Bridging the Gap between Hispanic, Latino, or Spanish-speaking Families with Children/Youth with Disabilities and Professionals

Presented by Jeanette Cordova, BS Human Services, Minor Psychology; LEND Fellow at JFK Partners
About me

• Parent of a young person who is chromosomally enhanced
• LEND Fellowship 2016-2017
• Started the first Spanish-speaking support group for Rocky Mountain Down syndrome – Cromosoma Del Amor
• 14 years working with the Hispanic, Latino or Spanish-speaking community
• Advocate
• CCTSI Grants

• El Grupo VIDA
  • Executive Director 11/2013 to 10/2016

• JFK Partners, Dr. Eric Moody
  • Assistant Professor
  • JFK Partners/University of Colorado Schools of Medicine and Public Health
  • Co-creator of Colorado Parent Mentor Program
• Year 1 – allowed us to develop a robust partnership that we use as a foundation for ongoing collaborations between the two organizations.

• Year 2 - better understand how to improve access to evidence based care for this community, through community engagement
Data Collection

• Data collected from CCTSI Year 1 and Year 2 collaborative grant JFK Partners and El Grupo VIDA
  • Stakeholder Advisory Committee – consisting of four parents (ASD), 1 person from CDPHE, two from JFK Partners
  • Focus Groups with Parents (ASD) – FG 1-10 parents, FG 2-10 parents
  • Focus Groups with Professional – FG 1-3 professionals, FG2-2 professionals

• Data collected from Evaluations at El Grupo VIDA Monthly support groups – 240 individual family members per year – ASD, CP, Ds, Global, TBI

• Bridging the Gap Workshop with Parents – May 15, 2017 – 8 parents – 2 Ds, 5 ASD, 1 Sensory
Why do we say Hispanic, Latino or Spanish-speaking families vs only one of the others?

HLSS Community
Bias - We all have them!

Cultural – all areas of professionals

- Cultural perceptions/bias/Lack of cultural sensitivity
- Assumptions of cultural stigma (lack of education because of Latino last name)
- Professionals who are HLSS– some don’t help, discrimination against other HLSS (cultural competency from other Latinos)
- Assumption that family is "non-compliant" – “non-compliance” could be a matter of cultural difference
Barriers/Burden

- Language

- Insurance/Medicaid
  - Insurance Issues/ High cost of co-payments/no coverage
  - No access to Medicaid or Insurance

- SSI
  - Perceived lack of professionalism
    - Misuse of power
  - Threat of deportation
Barriers/Burden

- Professionals-medical, therapists, community centered boards
  - Parents feel that some therapists are not trained for ASD or child’s specific issues
  - Parents feel that some health care professionals are not trained toward the special diagnosis
  - Parents feel that some professionals are not listening to their concerns when parents know there is something wrong (evaluation)
  - Long wait lists
  - Parents feel that they aren’t provided resources (ask what the family needs vs. suggesting resources to help the family based on listening to them)
  - Lack of information presented in a format that is easy to understand
Barriers/Burden

Specific to CCB’s and Therapists

- Parents feel that lack of therapists who are Spanish-speaking is a barrier to their learning how to support their child
- Some therapists canceling/changing schedule
- Perception that some professionals do not work for the family benefit
- Parents didn’t know what programs were available
- Parents didn’t know full scope of CCB support for their child
- In home therapists – families feel that they are not receiving a full hour of services being billed (May be an issues of contact time vs. charting time that may need to be explained to the family.)
Barriers/Burden

Schools

• Inappropriate comments from school staff due (Parents perception is that it is due to lack of training on working with individuals with ASD but could be cultural).
• Lack of resources of the school district (IEP) – Parents being told the school/district doesn’t have enough money to provide the service.
• Parents feel some professionals are not listening to their concerns when they suspect something is wrong (evaluation). Ignoring requests for Special Education evaluations
• Families feel some teachers bully their child which sets the tone for other students to bully the child.
Schools cont.

• Parents didn’t know what programs were available outside of school – feel school should help with educating families on resources
• Threats due to immigration status
• Not providing IEP in parents language
• Do not explain the evaluation results or IEP in a way parents can understand
• Lack of explaining technology available for the students with disabilities
• Families feel there is a lack of accountability of schools.
Barriers/Burden

Interpretation

- Interpreters not available
- Some not familiar with medical or school terminology sufficiently to interpret easily
- Interpreters use different dialects
- Interpreting simultaneously vs. non simultaneous – Parents feel they should be asked how they would best receive interpretation. (Simultaneous takes less time vs. non simultaneous interpretation which may be a policy or how an interpreter was trained.)
Interpreters – medical and schools

- Parents feel interpretation is more direct interpretation vs. interpreting the meaning and feelings the parents are trying to express. (This may related to assumptions of how interpretation should be done and may conflict with interpretation policies.)
- Parents feel it is a barrier to their access of information when interpreters need to leave early due to other appts. (this may be due to medical/school appointments going beyond the original time or not enough interpreters.)
Families barriers parents reported:
- Lack of family support and understanding
- Lack of understanding the actual diagnosis
- What to do AFTER the diagnosis
- Parent roles – provider, caregiver
- Fathers lack of acceptance and lack of help – cultural norms for fathers varies that reduces that amount of support a mother receives (moms are usually the main care givers.)
Families barriers parents reported

- Compromised quality of life
- Unpredictable outcomes
- Reduced community interaction/Isolation
- Mental health concerns – cultural view of mental health professionals
- Earning potential reduced
- Long term care
TIPS!

- Consider cultural meaning of disability to the family
  - ask family how their culture views disability

- Communicating the diagnosis – positive vs negative

- Warm-handoff of referrals vs “here is the info – call”
  - Get permission to make the referral to the community resources they need most – especially after initial diagnosis up to year

- Mental health resources to help those families grieving
TIPS!

- Reflective questions of parents vs yes/no questions – ask the family to repeat what they understood or repeat instructions
- If you are a staff person who helps families with resources – remember that services available to kids who aren’t born here
  - EI and CCB up to 18 if they meet eligibility
  - Stay in school until age 21 under IDEA
Refer to Spanish-speaking supports like El Grupo VIDA and Family Voices

- El Grupo VIDA is the only Spanish-speaking support for HLSS disability community in the state!
- Family Voices, a state affiliate of the national grassroots network of families and friends who care for and about children with special health care needs.
Final thought....

To work with the HLSS community it takes time to build trust but it is worth the extra time and effort in the long run both for families and professionals!

Jeanette Córdova, PRA, JFK Partners
Jeanette.cordova@ucdenver.edu
303-724-0473