

PacWest ITAC Learning Modules: Cultural Crossroads in Disabilities

Video Description, Interview Questions, and Discussion Questions/Reflections with Facilitator Talking Points

Video Title and Description	Interview Questions	Discussion Questions/Reflection	Facilitator Talking Points
<p>1. What is Autism Spectrum Disorder?</p> <p>Runtime: 27:06</p> <p>Developed by: Aubyn Stahmer, PhD UC Davis – MIND Institute LEND Program</p> <p>Interviewee: Venita Ayala Parent of Christopher Family Navigator UC Davis – MIND Institute</p> <p>Reviewers: Sandra Friedman Eileen McGrath</p> <p>Video Description: Single parent of an autistic young adult son who is non-speaking.</p> <p>Cultural Focus: Identifies as African-American.</p>	<ol style="list-style-type: none"> 1. How do you and your son identify in terms of culture and disability? 2. How did your identity affect you as you advocated for your son? 3. How has cultural identity affected access to services for your autistic son? Did his cultural identity affect how people address behaviors related to his autism? 4. How did trust (or lack of trust) relate to service access for you and your son? 5. Tell us about how your son learns and how you identify with him. 6. How would you like people to see your son? 	<ol style="list-style-type: none"> 1. What system issue may relate to delayed diagnosis and decreased service access in historically marginalized groups? 2. What cultural issues may relate to delayed diagnosis and decrease service access in historically marginalized groups. 3. What can we do to address systemic and cultural issues which limit access to care? 4. How might culture affect how people describe or understand some of the social communication and behavioral symptoms of autism? 5. What can you do to build trust with people in cultural groups that differ from your own? 	<ol style="list-style-type: none"> 1. Autism is a complex diagnosis and children may have very different characteristics and still have autism. 2. A person’s biology and the environment interact to influence brain development. Many different factors may be associated with autism, but it is not caused by poor parenting or vaccines. 3. Girls less likely to be identified as having ASD, likely due to differences in symptoms – such as better social communication when they are younger. 4. Children of color and those living in poverty are diagnosed later, access fewer services and services have lower quality than White children. 5. Provider lack of diversity and language choices, misunderstanding of cultural differences and systemic issues affect access to care

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<p>2. Intersection of I/DD + Mental Health</p> <p>Runtime: 42:46</p> <p>Developed by: Erika Ryst, MD Medical Director and LEND Director Nevada Center for Excellence in Disabilities University of Nevada, Reno, NV LEND Program</p> <p>Reviewers: Judy Reaven Aubyn Stahmer</p> <p>Interviewee: Austin Noriega Self-Advocate NV LEND Graduate</p> <p>Video Description: 27-year-old male with ASD and ADHD living in rural Nevada, single parent of a 4-year-old with a disability</p> <p>Cultural Focus: Italian, Mexican, identifies as Mormon</p>	<ol style="list-style-type: none"> 1. Tell us a little bit about yourself (Age, occupation, family, community where you live, things you like to do for fun). 2. What cultural group are you a member of and how do you or you culture think about disability? 3. What identities are important to you and how? (Parent? Religion? Ethnicity? Person with a disability?) 4. What are your current diagnoses, and how do they impact your life? 5. What was your experience with evaluation and diagnosis? 6. Did you experience any difficulty in accessing care and was there anything about your background that made it more challenging? 7. What are some things that you wished that teachers, doctors or therapists understood about you that would have been helpful? 	<ol style="list-style-type: none"> 1. How does cultural background impact the experience of disability? 2. How does an individual's intersectionality affect the expression and experience of co-occurring mental health needs? 3. How do mental health conditions present differently in people with ID/DD? And how does cultural background further influence the presentation? 4. What are the barriers to accurate identification and assessment of mental health conditions in individuals with ID/DD? 5. What can we learn from this individual's experiences as we strive to become evidence-based and person-centered professionals? 	<ol style="list-style-type: none"> 1. Important to understand the individual's culture (cultural humility) 2. Culture can impact the expression of mental health symptoms, stigma/shame regarding mental health conditions, whether and how individuals will seek help. 3. Cultural considerations can make it even harder to identify mental health conditions in ID/DD 4. Lack of provider knowledge, Lack of choice in services, Lack of crisis services, Lack of service coordination. 5. Psychosocial approaches just as important (maybe more important) than medication treatment. Psychotherapy can be adapted to individuals with ID/DD with high levels of efficacy. <ul style="list-style-type: none"> • Person-centered approach; getting to know the individual • Cultural awareness • Identity Intersections • Psychiatric comorbidity in ASD • Evaluation/diagnosis • Access to Care

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	8. Is there anything else that you would like to tell us about your experiences?		<ul style="list-style-type: none"> Family/Person-Centered Care
<p>3. Autism Spectrum Disorder and Deaf and Hard of Hearing</p> <p>Runtime: 50:58</p> <p>Developed by: Deborah Mood, PhD University of Colorado and Children’s Hospital Colorado, Developmental Pediatrics/JFK Partners, Colorado LEND Program and Robert Nutt, MD, MPH Developmental and Behavioral Pediatrics Clinic for Special Children Wilmington, NC</p> <p>Reviewers: Susan Wiley Jack Roush</p> <p>Interviewee: Meredith De Naples Parent North Carolina</p> <p>Video Description: Mother with a 7-year-old Deaf son with Autism Spectrum Disorder.</p>	<ol style="list-style-type: none"> Please tell us about your child and when you first had concerns about your child’s development. How important was it to you to have a provider who could directly communicate with your child? Please tell us about your experience accessing intervention. What has been helpful? What has been difficult? 	<ol style="list-style-type: none"> There are several ways that the concept of “access” and its importance for this community is discussed. Please describe some of these ways, and how you might adjust your clinical practice in response to what you learned. How families and individuals form their understanding of deafness and autism influences both identity development and what families need to feel supported. How might you engage families to understand their perspective? What are some specific ways that this understanding might influence your practice or interactions with families/individuals? 	<ol style="list-style-type: none"> Importance of determining language access in the child’s environment and developmental history. Language access during the evaluation- considerations for use of interpreter vs direct communication in a signed language if needed; modifications for children who communicate using spoken language but have reduced hearing. Reduced access to professionals who can provide direct communication, who understand the community, and who are trained to provide ASD evaluation. <ol style="list-style-type: none"> Hearing families may be adjusting to dx of hearing loss and may have difficulty understanding what symptoms are secondary to ASD vs hearing loss. Therefore, they may underreport symptoms on screeners/when interviewed. Hearing families with reduced sign language fluency may not understand the ways that their child’s atypical language features in a signed language present. Hearing families may vary in terms of whether they feel child’s

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<p>Cultural Focus: Deaf family who communicates using American Sign Language navigating access to care.</p>		<p>3. What are some considerations for providing a “fair” and “valid” assessment for members of the Deaf/deaf community? What are your professional guidelines regarding practicing within the scope of your training with individuals from cultural and linguistic backgrounds outside of your experience and how might that apply when working with the Deaf community?</p>	<p>reduced hearing or symptoms of autism interfere with their child’s developmental progress. Hearing families may feel they need support both for behaviors associated with ASD and to learn a signed language or navigate hearing related systems/concerns.</p> <p>2d. Deaf families may not have experience with ASD and may need support to understand ASD and ASD related intervention. Deaf families may have concerns about communication access when navigating intervention systems.</p> <p>3a. Best practice is to refer out when there is a provider dually trained in deafness and ASD who can communicate directly with the child in their preferred language.</p> <p>3b. Considerations for use of interpreters: shift dyadic nature of the evaluation to a triadic exchange which can impede ability to reliably assess reciprocity; interpreters are not trained in ASD features.</p> <p>3c. Consider building relationships with Deaf professionals and professionals who understand deafness (e.g., audiologists, speech/language therapists, teachers of the deaf) to build multidisciplinary teams where at least some members bring an</p>

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			understanding of typical development for deaf children.
<p>4. Don't Judge a Book by its Cover: The Intersection of Motor Disability and Culture</p> <p>Runtime: 26:03</p> <p>Developed by: Douglas Vanderbilt Staci Davis Hope Wills Kevin Blaine Shelby Surfes Maria Marquez Jeremy Wong Emily Haranin University of Southern California, Children's Hospital Los Angeles CA-LEND/DBP Program</p> <p>Reviewers: Sandra Heimerl Sarah Winter</p> <p>Interviewees: Maria Marquez CA-LEND Self-Advocate Discipline Director and Mother with a disability and Savanna Czerwinski Daughter of a mother with a disability</p>	<ol style="list-style-type: none"> 1. Did your family anticipate any difficulties prior to your birth? 2. Describe the transition from special education classroom into a general education mainstream environment. 3. Did you notice other kids or people in the community looking at your mother differently? 	<ol style="list-style-type: none"> 1. What was remarkable to you about how Maria and her family saw her cerebral palsy? 2. What other identities were salient to Maria in her daily life? 3. How do you see Maria's story fitting into the ICF classification system? 4. How would you explore learning more about how Maria's culture relates to her disability? 	<ol style="list-style-type: none"> 1. Reflect on Maria's stories of her strengths and weakness and how other saw her and what she could do. Discuss how her family did not see (just) her disability. 2. Many options: mother, grandmother, self-advocate, daughter, Mexican American, etc. 3. Apply any of the 6 F's to Maria's story and how they interrelated as promoting or inhibiting her potential. 4. Discuss approaches to asking honest respectful questions to understand another person's identity to find strengths to maximize their function.

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<p>Video Description: Self-Advocates can make a difference. They may need assistance but are more than their disability.</p> <p>Cultural Focus: Mexican American and Intercultural Development</p>			
<p>5. Serving the Spanish-speaking ASD Community</p> <p>Runtime: 39:14</p> <p>Developed by: Silvia J. Acosta, PhD University of New Mexico, Center for Development and Disability, LEND Program</p> <p>Reviewers: Nuri Reyes Sydney Rice</p> <p>NOTE: <i>Interview is in Spanish and captioned in English. The parent is not captured on video – you will only hear her voice.</i></p> <p>Interviewee: Lourdes Arrellano</p>	<ol style="list-style-type: none"> 1. Which cultural group are you a member of and how you or your cultural thinks about autism spectrum disorder? 2. What was your experience with evaluation and diagnosis? How did speaking mostly Spanish impact your ability to access this service? 3. What was your experience about receiving related services and how did those services mesh with your cultural values? 4. What are the most helpful programs for you? 5. If you are active in the community, what activities are you involved in? Do you feel accepted among others? 	<ol style="list-style-type: none"> 1. What myths about bilingualism were surprising to you? 2. What were the barriers discussed in the presentation that this family experienced in accessing services for ASD? How did the cultural background and primary language of the family impact their ability to access diagnostic services? What culturally responsive practices would have been appropriate to serve this family in the diagnostic process? 	<ol style="list-style-type: none"> 1.a. The presenter mentioned that a recommendation for bilingual families has been to choose one language over the other. As a provider, self-advocate or family member, how would you address this myth? 1.b. The family member mentioned her choice to use Spanish only with her child. What was your reaction to her decision? 2. The family member discussed having to obtain two separate evaluations to receive a diagnosis of ASD for the child due to the lack of specialists. In addition, the location of the evaluation cite was distance. The family member mentioned cultural aspects such as being “scared” about the diagnosis of ASD. What other cultural values were discussed?

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<p>Parent of a child with autism, Spanish is her first language</p> <p>Video Description: Bilingual mother discusses experiences with her son's ability to access an autism diagnosis and therapy, the lack of information in her language and culture and more.</p> <p>Cultural Focus: Hispanic, Spanish-speaking cultural and linguistic group, Mexican descent</p>	<p>6. What are some things you wish your providers knew about you that would have helped you?</p>	<p>3. What were the strengths and factors that supported the family in their journey thus far?</p> <p>4. What culturally responsive practices could you implement to serve Spanish-speaking families in the short-term and in the long-term?</p>	<p>3. The family member discussed access to interventions in the chosen language. The family member had access to information and support in the community and cultural factors that may contribute to feeling supported by other members of the same cultural background. The family member felt supported by the larger community with access to inclusive services and activities (e.g., sports).</p> <p>4. The family member perceived the service providers (school-based services and community therapies) were responsive to the family's desire to be bilingual and communicate with the family. What are the resources available for you to make culturally responsive changes to service delivery for Spanish-speaking families in your community/agency/family?</p>
<p>6. Down Syndrome in the Latinx Community</p> <p>Runtime: 20:20</p> <p>Developed by: Lisa D. Herzig, MD Lisa T. Mattson, MD, PhD Sue Adelman, Family Faculty University of Washington LEND Program</p>	<p>1. Please describe yourself and the groups you identify</p> <p>2. How have you interacted with the health system?</p> <p>3. Which programs have you found most helpful?</p> <p>4. Tell me about things you have learned along your journey</p>	<p>1. What stood out to you most when listening to the family interview?</p> <p>2. How do you plan to approach families from other cultures differently based upon what you learned today?</p> <p>3. What can we do as groups or individuals to be more inclusive?</p>	<p>1. Many answers here- importance of listening and compassionate care is one</p> <p>2. Many answers here too- get to know a family, try to slow down and understand their story and their values. Remember the human experience and connection.</p>

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<p>Reviewers: Douglas Vanderbilt Amy Costanza-Smith</p> <p>Interviewees: Catalina Angel, MSW LEND Family Graduate with daughter Salome Angel</p> <p>Video Description: Spanish-speaking family; parents immigrated to the United States in 2006 and their daughter was born in 2009 with a heart condition and Down syndrome.</p> <p>Cultural Focus: Catalina is a Latinx woman who immigrated from Colombia, South America 16 years ago. Salome is first generation born in United States bilingual young girl with disabilities.</p>	<ol style="list-style-type: none"> 5. How do you think you were treated differently? 6. Please share some examples 7. What do you want people to take away from this video? 		<ol style="list-style-type: none"> 3. Inclusionary practices should be embedded, “part of the water” as Catalina said. As we become leaders in the care of individuals with neurodevelopmental differences, we should aim on a daily basis to provided compassionate, culturally responsive care to our patients and their families. This work starts with us and continuing to educate ourselves and be aware of the role that different cultures, perspectives, experiences -- both our families and our OWN – play in the care we provide.
<p>7. Autism and Transgender Health</p> <p>Runtime: 33:57</p> <p>Developed by:</p>	<ol style="list-style-type: none"> 1. How can a clinician/staff member make your make your medical experience better? 2. What things can your medical provider address/talk about to 	<ol style="list-style-type: none"> 1. How do your pronouns effect you in your life? How would you feel if someone used the wrong one’s for you? 	<ul style="list-style-type: none"> • Focus on creating nonjudgmental environment for treatment of this population • Avoid any and all assumptions

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<p>Stacey Weinstein, MD, Kassia Rosenau, PhD and Kary Calderon UCLA Center for Excellence in Maternal and Child Health, LEND Program</p> <p>Interviewees: Grayson Moore (he/him)</p> <p>Video Description: Transgender teen whose diagnosis of autism was more difficult possibly due to being female at birth.</p> <p>Cultural Focus: Transgender with autism and the intersection of the two.</p>	<p>enhance your health and your healthcare related experience?</p> <p>3. Are there any programs that you found helpful in understanding transgender, coming out, or the link between autism and transgender?</p> <p>4. Do you feel that your healthcare providers and service providers have been accepting with your coming out and have they provided you with gender affirmative care?</p> <p>5. How do you feel that receiving gender affirmative care has helped you?</p> <p>6. Did it help to have your new name and your pronouns in your medical record for other health professionals to provide you with better care?</p> <p>7. Is there anything you wish your providers, teachers, other people you encountered that they knew about you that would have helped you?</p>	<p>2. What are some of the best approaches you've seen/used for a sensitive physical exam (i.e., in a transgendered person who has anxiety from their discordant anatomy)</p> <p>3. What are important specific social determinants of health to keep in mind when caring for this population?</p>	<ul style="list-style-type: none"> • Communicate clearly and concretely when asking and answering questions and performing physical exam • Consider all health disparities that transgender pts (i.e., increased homelessness, increased mental illness) and ASD pts (i.e., stigma, social issues, comorbid mental illness) face

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<p>8. Adolescent-to-Adult Transition for Youth with I/DD</p> <p>Runtime: 56:50</p> <p>Developed by: Amy Costanza-Smith, PhD and Kim Solondz, MS, OTR/L, Oregon Health and Sciences University LEND Program</p> <p>Reviewers: Jessica Soloman Sanders Sarah McSwegin</p> <p>Interviewees: Maria, Mother and Amy, 21-year-old with Rett's Syndrome</p> <p>NOTE: <i>Interview is in Spanish and captioned in English.</i></p> <p>Video Description: Spanish-speaking mother speaks about non-speaking daughter as she transitioned to adulthood.</p> <p>Cultural Focus: Spanish-speaking family talks about how their culture views the</p>	<ol style="list-style-type: none"> 1. Which cultural group are you a member of and how do you or your cultural think about disability? 2. Tell us a little bit about your daughter, Amy. (We expect her to bring up her disability here.). What does she like to do? What are some of her strengths? 3. When did someone first bring up transition to adulthood with your family? What did you think or feel about transition at that time/what were your initial feelings about it? 4. How was Amy's experience transitioning from the high school community transition program to post high school life? 5. What has your experience been in finding adult medical providers to support Amy's needs? 6. What would you want your providers to know about your culture when caring for your family? 	<ol style="list-style-type: none"> 1. The Latinx is only one culture. How might you consider supporting adolescent transition in the other cultures you work with? 2. One big issue in health care transition is that it is time consuming. Adding a language barrier adds more time for interpretation. How do we better prepare adult health care providers to support transition needs? How can we better prepare families to discuss these topics in the short time allowed during a medical appointment? (e.g., one-page profiles, portable medical summaries) 3. Many families do not consider transition until it must happen (reacting to instead of planning). How do we teach self-advocacy skills from a young age? How do we as providers encourage more self-determination skills in youth so that they can advocate for their needs in transition? 	<ol style="list-style-type: none"> 1. Importance of asking questions related to culture when talking about transition. Ask what is important to their family and about their family values. 2. Bring up transition often and early when working with families. Ask youth & families about their goals for the future 3. All providers in a practice should be aware of issues related to transition. Translated materials and resources should be readily available 4. Ask questions directly to the youth regarding what is important to them. 5. Utilize Family-to-Family Health Information Center resources to connect families with similar backgrounds

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<p>progression from childhood to adulthood.</p>	<ol style="list-style-type: none"> 7. Did they experience any difficulty in accessing care and was there something about their background that made it more challenging? 8. What supports have been most helpful for you during Amy's transition to adulthood? 		
<p>9. Disability from a Cultural Perspective</p> <p>Runtime: 26:37</p> <p>Developed by: Vanessa Hiratsuka, PhD, MPH, University of Alaska Anchorage, Center for Human Development LEND Program</p> <p>Reviewers: Janice Enriquez Renee Charlifue-Smith</p> <p>Interviewees: Tracy Charles-Smith, mother of five children, two with developmental and physical disabilities (one with autism) and caretaker for her nephew with Fetal Alcohol Spectrum Disorder and several foster children. Tracy grew up in the</p>	<ol style="list-style-type: none"> 1. Did your family anticipate any difficulties prior to your birth? 2. Describe the transition from special education classroom into a general education mainstream environment. 3. Did you notice other kids or people in the community looking at your mother differently? 	<ol style="list-style-type: none"> 1. What was remarkable to you about how Maria and her family saw her cerebral palsy? 2. What other identities were salient to Maria in her daily life? 3. How do you see Maria's story fitting into the ICF classification system? 4. How would you explore learning more about how Maria's culture relates to her disability? 	<ol style="list-style-type: none"> 1. Reflect on Maria's stories of her strengths and weakness and how other saw her and what she could do. Discuss how her family did not see (just) her disability. 2. Many options: mother, grandmother, self-advocate, daughter, Mexican American, etc. 3. Apply any of the 6 F's to Maria's story and how they interrelated as promoting or inhibiting her potential. 4. Discuss approaches to asking honest respectful questions to understand another person's identity to find strengths to maximize their function.

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<p>Alaskan village of Dot Lake with Athabaskan spoken in the home.</p> <p>Video Description: Shared historical trauma from tribal community and how cultural norms change within a person's lifetime.</p> <p>Cultural Focus: Alaska native, Athabaskan culture.</p>			