leader, parents may often be surprised at the skills that their children possess. The young adults also benefit from the program's not

only college readiness knowledge but also in practicing social skills with each other. In fact, the last session of the program is usually reserved for a social event, such as going out socially together. Here, the young adults are able to converse about similar interests.

Connecting parents through ASD interventions

Leadership is a skill that Grupo SALTO helps facilitate in families. An example of this is the Bilingual-Spanish IEP Parent Support Specialist training. During a six-part training, parents learned how to become IEP coaches for other parents to best resolve disputes that may arise between the schools and the parents of children with ASD. Another example of the leadership that parents may partake in is the *Promotoras de Salud /Parents Taking Action*, a research study at the Department of Disability and Human Development University of Illinois at Chicago where mothers of children with ASD are trained to mentor other mothers of children with ASD. The goal is that parents can mentor each other to create a better system of interventions.

Creating success stories with each step

In 2013 a grant from the UIC Institute for Policy was used to promote civic engagement to promote special education advocacy training for families of children with disabilities. The Family Clinics partnered with TAP, Easter Seals of DuPage County, Grupo SALTO, and the Family Resource Center on Disabilities. They set up a series of trainings with a focus on the reauthorization of the Individuals with Disabilities Education Act (IDEA). They also conducted training in Spanish for the Latino community. At the end of the training, participants recorded their testimonials regarding the experience. These testimonials can be seen at the Family Clinics website: http://www.ahs.uic.edu/dl/family_clinics/advocacy/.

During this past summer, Latino fathers who attended Grupo SALTO sessions were encouraged to participate in a Father's Retreat called *La Esperanza: Creciendo y Mirando Hacia Adelante* (Growing and Looking Forward with Hope). Six fathers participated in the all day retreat at the Family Clinic. The group was composed of new opportunities to learn more about ASD and self-care

as a parent to a child with a disability. The open-question environment was aided with activities to facilitate the sharing of experience. The Father's Retreat stemmed from an annual women's support group, also called *La Esperanza*, which meets during the fall.

More success stories can be found in the Family Clinics Newsletters, available at: <http://www.ahs.uic.edu/cl/familyclinics/newsletter/>.

Conclusion

With the help of parents, volunteers, DDFC/TAP (The Autism Program) staff, and IL LEND trainees, Grupo SALTO is able to move forward with its mission. The organization creates opportunities for parents of children with ASD in leadership trainings and ASD education, as well as opportunities for young adults with ASD to have a voice of their own. As Grupo SALTO grows, it will continue to lessen the void felt by many families in the Latino community upon learning someone in their family has ASD. Creating a culturally embracing environment with volunteers that care about providing much needed services is what we are all about.

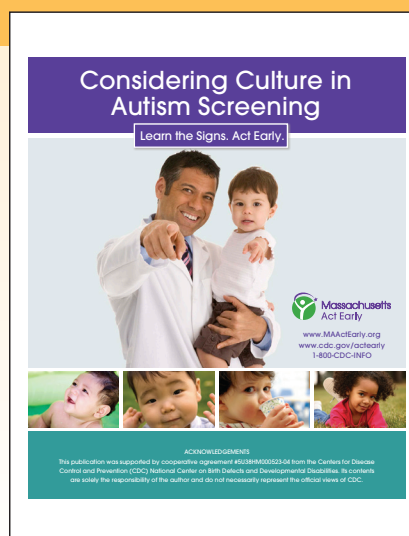
Massachusetts Act Early

This resource is available for everyone to use. Learn more by clicking on the link below.

Considering culture in autism screening kit

www.maactearly.org/considering-culture-screening-kit.html

The Massachusetts Act Early team developed materials for pediatric clinicians and community health center providers to use when conducting autism screening with children from families whose primary language is not English. These free materials may be downloaded and printed for use in practice.



Taking care

Maria and Eileen discover support in TAP Center at UIC Family Clinics

When her daughter Eileen was first diagnosed with ASD at age three, Maria felt lost. "Eileen wasn't like other kids. She didn't show emotion, play with toys, or talk," her mother explains. "I felt very sad, thinking about my daughter's future. I didn't know what to do or where to go." But then Eileen's social worker referred Maria to Family Clinics at University of Illinois-Chicago. This center, now run in partnership with The Autism Program of Illinois (TAP) under The Hope Institute, offers clinical services to children with ASD.

Eileen's speech and language interventionist at the TAP Center/UIC Family Clinics has helped her develop skills she once struggled with — processing information, taking turns and good sportsmanship. She's taught her how to express her emotions and helped her build social skills by working in groups with other kids.

Today a vibrant, loving, 11 year old, Eileen has reached many goals and continues aiming for new ones. Now Eileen is developing her concentration

skills. She practices therapeutic games to help her focus her attention, then applies the skills she learns in school.

Eileen's love of dance also helps her focus - and build relationships. ASD makes it hard for Eileen to relate to other children her age. They often see her as different and don't understand her. But her participation in a Mexican dance troupe for the past three years has allowed her to socialize with other kids in a setting where she feels at home. Her best friend, Tony, is in the dance company.

Maria has found solace at The TAP Center, too. She participates in Grupo SALTO a monthly parent support group for families that have children with ASD and that addresses topics such as behavior management strategies, communication and navigating special education services at school.

Today, Maria no longer feels lost. "I'm amazed at the progress Eileen has made. If it weren't for the clinic, I don't know where we would be today." One of Eileen's favorite places to be is on stage with the Mexican Folkloric Dance Company of Chicago.



The Mexican Folkloric Dance Company of Chicago performers (3 of them with with an ASD)

Minneapolis Somali autism spectrum disorder prevalence

Kristin Hamre*, MPH and Anab Gulaid, MPA

Introduction

The Centers for Disease Control and Prevention (CDC) estimates one in 68 children have ASD (CDC, 2014). This prevalence rate is estimated via the CDC's Autism and Developmental Disabilities Monitoring Network (ADDM). Autism spectrum disorder (ASD) is a group of developmental disabilities that can cause significant social, communication, and behavioral challenges (CDC, 2014). In 2008, Somali parents and others in the Twin Cities metro area expressed concern about the seemingly higher rate of Somali children enrolled in preschool special education programs. MDH agreed to examine administrative data and in 2009 released a report describing the higher proportion of Somali preschoolers' participation rates in public school

programs serving children with ASD. In response to this report and ongoing advocacy efforts, the CDC, along with the National Institutes of Health (NIH) and the advocacy organization Autism Speaks, provided technical assistance and funds to the University of Minnesota to examine the issue.

Purpose and method

The ADDM methodology includes record review of children's health and, when available, education records. Records are reviewed for triggers, as defined by the CDC that may indicate ASD. Records are abstracted for information and then reviewed by trained and reliable clinician reviewers to determine case status.

The project replicated the CDC's Autism and Developmental Disabilities Monitoring Network (ADDM)

methodology to estimate prevalence of ASD in Minneapolis, MN. The primary goal of the project was to determine whether there are differences in ASD prevalence between Somali and non-Somali children. The project conducted surveillance in the city of Minneapolis to determine an ASD prevalence rate for children between the ages of seven and nine who had one parent or legal guardian living in the city of Minneapolis in calendar year 2010. The project accessed health records as well as education records at Minneapolis Public Schools and several charter schools.

While the project closely replicated ADDM methods, unique to this project was collecting information on Somali status, as well as the convening of an advisory board made up of community stakeholders.

Figure 1. Estimated prevalence of ASD per 1,000 children aged 7-9 years, by race/ethnicity and Somali status: Minneapolis, Minnesota, 2010 (Hewitt et al., 2014)



Race and ethnicity	Children with ASD identified/ Total population	Prevalence estimate (prevalence per 1,000 children)	95% Confidence interval*
Overall	255 of 12,329	1 in 48 (20.7 per 1,000)	18.3 — 23.4 per 1,000
Somali	31 of 1,007	1 in 32 (30.8 per 1,000)	21.6 — 43.8 per 1,000
White	120 of 4,336	1 in 36 (27.7 per 1,000)	23.1 — 33.1 per 1,000
Black (non-Somali)	53 of 3,312	1 in 62 (16 per 1,000)	12.2 — 20.9 per 1,000
Hispanic	30 of 2,399	1 in 80 (12.5 per 1,000)	8.7 — 17.9 per 1,000

Note: We are unable to report on Asian/Pacific Islanders and Native Americans due to their low numbers.

* 95% confidence interval is the range in which an estimate is likely to fall.



Results

Analyses were conducted by researchers at the University of Minnesota and the Minnesota Department of Health, as well as independently verified by analysts at the CDC (Hewitt et al., 2014). Somali and White children were about equally likely to be identified with ASD with prevalence rates of 1 in 32 and 1 in 36 respectively. Somali and White children were more likely to be identified than Black or Hispanic children, who had prevalence rates of 1 in 62 and 1 in 80 respectively. In records, which included Intelligence Quotient (IQ) data, Somali children with ASD were much more likely than all other groups to also be identified as having an Intellectual Disability (ID).

The average age when children were diagnosed with ASD was around 5 years for Somali, White, Black (non-Somali), and Hispanic children. Children with ASD can be reliably diagnosed around 2 years of age, suggesting a need for further research to understand why children, especially those with ID, are not getting diagnosed earlier.

For the children found to have ASD, evaluations were found in either health, education, or both types of sources. Somali, White, Black (non-Somali), and Hispanic children with ASD were about equally likely to be identified at school and health sources.

Further, a focused discussion occurred in an effort to gain insight in to the perspectives of community members about how ASD affects families. Community members and providers shared the stigma around an ASD diagnosis, and both challenges and joys and strengths they have gained through the process of caring for a child with ASD. Among the many important perspectives shared was the perception that Somali families are not being reached, and are often unaware of what services and funding are available for their children with ASD.

Limitations

The results are limited to Minneapolis, Minnesota. The findings suggest a need for additional research on how and why ASD affects Somali and non-Somali families differently.

Recommendations

The findings from this project are relevant to families, service providers, advocates and policymakers, as well as researchers. In addition to raising awareness and promoting early identification, the results are useful for planning for service delivery system needs, developing policy to promote early identification and equity in access to services, and to inform future research, including that focused on identification of tools which take in to account cultural differences to screen and diagnose children with

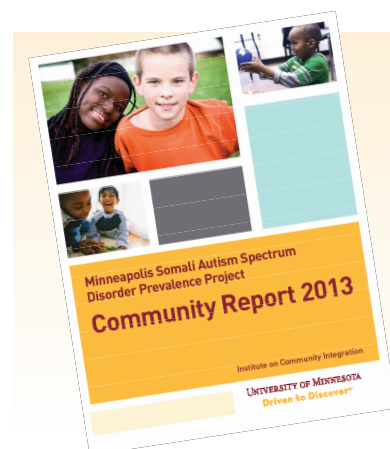
developmental disabilities. This study is limited to estimating prevalence and does not investigate causes of ASD, an important area for additional research.

References

- Centers for Disease Control and Prevention (CDC). (2014). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity & Mortality Weekly Report*, 63 (No. SS 2), 1–21.
- Hewitt, A.; Punyko, J.; Esler, A.; Hamre, K.; Reichle, J.; Hall-Lande, J.; Gulaid, A.; Adawe, A.; Parker-McGowan, Q. (2014). *Minneapolis Somali Autism Project Technical Report*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Kristin Hamre, MPH, is a research assistant at the University of Minnesota's Institute on Community Integration, where she works on an interdisciplinary team exploring the prevalence of autism spectrum disorders in the Twin Cities Somali community. She is concurrently working towards her PhD and MSW in the School of Social Work at the U of M.

Anab A. Gulaid, MPA, has worked in public health policy and prevention, nonprofit management, program development, qualitative research, and community building. Ms. Gulaid is involved in number of research and training projects that call for the collaboration of community providers, and advocates of people with intellectual and developmental disabilities. She has an Environmental Health degree from Ryerson University and a Masters of Public Affairs from University of Minnesota's Humphrey Institute of Public Affairs. She was a Bush Leadership Fellowship recipient in 2009-2010.



Learn more

For more information about the project and links to helpful community resources at can be found online at

rtc.umn.edu/autism.

Developing intervention programs for culturally diverse communities

Beth Fagin, LICSW and Susan Berdahl, BA

St. David's Center has operated a successful autism day treatment program for six years at our Minnetonka campus. The process of customizing the program to effectively serve a new immigrant populations from a rich and vastly different cultures has proven to be a challenging and incredibly rewarding experience.

St. David's Center has a rich history of serving a diverse range of children and families across the Twin Cities area for more than 50 years. In the past year, we served more than 2,400 individuals with a variety of developmental services, including early childhood education, pediatric therapies, mental health services and services supporting those with enduring special needs. As we have grown, we have seen an exponential increase in need for ASD services. While one in 88 children was diagnosed with ASD when we first launched services specifically designed to treat it, statistics now show that one in 68 children is on the spectrum (CDC, 2014).

Three years ago, we recognized that there was an especially great need for ASD-specific early intervention in the Metro area's growing Somali community. Public school districts were seeing large numbers of Somali students struggle in the classroom and exhibiting behaviors often associated with ASD, and we saw the need first-hand when Somali children began enrolling in our autism day treatment program in Minnetonka.

When the University of Minnesota study released in December 2013 identified one in 32 Somali children in Minneapolis Public Schools having ASD (Hewitt et al., 2014), our plans to create a culturally responsive program were already underway.



We began our journey by requesting funding from the Medica Foundation to help develop and design the critically needed program to suit Somalis. Our existing ASD day treatment model primarily served

community perceives ASD and ASD treatment. They were also an invaluable resource in connecting us with the larger community, getting educational and religious leaders on board with stressing the importance

The cultural guides and consultants we had were invaluable in connecting us with the larger community, getting educational and religious leaders on board with stressing the importance of early intervention, and garnering support and acceptance for the day treatment program we intended to launch.

caucasian children and non-immigrant families, so we had to carefully research and think about how to modify that program to best serve Somali immigrants. The Medica Foundation granted us funding for staff time to assemble an advisory board that included two key members of the Somali community: one with early childhood education experience and another with experience in public health and health initiatives. These individuals were vital to helping us understand how the Somali

of early intervention, and garnering support and acceptance for the day treatment program we intended to launch.

We believe a key component to the success of our autism day treatment program in Minnetonka has been how it operates alongside our early childhood education program, which serves typically developing children. Not only does this structure allow for families with children of varying developmental abilities to access care for all of them in a single

place, but children in treatment also have the opportunity to interface with a “typical” school setting. In fact, when children in day treatment are getting ready to graduate from the program, they spend time in regular classrooms to experience interactions and develop skills that will prepare them for entering mainstream kindergarten.

The Somali members of our advisory board helped connect us with Children’s Choice Center (CCC) to replicate this side-by-side childcare center model at our new site as well. CCC, a licensed childcare serving infants through school-age children, is owned and staffed by Somalis dedicated to serving the community. We are now co-located at a site in northeast Minneapolis and growing together.

While working out these logistics for our new ASD day treatment site were challenging, the most formidable barrier we’ve faced is explaining across culture what day treatment is for a small child. There is still some stigma and denial in the community about the prevalence of ASD, but many Somali-led organizations and groups have also stepped up to address the crisis ASD is presenting within the community. These groups have given resource information and emotional support to families. However, while these advocacy groups have given a voice to the issues, no one who is culturally knowledgeable has been in a position to treat children with ASD. This “missing piece of the puzzle” was our call to action and the key to St. David’s Center deciding to make a difference within the community.

We began by hiring three Somali mental health staff members to work at the site as paraprofessionals and mental health practitioners. They trained alongside our team in Minnetonka to learn how our treatment model works before moving over to the new site. Also moving over to

the new site were some of our most experienced occupational therapists, speech and language therapists and mental health professionals. Together they have made culturally informed and supported treatment possible.

Our Somali staff have proved to be crucial to the day treatment site’s

connection of that child’s family to our services and in gaining a high enough level of their trust to enroll him or her. Once a child is participating in the program, our staff have seen cultural difference quickly drop away. As Somali staff members say, “Parents love what their children

We tell parents of children struggling with ASD, “Everything in the program is designed just for you and you can feel safe. You are coming to a place where you won’t get lost.”

success both inside the treatment room and in the community. The Somali representatives on our advisory council educated our staff on the Somali “oral culture” and informed us how to best market and explain our day treatment program to families affected by ASD within the community. They spoke of the importance of word-of-mouth information and face-to-face meetings as the most effective methods rather than brochures and written public announcements, so our Somali staff have gone door-to-door with child development materials in Somali neighborhoods. The effort has been hugely successful, with our staff being not only invited into homes, but also being told about and connected with other struggling families with children on the spectrum. Additionally, our staff have hosted events to educate and inform the community, as well as at-

love. They see all staff interacting in a positive way. Children are comfortable. The language between parent and some of our staff may be a barrier, but the happiness they see when their child works with staff overcomes and outweighs that.”

Lessons learned

Developing any new program takes time and patience. When developing a program that reaches beyond the majority culture and into another community, it is incredibly important to —

- **Secure funding that will allow taking time for understanding that culture before proceeding.** It is also crucial to be flexible and patient during the process.
- **Allow enough time.** Plan that launching the program will take more time than you originally

“When I go on home visits, I go into the homes of our families, take off my shoes, chit chat, have tea, and they pour their hearts out to me. This level of rapport is not impossible for people of a different culture, but more likely to develop quickly when a family can recognize that a person will already understand their language and culture.” ~ Izhar Mohamed, St. David’s Center mental health practitioner

tended Somali-organized health and education events to represent and promote our program.

Treating a Somali child with ASD has its greatest barriers in the initial

expected, and make sure you get the right people in place to help. Our cultural consultants, guides and advisory board members were vital to getting the model of the new site correct, and we would not have had

success without the support and information they provided.

- **Incorporate native members of the community into your program staff.** When an initial phone call or first visit is done by someone representing the client's culture, there is an implied level of understanding and ease of communication that makes the process more comfortable, and therefore more accessible and effective.
- **Expect to learn and grow professionally.** Working cross-culturally will present possibilities and opportunities for learning that are impossible to anticipate. You must remain open to what changes from your original planning may arise.
- **Approach developing the program by first considering the strengths that already exist.** We have learned that Somali families are strong advocates for their children, and have not let language or cultural barriers stop them from seeking resources. Once they have enrolled their children in our program, the parents want to know what they can do at home to continue to learn, grow and support their treatment.
- **Be aware that a universal perspective of disability does not exist.** Disability is perceived differently by different cultures and even among individuals within one culture. For nearly all parents of children with ASD, no matter to which cultures they belong, there is a level of denial and finding a level of acceptance with the diagnosis is incredibly personal. Our staff have found that more and more people in the Somali community are accepting that ASD cannot be "outgrown" but that resources exist to help families living with it. The families we are currently serving show that they are now comprehending a diagnosis of

ASD and the treatments available by making statements like, "I wish I knew this before," and that they understand the importance of early intervention by making statements like, "I wish I had done this earlier."

- **Recognize that systems can be complex and confusing, and that it is important to avoid jargon and be able to explain mental health services and billing in multiple ways.** Explaining our system of mental health services and billing is a challenge across all cultures, but in the Somali language there are few words that even describe the specific elements included within that system. Even some of our native Somali staff have found themselves struggling to find the right words to explain the components of our day treatment program in a way that makes sense to families, so they focus on emphasizing big concepts, such as that day treatment will provide safety and hope. One of our Somali staff members said, "I tell the families I talk to whose children are struggling with ASD that everything is designed just for them and that they are coming to a place where they won't get lost." They are able to explain the context of the program more fully because they saw how it works at our site in Minnetonka, proving that training time they had was critical to the new site's success.
- **Be open to possibilities.** Knowing we had a program that works was a great start, but we had to be flexible and open to other possibilities in order to adapt to and respect cultural needs. We created a team of experienced ASD staff working alongside culturally knowledgeable Somali staff, and there has been a mutual learning curve for both parties. The team

has already evolved to the point of being able to ask and tell each other how to be most effective, whether it's in treating ASD or in interacting and understanding a Somali family in a way that respects cultural needs. For example, we are closing our program for Somali holidays, are mindful of the fasting that happens during Ramadan and are honoring religious dietary restrictions in the program. In respecting the Somali "oral culture," and the universal need for parents to connect with others experiencing the same issues, we have also modified the program to add more time than what is included in our original treatment program to bring families together to meet each other and connect. The Somali support group is lively and an important part of needed support for the families.

Conclusion

We have learned that bridging a cultural divide takes time, patience and deep respect for the process. It is not only important to strive to understand the elements embedded within the culture of the families a program serves, but also to understand the boundaries and barriers that exist in our own culture and systems.

References

- Centers for Disease Control and Prevention (CDC). (2014). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity & Mortality Weekly Report*, 63 (No. SS 2), 1–21.
- Hewitt, A.; Punyko, J.; Esler, A.; Hamre, K.; Reichle, J.; Hall-Lande, J.; Gulaid, A.; Adawe, A.; Parker-McGowan, Q. (2014). *Minneapolis Somali Autism Project Technical Report*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

OICALI: Working together across agencies, across the state, and across the lifespan

Donna M. Owens, MA, Amy Hess, BA, MA Certificate, and Jody Fisher, M.Ed.

Introduction

The state of Ohio established a planned infrastructure to coordinate the state response to the growing needs of its citizens with autism spectrum disorder (ASD) and their families. It is important for there to be a systems approach to ASD so that effective programs, policies and services can be developed, implemented and evaluated that will have the greatest impact on providing supports and services to children, youth and adults with ASD. States approach these coordinated efforts in many ways. This article describes the state of Ohio's approach.

The Ohio Center for Autism and Low Incidence (OICALI) was established in legislation in 2005 and is designated as Ohio's statewide ASD center. OICALI is a shared resource for ASD that informs public policy; provides consultation; and researches, develops and deploys evidence-based practices throughout the state's agencies and service organizations. With a lifespan focus, OICALI's mission is to build state-and system-wide capacity to improve these individuals' outcomes through leadership, training, professional development, national and state level collaboration, and the use of state-of-the-art technology. It serves families and professionals working with individuals with ASD and low incidence disabilities, including multiple disabilities, orthopedic impairments, other health impairments, and traumatic brain injuries.



Interagency work group on Autism (IWGA)

IWGA's mission is to equip Ohio's multiple systems of services and supports with tools and resources to be responsive to Ohioans with ASD and other developmental disabilities and their families across the lifespan. With OICALI as its hub, membership

includes representatives from the state agencies that serve individuals at various points across the lifespan. The IWGA includes: Governor's Office, Office of Medicaid Administration, Opportunities for Ohioans with Disabilities Agency (the state Vocational Rehabilitation agency), and the Ohio Departments of Mental Health and Addiction Services, Education, Job and Family Services, Health, and Developmental Disabilities.

OICALI advisory board

The OICALI advisory board membership includes people with ASD and low incidence disabilities, parents and family members, educators and other professionals, medical professionals, service providers, higher education, and state agency representatives. Their role is to provide

advice and input on various activities in Ohio related to ASD.

This statewide triad approach to infrastructure development provides a strong foundation for ASD policy development and implementation for the state. The model was conceived by committed groups of parents, individuals, legislators, state leaders, and service providers to place ASD at the forefront of policy discussions across agencies and to create a mechanism that could move policy to action. Various projects coordi-

The model was conceived by committed groups of parents, individuals, legislators, state leaders, and service providers to place ASD at the forefront of policy discussions across agencies and to create a mechanism that could move policy to action.

nated by OCALI are described in the remainder of this article to illustrate the breath and depth of this systems approach to ASD.

A focus on early identification and intervention

In 2008, OCALI became involved in a statewide effort to promote early identification and early intervention

Collaboration with and across agencies and organizations to reach a common goal of improving supports for individuals with ASD is a part of the OCALI's DNA

by reaching under-served families. This project was particularly important because nearly one-third of Ohio's children live in rural areas where there is a scarcity of personnel trained in ASD. The Family Child Learning Center and Akron Children's Hospital with support from the Departments of Developmental Disabilities and Health, the Autism Diagnosis Education Project (ADEP) was designed to help communities develop a local solution to ensure children are identified as early as possible. The project provides ASD-specific training and facilitates unique partnerships between community-based physicians and professionals providing early childhood services.

To date, 47 of Ohio's 88 counties participate in ADEP and have formed diagnostic partnership teams. The network includes 43 partner physicians and 317 participating early intervention service providers. ADEP outcome data indicate an overall decrease in the lag time from initial family concern to diagnosis with an average age of diagnosis of 30 months. This is well below the national average age of diagnosis of 53 months reported by the Centers for Disease Control and Prevention (CDC) (Centers for Disease Control and Prevention, 2014).

Promoting change through targeted partnerships

Through a 2011 State Implementation Grant for Improving Services for Children and Youth with Autism and Other Developmental Disabilities (SIG) an innovative group of collaborators were brought together to work with OCALI to expand its efforts to empower and educate families through new partnerships,

statewide information dissemination, and extend its outreach to minority and underserved populations. Included in the collaborative partnership were —

- Act Early Ohio Team
- Ohio Chapter of the American Academy of Pediatrics
- Family Child Learning Center/Akron Children's Hospital,
- Nisonger Center, The Ohio State University
- Cincinnati Children's Hospital Medical Center/University of Cincinnati
- Nationwide Children's Hospital Autism Treatment Network
- Ohio Autism Coalition

Through this project several initiatives have been launched in Ohio to improve OCALI's outreach to families statewide, and for the first time, to target outreach and service delivery to minority and under-served populations.

Statewide information dissemination

OCALI's charge is to ensure that all Ohio families receive information to help them find and access the services they needed to obtain a timely diagnosis and intervention as close to home as possible. To reach families

statewide in partnership with Autism Society of Ohio (ASO) and its Ohio Autism Coalition (OAC), a statewide group was established to give voice to all ASD family support/advocacy groups. The OAC functioned to influence policy and legislation and provided a broad information dissemination platform throughout the advocate community across Ohio. Materials developed and/or disseminated through this partnership include —

- **Ohio's Parent Guide to Autism Spectrum Disorders**, an extensive resource available for download from the OCALI website (or mailed to families upon request).
- **Parent Guide DVD**, developed for those families who do not use printed material as their primary source of information. OCALI transferred the Ohio's Parent Guide to Autism Spectrum Disorders onto a DVD narrated by the parent of a child with ASD. The DVD summarizes each chapter and highlights resources and phone numbers parents may want to pursue;
- **OCALI printed copies of CDC's Learn the Signs. Act Early.** Free material resources include Milestone Moments booklet and Milestones brochure for broad dissemination;
- **Publicity cards with OCALI's toll free number**
- **Social Media Toolkit**, a document listing annotated ASD resources and hyperlinks to allow for easy download and social media dissemination.

Outreach efforts to minority and underserved populations

Since 1990, the share of Ohio's foreign-born individuals rose to 4.0% of the overall population according to the American Immigration Council (2014). In 2013, Ohio's Hispanic

population reached 3.4% of the population; and its Asian population reached 1.9%. African Americans make up 12.5% of Ohio's population (United States Census Bureau, 2014). Further, Ohio has the second largest Somali population in the United States estimated in 2009 at 45,000 individuals (American Immigration Council, 2014). The Somali population is included above in the African American classification, but is distinctly different in terms of lan-

guage and community identification. To meet the needs of these diverse groups of Ohioans, OCALI targeted activities to inform and connect families who are often excluded from typical outreach efforts because of the barriers of language, race or ethnicity. The first step in this outreach was to identify partners (see Table 1) and plan targeted outreach activities with each partner.

Table 1. OCALI partner organization table

Partner organization	Organization purpose and outreach target	Strategies
Ohio Department of Health, Help Me Grow	Ohio's early intervention system (Children 0-3)	Provided access to multiple free ASD resources
Autism Treatment Network, Nationwide Children's Hospital	A hospital-based initiative dedicated to providing high-quality family centered care (Somali community)	Translated 3 ATN Toolkits: ABA, Toilet Training and Behavior Management
Ohio Coalition for the Education of Children with Disabilities, Multicultural Outreach Program	Information and training organization for parents of children with disabilities statewide (Hispanic families)	Provided translated materials: Four Steps Guide to Services, Parent Guide DVD, CDC's Milestone Moments and Milestones brochure
Living Beyond Autism	Advocacy and support network for African American families in Central Ohio (African American community)	Conducted focus group and developed PSA content based on feedback
Ohio Association of Community Health Centers	Support network for Federally Qualified Health Centers (Economically disadvantaged)	Offered materials to educate providers and to support families
Ohio Association for the Early Education and Care of Young Children	Support network for early education and care providers (Families of young children)	Offered free materials to educate providers and support families
Autism Society of Ohio and Ohio Autism Coalition	Support and advocacy network for all families of children with ASD (all families)	Supported dissemination of <i>Ohio's Parent Guide to Autism Spectrum Disorders</i> and other resources to all families

Targeted outreach strategies

OCALI employed a variety of strategies through its partnerships to meet its goal of outreach including —

Public Service Announcements (PSAs)

OCALI provided outreach to the Hispanic and the African American communities through the creation of two public service announcements (PSAs) featuring an African American and Hispanic parent, delivering the message that ASD is on the rise and urging parents to contact their child's physician if they have questions. The PSAs were distributed in a 30-second and a 10-second format and were offered to 55 broadcast television stations across Ohio.

Autism Minority Outreach Initiative (AMOI)

Living Beyond Autism (LBA) convened two focus groups of African American families in Central Ohio to discuss their experiences in obtaining their child's diagnosis and services. Parents reported that their concerns were initially minimized and their children were often initially misdiagnosed, consistent with current research. The AMOI report summarizes their experiences. These family representatives recommended utilizing faith communities as a way to reach other African American families.

Translating tools

The Parent Guide DVD was translated into Spanish with a Hispanic mother of a child with ASD providing the narration. In addition, OCALI's short guide for families on how to obtain an assessment, *Four Steps to Services*, was translated into Spanish and printed Spanish copies of CDC's *Milestones Moments* booklets and the *Milestones Brochure* were made available.

To disseminate these resources more broadly, OCALI partnered with Ohio Coalition for the Education of Children with Disabilities (OCECD), which runs three support groups for Hispanic parents in Cleveland, Columbus and Cincinnati. Through this organization, 1,590 Spanish resources were distributed to families.

Given the concentration of the Somali community in the Central Ohio area, OCALI worked with the Autism Treatment Network (ATN) at Nationwide Children's Hospital that was involved in outreach to the Somali community. The SIG partnership allowed for translation into Somali of three ATN Toolkits on toilet training, applied behavior analysis (ABA), and behavior management. These topics were selected based on a survey completed by Somali families.

Reaching the economically disadvantaged

The Ohio Association of Community Health Centers (OACHC) served as a conduit for providing ASD information to medical centers serving over 550,000 Ohioans. Of these patients served by the Health Centers, 33% are uninsured, 42% are on Medicaid, and 32% are 0-19 years of age, and 32% are Black/African American, and 7% are Latino/Hispanic (Ohio Association of Community Health Centers, 2014). ASD information packets were introduced at no cost through OACHC's semi-annual conferences.

Reaching early childcare providers

OCALI introduced and exhibited its range of ASD resources at the annual conference of the Ohio Association for the Education of Young Children (OAEYC), an organization that represents and informs early educators and care providers. While this group does not focus on special populations, these providers are often the first to notice the characteristics

of ASD in the children they serve. Conference participants received a sample packet of information and order forms to obtain additional free resources.

Reaching school personnel

OCALI's experience in working with educators in Ohio since 2006 indicated that school district personnel were reluctant to identify students under the ASD category without a corroborating medical diagnosis. IDEA requires schools to identify all children with disabilities eligible for special education services. To address

Ohio is piloting 'virtual' home-based services to bring much-needed specialized service to families in rural and resource poor areas of the state.

this need, OCALI provided training to Ohio educators on the identification of ASD. Two five-day trainings were conducted for school teams to address this issue. A webinar followed each training series after six months to respond to issues and questions educators experienced in applying their knowledge and skills. Two-hundred seventy-five school personnel were trained. A follow-up study is underway to determine the extent to which trainees put their training into practice.

Tele-Early Intervention for Autism Spectrum Disorders

Through the SIG, Ohio is piloting 'virtual' home-based services to bring much-needed specialized service to families in rural and resource poor areas of the state. This innovative, cost-effective approach to service delivery is coordinated by the Family Child Learning Center and Akron Children's Hospital. It provides families with evidence-based intervention in a family's home; in-the-moment coaching and ongoing support; enhanced collaboration; and sharing of expertise. This model offers training

and support to the local service providers as well as to family members.

Information sessions for families

Through a partnership with the Autism Treatment Network, OCALI and the Central Ohio Autism Society, ten free community education sessions focusing on ASD medical care and treatment were offered. The Families with Autism Medical Lecture Series (FAMLS) sessions covered a variety of topics. Three of these training sessions were broadcast through the OCALI website starting the development of a collaborative training

partnership. Future training sessions will now be publicized and broadcast to a wider audience using OCALI's unique technological capability.

Educational opportunities for medical students

Nisonger Center at The Ohio State University has developed an ASD curriculum. It is now incorporated into the education program of all 3rd year medical students at The Ohio State University during their Family Medicine rotation. This initiative paves the way for future medical professionals to enter the field better prepared and able to provide quality care to families of children with ASD.

Conclusion

Through all its activities, collaboration has become the foundation for OCALI's work, extending its expertise, its personnel, and its resources. This article shares OCALI's commitment to reach all Ohio families who seek connection, support, and resources. The partnerships and strategies described showcase the level of investment that OCALI and its partners share in reaching mi-



nority and underserved populations. Through its collaborative work, OCA- LI has brought together the collective expertise of individuals and their families, the public service system, the medical community, the university community, and service providers. As the state's clearinghouse for ASD, OCA LI stands as a leader, but most important as a connector, across systems, across the state, across the lifespan.

References

- American Immigration Council (2014). *New Americans in Ohio*. Retrieved from <http://www.immigrationpolicy.org/just-facts/new-americans-ohio>
- Centers for Disease Control and Prevention (2014). *Community report on Autism 2014*. Retrieved from http://www.cdc.gov/ncbddd/autism/states/comm_report_autism_2014.pdf
- Ohio Association of Community Health Centers (2014). *We are OACHC*. Retrieved from <http://www.ohiochc.org/?page=178>
- United States Census Bureau (2014). *State and county quick facts: Ohio*. Retrieved from <http://quickfacts.census.gov/qfd/states/39000.html>

Donna M. Owens, MA, is the program director for the Family Center at OCA LI where she has led the Ohio Act Early family outreach activities through Ohio's State Implementation Grant. She has worked at OCA LI since it was established in 2004 providing training and technical assistance to schools, families and community agencies. She provides leadership for OCA LI's family support programs coordinating activities within OCA LI and with both public and private service agencies and consumer organizations.

Amy Hess, BA, MA Certificate is the site coordinator for the Autism Speaks Autism Treatment Network (ATN) at Nationwide Children's Hospital (NCH) where she is actively engaged in community outreach, clinical quality improvement initiatives, research coordination and family centered care development. Amy serves on the Family Advisory Council at NCH and the Vice President of the Autism Society, Central Ohio. She is the parent of a cute, free spirited child with Autism Spectrum Disorder and his charming older sister.

Jody Fisher, M Ed, is an autism project manager for the Ohio Department of Developmental Disabilities. Her 30 years in the field of developmental disabilities has included direct service in a variety of settings as well as state and national policy work. Most recently, Fisher has coordinated Ohio's Interagency Work Group on Autism, partnering with families, service providers, advocates and state leaders for continuous improvement of the statewide system of services and supports for Ohioans with ASD and other developmental disabilities.

Resources

Autism Speaks

www.autismspeaks.org

A resource for information about ASD, research into its causes, and treatments. Autism Speaks offers numerous toolkits and best practices for working with families with children and adults with ASD. Some materials and resources offered in multiple languages.

Autism Online

www.autisonline.org

A comprehensive online resource focused on connecting families of children and adults with ASD with education, support, resources, and high quality products in their own language. Includes information in at over 20 different languages.

American Academy of Pediatrics

www.aap.org

Resources for parents and providers, including interviews with pediatricians, researchers, and parents. The AAP has developed "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children".

American Speech Language Hearing Association (ASHA)

www.asha.org

ASHA is the national professional association for audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students. ASHA has developing a set of best practices for assessing diverse students with ASD. *Assessing Diverse Students With Autism Spectrum Disorders* by Tina Taylor Dyches.

Learn the Signs. Act Early.

www.cdc.gov/ActEarly

Resources from the CDC about child development, developmental delays, examples of what to say to health care professionals, and tips about what to do if you have to wait for an appointment. Many materials are available in multiple languages. Somali and Hmong version available at: rtc.umn.edu/autism

Considering Culture in Autism Screening

A resource guide for pediatric clinicians, health care providers, and community professionals to use when completing ASD screening with children from culturally diverse families whose primary language is not English. Developed by the Massachusetts Act Early team.

http://www.maactearly.org/uploads/9/2/2/3/9223642/4_considering_culture_asd_screening.pdf

Educating Children with Autism

A comprehensive review of early intervention, preschool, and school-aged programs developed for young children with ASD by the National Academy of Sciences. www.nap.edu/books/0309072697/html/

National Autism Center

www.nationalautismcenter.org

Provides comprehensive information, promotes evidence-based best practices, and offers resources for families, practitioners, and communities.

PACER Center

www.pacer.org

Parent Advocacy Coalition for Educational Rights is a parent advocacy center with resources and staff committed to outreach to culturally and linguistically diverse communities. Content available in Hmong, Somali, and Spanish.

St David's Center

www.stdavids.net

Offers a variety of intervention services such as early childhood education, early intervention, pediatric therapies, and life phase services. St David's offers many model intervention programs for outreach for culturally and linguistically diverse families.

Selected journal articles and reports

Begeer, S., El Bouk, S., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of ASD in ethnic minorities. *Journal of Autism and Developmental Disorders*, 39, 142–148.

Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34, 211–222.

Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J., & Reiff, M. (2013). *Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGiuseppi, C., Durkin, M. S., et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99, 493–498.

MN LEND Program

Leadership Education in
Neurodevelopmental Disabilities

lend.umn.edu

Institute on Community Integration,
University Center for Excellence in
Developmental Disabilities

University of Minnesota School of Medicine,
Department of Pediatrics

College of Education + Human Development,
Department of Educational Psychology

College of Liberal Arts, Department of Speech
Language and Hearing Services

LEND Brief: ASD & Culture

Editor: Amy Hewitt, PhD

Managing editor: Kelly Nye-Lengerman

Graphic design: Connie Burkhart

LEND Director: Joe Reichle, PhD

LEND Brief is a bi-annual publication of the MN LEND Program (Leadership Education Neurodevelopmental Disabilities) at the University of Minnesota. This issue was supported in part by grant #2-T73MC12835-03-00 from the Maternal & Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services awarded to the University of Minnesota.

The opinions expressed are those of the authors and do not necessarily reflect the views of affiliated centers, schools, colleges, the U of M, or their funding sources.

The University of Minnesota is an equal opportunity educator and employer. This document is available in alternate formats upon request.

MN LEND Program
University of Minnesota
150 Pillsbury Dr. SE, 204 Pattee Hall
Minneapolis, MN 55455