



Innovative and Promising Practices Spotlight



Early Hearing
Detection & Intervention

a program of the American Academy of Pediatrics

Collaborating w/ LatinX Families to Disseminate EHDI Resources

The [Center for Family Involvement](#) is a Virginia-based family advocacy organization that uses a “localization” process to disseminate information about the Early Hearing Detection and Intervention (EHDI) program to parents/caregivers from LatinX heritages. Localization is the process of adapting a product to a specific target market. Through this process, LatinX families identified preferences regarding how information was communicated and delivered. LatinX families reviewed the [EHDI 1-3-6 model](#), and in their own words, described how to tell the story about the “1” for screening and “3” for diagnostics. The final products developed were two fotonovelas¹, a [Part 1](#) and [Part 2](#). Part 1 is for infants who do not pass the hospital-based hearing screening. Part 2 is for children under 3 who have seen an audiologist, have received a diagnosis of hearing loss, and need to move to early intervention services. These resources can be implemented within medical homes serving LatinX communities on the 1-3-6 model, in addition to supporting the Virginia (VA) EHDI program. The fotonovelas are available in both Spanish and English.

¹Fotonovelas are short printed documents that use photographs or illustrations with dialogue bubbles (similar to a comic strip) to highlight a story or struggle being put into a positive light.

PROJECT HIGHLIGHTS

- The VA EHDI project disseminates fotonovelas within information packets (American Sign Language (ASL) resources brochure, a Family to Family brochure, a 64 page guidebook to understanding your child’s diagnosis, and a letter from the EHDI program) to families through EHDI learning communities (hospitals, audiologists, and parent support organizations), and 1-3-6 partners in the Virginia Commonwealth University.
- LatinX families report satisfaction with, and trust in the information of, the fotonovelas.
- Lost to follow-up rate for LatinX babies are being monitored through a Plan Do Study Act process with newborn screening teams at 2 hospitals who serve a high number of Spanish-speaking mothers.
- In addition to fotonovelas and the 1 on 1 emotional, informational, and systems navigational support offered through the Center for Family Involvement to families, there is a large repository of resources for families, including: printed and virtual guidebooks, appointment cards, ASL resource brochures, Facebook pages, Facebook live events, podcasts, and videos.

IMPLEMENTATION STRATEGIES

- Use a localization process with families from a community that is the focus of the outreach to ensure a firm understanding of how culture and language issues may impact communicating important information between the family and medical home.
- Convene a small group of parents/caregivers of children that have been diagnosed as deaf or hard of hearing (D/HH) to share customs, traditions, and family-preferred information formats on hearing screening and diagnostics. Identify terms that may not translate from English to Spanish (such as “audiologist”, “early hearing detection and intervention”, or “genetic disorders”) which may be written in the family’s primary language and dialect. If able, provide compensation for the parent/caregiver for their input.





HOW PEDIATRICIANS CAN SUPPORT THIS WORK

- Connect families with their [state EHDl program](#) and [Family Leadership in Language and Learning \(FL3\) center](#).
- Provide families with plain language materials developed through a localization process (English language on one side and native language on the other side) that they can review later to help them to remember and retain important information about next steps. There is so much information communicated in a single pediatric appointment that it can be extremely challenging to retain all of what is shared. This challenge may be amplified during a particularly stressful visit, such as when a diagnosis is delivered, or the pediatrician is recommending follow through with missed screenings/diagnostics.

EVALUATION AND EXPANSION PLANS

- The Center for Family Involvement is currently working with the VA EHDl program on a Plan Do Study Act process with the fotonovelas with two hospitals with large numbers of LatinX birthing mothers.
- Based on the results from the fotonovelas initiative, the Center for Family Involvement will develop similar resources for families in Arabic and Chinese (Mandarin, Cantonese) through localization activities.

ADDITIONAL CONSIDERATIONS

- Using a ‘localization’ process can take time to implement, (whereas simple English to Spanish could take a week using a translation service) but it ensures materials and messages are more meaningful, culturally responsible, and effective for the targeted population.
- Producing materials in multiple languages (e.g., Arabic, LatinX) requires sharing drafts with a variety of people in a community (e.g., parents, social workers, teachers) to ensure the information is accurately translated before it is finalized and distributed (there may be many dialects within a language). Getting started may be as simple as contacting state parent partners (e.g., [Parent to Parent USA](#), [Family Voices](#), [Hands and Voices](#)) and/or connecting with refugee and migration service partners (e.g., [United Nations High Commissioner for Refugees](#)).

BACKGROUND INFORMATION

The Center for Family Involvement at the Partnership for People with Disabilities at Virginia Commonwealth University partners with the Virginia Departments of Behavioral Health & Developmental Services (DBHDS), Education (VDOE) and Health (VDH), the federal Maternal and Child Health Bureau (MCHB), the Administration on Developmental Disabilities (AOD), and others in supporting a variety of activities to strengthen family involvement.

- **Type of Practice:** Family advocacy organization
- **City/State:** Richmond, VA
- **Population Served:** Families of children diagnosed as D/HH, deaf, blind, and other intellectual and developmental disabilities/special health care needs

MORE INFORMATION

- For more information, contact [Dana Yarbrough](#), Director, [Center for Family Involvement](#).
- For more information about American Academy of Pediatrics (AAP) EHDl program, visit aap.org/ehdi.



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