

Event:

-Tuesday, May 8, 2018
WL Henry Elementary School,
Hillsboro, OR
-Principal Investigator:
Breanne Toney, M.S. CF-SLP
-Co-Investigator: Hannah
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-Facilitated and Translated
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Purpose:

Gather feedback from Spanish-speaking families on healthcare services for children experiencing disabilities to inform future IDD Diversity & Inclusion Task-Force plans to “improve access to healthcare for diverse families and populations.”

Participants:

13 participants, adult/female
-8/13 self-identified as having a child experiencing disability,
-1/13 self-identified as having participated in a CDRC clinic.

Method:

-Open ended questions on a variety of topics related to disability, clinic logistics, interpretation and translation
-Conducted in Spanish, audio-recorded and transcribed by native speaker
-Responses summarized and organized by theme
-Selected quotes presented as data

Spanish-Speaking Family Perspectives on Developmental Disabilities

Listening Session with Adelante Mujeres

Disability Experience

What are some challenges facing children with disabilities in your community?

- Rejection from the community and sometimes own family
- The cultural belief they are just misbehaving, instead of having a disability
- Lack of education about disability, and the fear of being looked at as an incompetent parent
- Segregation at school from educators and peers

How is your child's disability viewed in your family and community?

- As a non-existent and something we are trying to use to explain our lack of parenting skills
 - ...or as something we did wrong as parents.
- Sometimes male partners don't want to accept the disability

What do we do that we should continue? (Positives)

- Having toys and some entertainment for children at the clinics
- Having bilingual staff (some clinics)

What should providers know about working with Spanish speaking families?

- They appreciate being included in the conversation when they bring their teenaged children to the doctor
- Ask for parent's permission and opinion in anything related to their children
- Be respectful and listen when they have concerns and ask for answers
- Provide information in their own language, especially for treatments and medication
- Provide interpretation in person if possible
- That “it's normal” is not always an answer that makes families feel like everything is okay.

Clinic Logistics:

What information would be useful for you to have before a visit to clinic?

- Maps, parking, and direction in their own language
- Transportation options in case the family doesn't drive

Feedback:

After the visit, how do you like to receive feedback about your child?

- In their own language
- Easy to follow and understand
- Medication information (instruction on how to administer and side effects)
- Follow-up instructions, next-steps

How do you give feedback to your provider about your experience?

- Most prefer anonymously, but others will do it verbally to providers
- A postcard can be good, but if the location is too close to the check in area they don't feel confident of anonymity
- Provide a phone number they can call

Interpretation and Translation:

How has your experience been working with interpreters? Have they worked well with your child?

- Some had good experiences like "interpreters very respectful and trying to use words that they will understand" "turning around in the room, giving people privacy"
- Others had bad experiences like interpreters being rude and using their phone during the visit
- Some noted that interpreters don't translate everything the doctor is saying or vice versa
- All agreed that interpretation in person is better for them
- They are grateful for having interpretation available.

What information is most important to have translated?

- After visit summaries,
- medication instructions and side effects,
- maps and directions

"That little difference between one as a professional and as a parent, which is the difference in how we feel things. For them it could be something common, but for us it's not."

<<Eso poco la diferencia cierto uno como profesional y otro como padre cuál es la diferencia en cómo nos siente la cosas ¿no?, para ellos puede ser lo común pero para una no lo es.>>

"Also, many times the person translating doesn't say what the doctor is saying and says other things and sometimes you understand what the doctor's talking about but you can't answer."

<<O muchas veces también la persona que está traduciendo no dice lo que el doctor está diciendo dice otras cosas y a veces que las personas entienden lo que el doctor está hablando pero tú no puedes contestar.>>

"He [my husband] heard the doctor's word [normal] and said to me "look the doctor already told you, the boy's seven, he's not bad" but I'm sorry no, he's not normal. My son has a problem and I need to find it out."

<< El [mi esposo] escuchó la palabra [normal] de la doctora y me dice <<ya le dijo la doctora que es siete, el niño no tiene mal>> pero lo siento no es normal mi hijo tiene un problema y necesito averiguar. >>

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