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## A Community-Based Participatory Research Project Involving Latino Families of Deaf and Hard-of-hearing Children

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### Cover Page Footnote

Acknowledgements: A special thanks to Jennifer Salazar for her vision and help with getting the project off the ground. I would also like to thank everyone who helped with this project: Christine Reese, Andrea Vega, Marissa Diener, Teresa Molina; Sonia Vega, Ana Fernandez, Kristie Millet, Martha Perez, Maison Evensen, and the teachers and staff of USDB. My gratitude also goes to the University of Utah VPR office and CBR committee for their financial support. Thank you to the reviewers for their feedback and encouragement. Finally, I especially appreciate the families who attended and participated in this project.

# A Community-Based Participatory Research Project Involving Latino Families of Deaf and Hard-of-hearing Children

Tanya L. Flores

## Abstract

The community-based participatory research project described in this paper was designed to help Spanish-speaking families of deaf and hard-of-hearing children gain access to necessary health, education, and local resource information. The project was motivated by the need to improve communication between medical and education resource centers with Spanish-speaking families. This paper reports on the specific methods and implementation of the partnership approach, the development of the project, and lessons learned for future projects of this type.

## Introduction

In Utah, the population of deaf Latino children is growing and these children tend to stay in special programs longer than their non-Latino deaf peers. One of the main reasons is the longer delay period between the time of initial diagnosis and the time of hearing-specific intervention. This delay of up to two years correlates closely with delays in language acquisition, which in turn affects schooling (Bennet, 1988; Cohen, Fischgrund, & Redding, 1990; Yoshinago-Itano, Sedey, Coulter, & Mehl, 1998; Moeller, 2000; Genesee, 2007). There is a lack of proper access to health and education program information by Latino families during crucial decision-making times. This includes decisions about hearing aids, cochlear implants, and American Sign Language (ASL), or spoken language education routes.

The primary goal of this community-based participatory research (CBPR) project was to facilitate access to educational resources regarding deafness for Spanish-speaking families by providing oral and written materials in Spanish. This included basic information about audiology and the deaf child's experience, along with information about the local resources available. In addition to the language barrier, there were cultural and financial considerations that were taken into account for the project's success. A few unexpected challenges that surfaced throughout the process will be discussed here, as well as how they can be prevented or resolved in the future.

## Background and Motivation

Deaf and hard-of-hearing (DHH) children from minority groups have been shown to experience greater difficulty in school than their non-minority peers (Bennet, 1988). Despite growing research on DHH populations, minimal research attention has been paid to the language development of children from non-English language backgrounds (see Guardino & Cannon, 2016). In the United States, these groups face several added challenges based on language barriers and, often, race-related discrimination.

In the 2015–2016 school year, the Utah School for the Deaf and Blind (USDB) served 936 deaf or hard-of-hearing individuals across the state, at least 530 of whom were children. For the past few years, approximately 30% of the deaf and hard-of-hearing children served in Salt Lake County were Latino children whose home language is Spanish (Salazar, 2016). Because Latino families want their children to learn Spanish and English, they tend to choose the spoken language route, rather than ASL once they connect with the USDB. Only one Latino child in the program is completely deaf (no hearing assistive devices) and attending the ASL program full time. Additionally, two of the preschool children attend the ASL program part-time, but their families do not use sign language at home. Our speaker series was open to and attended by Spanish-speaking families from all programs—ASL, Listening and Spoken Language, and Personal Independence Payment,

and also families not enrolled in any program. Our goal was to provide accessible information and answer questions about deaf issues in general.

By contrast to their hard-of-hearing peers who receive hearing aids before age 1, most Latino DHH children in Utah were fitted with hearing aids after the age of two. The delay in receiving any audio signal (including speech sounds) leads to a delay in the language development of both Spanish and English. This has resulted in Latino DHH children attending the USDB's Listening and Spoken Language program two to four years longer than their non-Latino peers. Latino DHH children who leave Listening and Spoken Language also tend to move to full-time special education programs in their neighborhood schools rather than transitioning directly into traditional classrooms (Salazar, 2016).

Based on research from the fields of linguistics, speech science, and education (Bennet, 1988; Cohen et al., 1990; Cummins, 1992, García-Vázquez, Vázquez, López, & Ward, 1997; Collier & Thomas, 2004; Genesee, 2007; Ertmer, True Kloiber, Jung, Connell, Kirleis, & Bradford, 2012), the earlier the child is enrolled in early intervention, the greater their academic success rate. Similarly, if spoken language is the goal, speech production accuracy is correlated to the amount of time the child can access audio signal using a hearing device.

In Utah, there has been a need to improve communication with Latino families to encourage earlier medical action and/or earlier enrollment in any USDB program. This project is a collaborative effort by the author (principal investigator) and the community partner, the USDB's Listening and Spoken Language program director, to address this need. Initially, we assumed delayed intervention was motivated primarily by financial difficulties; however, through conversations with the USDB staff and parents of the children, it became clear that the greater obstacle, at least locally, was the general lack of accessible information. Challenges include few qualified interpreters/Spanish speakers at every stage of the medical process, limited materials on the medical and non-medical options that are presented in Spanish or accessible English, and a general misunderstanding and/or dismissal of cultural differences surrounding deafness. Improvements are needed in terms of medical and educational information that is available to families in Spanish.

Currently, local Latino families receive limited, if any, written information in Spanish at the time

of deaf diagnosis; there is one pamphlet regarding cochlear implants and a few handouts about medical services. These materials are provided in local medical (ear/nose/throat, otolaryngology) offices but are produced for national audiences and tend to use specialized medical language. Most of the written materials they receive, including hearing aid catalogs, are produced only in English. Additionally, none of our local ear/nose/throat offices have Spanish speaking medical staff. Non-English speaking families generally bring a bilingual family member, often an older child, to help interpret. While these children or family members may speak more English than the parents, they do not necessarily know any medical terminology or understand the scope of the medical issue. Older children interpreters (as young as 8 in this sample) may also lack the maturity to handle the situation.

Once families are connected to the USDB, which is optional, they do receive more help, though not necessarily in Spanish. The USDB does not produce any official Spanish language written materials; however, they do have a few Spanish-speaking employees who help serve the Latino families in their programs from infancy—the Parent Infant Program—through elementary school through the Listening and Spoken Language program. There are three Latino employees in this program who are native speakers of Spanish and several employees who understand and/or speak Spanish, including a pediatric audiologist. Although the ASL program serves DHH children longer (into adulthood) than the Listening and Spoken Language program (usually into second grade), the ASL program operates in ASL and English only. For Spanish-speaking families, the Listening and Spoken Language program is more accessible, but does depend on children having hearing assistive devices.

Creating accessible materials is critically important in helping Latino families make informed decisions for their DHH children in a timely fashion. Beyond the language barrier (and even for bilingual families where language is not the major barrier), there are also cultural differences regarding the perceived “permanence” of deafness and treating deafness in infants that are not being addressed. When asked directly, many of the parents in our program did not understand that a newborn deafness diagnosis required intervention. Several parents told us their children received different (conflicting) diagnoses at different screenings and so they thought the diagnoses were temporary or

unreliable. A few of our Latino families also have deaf relatives in Spanish-speaking countries, and therefore had some experience with deafness being left untreated outside of the United States. The combination of these information-related factors are greatly contributing to delayed intervention among Latino families, despite the fact that most of these children qualify for hearing assistive devices that would improve their hearing.

A CBPR approach was adopted to help parents of deaf and hard-of-hearing children gain access to the health and local resource information they need. This partnership approach with parents encourages the participating families to be involved in all stages of the project, from planning to follow up. CBPR has been shown to be more successful than top-down approaches for educational projects similar to this one (Israel, Schulz, Parker, & Becker, 1998; Minkler, 2005; Henderson, Barr, An, Guajardo, Newhouse, Mase, & Heisler, 2013). This paper reports on the specific methods implemented, the development of the project, and lessons learned for future projects.

### **The Current Project**

Together with parents, the project principal investigator and Listening and Spoken Language program director decided that a speaker series would be beneficial, since the information would be provided in Spanish orally and interactively. In each session, a local expert would present a different topic related to deafness and deaf children issues. Following CBPR guidelines (Israel et al., 1998, Henderson et al., 2013), the presentations were not only conducted in Spanish and presented in layman's terms, but all materials were culturally sensitive and appropriate for the local audience.

The discussions following the presentations were just as critical as the presentations themselves. Following each presentation there was a scheduled question and answer session with the presenter, which provided the parents with time for the important conversations that they should be having with health care providers, educators, and community agencies. After the Q&A, there was a wrap up session led by a moderator where parents could talk about their own experiences. Parents were given note cards to ask any lingering questions related to the presentation topics; we followed up with them as needed. During the wrap-up session, we also announced the next presentation and fielded questions for the next presenter. The PI gathered these questions and shared them with

the next presenter during a pre-session meeting so that presenters could include the information. The presenters appreciated this step as it helped them tailor their presentation for this specific audience.

At the end of the series, the PI compiled the presentation slides and handouts from all of the sessions, along with Spanish handouts from deaf education sites and local parent resource information to create a parent handbook. The handbook was distributed by USDB to the Latino families. The PI also distributed the handbook to local providers of deaf services including the University of Utah's Speech-Language-Hearing Clinic and local ear/nose/throat medical offices. The university clinic not only serves DHH children, but is also a training site for graduate students in the speech-language pathology and audiology programs.

### *Participants*

An average of 20 Latino families attended each session. At least one parent, and usually both, is a native speaker of Spanish. All of the families have a child between one month and 12 years of age who is deaf or hard-of-hearing. Many families have other children with normal hearing. All of the parents were normal hearing adults. Most families who attended live in Salt Lake County, and one regularly attending family came from Ogden, about an hour away.

### **Methods**

#### *Initial planning and preparation*

The PI and the community partner, the USDB's Listening and Spoken Language program director, met three years prior to the beginning of the CBPR project. The PI had been conducting a long-term linguistics research project with the same USDB children that this project serves. The director came up with the idea for the Spanish-language speaker series and the PI contributed the CBPR methodology and funding.

Grant writing for the series began almost two years before the first session. The budget included stipends for the presenters, but the larger budget requests were to cover logistical costs for serving this community. For the series to be successful, families had to be able to commit to the program. Based on work schedules, the presentations would have to happen on a weeknight, which required budgeting for major obstacles to the families' participation. Therefore, the grant covered the cost of dinner, provided childcare with USDB trained employees, and we offered transportation/carpooling. The

grant also paid for a Spanish/English interpreter and the USDB provided ASL interpreters. The goal was to prepare for major obstacles to the families' ability to attend the sessions.

The speaker series was planned as seven (roughly monthly) sessions to be held during one academic school year. The more detailed planning for the individual sessions began during the school year prior, when we met with a parent focus group to generate topics. The parents' input led to the topics and then we recruited presenters for each session. We anticipated the hearing and language related topics, but the focus group was also interested in parenting strategies for special needs children in general. The sessions were originally planned as follows:

- September: Audiology and causes of deafness
- October: Language development for DHH children
- November: Strategies for parenting DHH children
- January: Counseling/emotional wellness for families
- February: Language research on bilingual DHH children
- March: Medical specialist session (surgeries, etc.)
- April: Parent-to-parent advice panel and resource handbook

Two sessions were moved around based on speaker availability, and we did not end up offering every session. These changes are discussed in detail in the following.

For the presentations, native speakers of Spanish were recruited, and interpreters were hired on-call for sessions that might have to be presented in English. Every effort was made to recruit local experts for the purpose of providing local resources to the families. For instance, we decided that it was better to have one of the local ear/nose/throat surgeons come with an interpreter than a Spanish-speaking surgeon from another state. Parents in the Parent Infant Program would therefore have a chance to interact with the surgeon who would actually perform their child's surgery.

Once the speakers were selected, the PI met with each presenter before their presentation to review the language of the materials. Even the English-speaking presenters prepared slides and/or handouts in Spanish. We also discussed the

parents' questions and reasons for requesting the specific topic so that the presenters could tailor the information and prepare for possible questions ahead of time. Guest speaker hiring paperwork was also filled out at that time.

The Listening and Spoken Language director recruited teaching assistants, who were trained to work with DHH children, to provide childcare. Fortunately, since the sessions were held in the conference room of a USDB school, we were also able to use a preschool classroom and outdoor playground for the childcare service. The director's office aide helped distribute our flyers to the families, and the Spanish-speaking teacher's aide also called the families to remind them of the events. I also hired a parent to help during the sessions with room set-up, greeting families, signing children in for childcare, and helping everyone with name tags. We also put together flyers to announce the series, in Spanish and English (see Appendix A), and then flyers in Spanish to announce each session and speaker (see Appendix B for example).

Funding for the project came from the University of Utah's community-based research grant, awarded to the PI. Using the funds required several training workshops from the university purchasing office in order to administer my own account, use the university's online shopping program, and get my own purchasing card. For each event, I was responsible for hiring the invited speakers, ordering the catering, and paying all of our team members (childcare, driver, moderators, greeter/floater, and interpreter). I was also responsible for filing all the purchasing and payment paperwork with the administrator of my academic department.

### Implementation

Sessions were held on the fourth Wednesday of the month from 5:30–7:30 p.m. Dinner was served during the first part, followed by the speaker presentation, and ending with a discussion time (see Appendix B). The program was structured as follows:

1. Families arrived and were greeted by PI/team members.
2. Families signed in and dropped off children for childcare.
3. Adults then proceeded to the meeting room for a catered dinner.

4. During dinner, team members continued to welcome families and talk to attendees.
5. The PI provided a welcome and introduction of the presenter.
6. Presentation
7. Q&A with presenter
8. Conclusion with parent moderator and/or PI
9. Childcare pickup

All speakers used visual aids, such as PowerPoint slides, handouts, and the whiteboard. Presentations were held in a large conference room at the USDB. Presenters tailored the language they used to ensure that technical information was accessible and clear. Many of the slides had provided definitions and images. Several presenters encouraged questions and dialogue throughout as well as after presentations.

A parent facilitator was hired to help initiate conversations and community building during the speaker series. Families were encouraged to ask questions throughout any part of the program. At every session, the PI asked the parents, teachers, and staff for feedback.

For every session, childcare was provided free of charge for families and we also provided transportation to one family. There were at least three childcare providers, a session moderator, a greeter/floater, a driver, and for one session, a Spanish-English interpreter.

Ongoing feedback was crucial to the design and implementation of the project. Team meetings took place periodically to evaluate and provide feedback on the series as it went along. Team members talked to the attendees before and after every session. Families could leave feedback anonymously on notecards provided at every session.

### **Parent Handbook**

At the end of the project year, I compiled a resource handbook in Spanish for the families. This included the information from the speaker series presentations, additional Spanish handouts from the John Tracy Clinic and the Center for Hearing and Communication, and a directory of local resources for disabled individuals provided by a local parent center. The manual was given to the Latino families in the USDB programs, including Parent Infant Program, families in the University of Utah's Audiology clinic, and a few select local pediatricians, who could provide the handbooks to Latino parents at the time of the deaf diagnosis.

Since not all local medical offices have Spanish-speaking staff and timing is critical, it is our hope that the handbook can provide immediate access for years to come to Spanish language information that is informative without being medically technical. It should also encourage new families to seek out the services of the USDB.

### **Accomplished Goals**

The speaker series succeeded in its primary goal of providing accessible information on deafness and childhood deaf issues to local Latino families. The series gave families the opportunity to ask questions of local professionals who work with deaf children, including a pediatric audiologist and the parent-infant deaf program coordinator. Parents also learned about how to help their child transition from a special program to a mainstream program during a session with a special needs educator. All of the Q&A sessions were very popular.

We also succeeded in connecting families with necessary services. For example, at least one family that was not already in the USDB system was invited to a session by the PI. This family subsequently enrolled in USDB services for the first time as a result of attending the series. The family set up an appointment with the USDB audiologist who discovered that the child actually needed two hearing aids; the child, who was 8 years old, had been using only one hearing aid for three years because one ear had a more severe hearing loss. Some existing USDB families also learned of additional services to those they were already receiving that are available through USDB, such as their battery replacement program. At least one Listening and Spoken Language teacher attended a session and connected with a family she was having a hard time reaching.

The series also facilitated a major step toward community building for local Latino families of DHH children, many of whom were meeting each other for the first time. At the first event, one of the parents took the initiative to create a Facebook group and invited all attendees to join. The idea is to facilitate communication within the group, exclusively parent-to-parent.

Although we did not conduct any exit surveys or official impact assessments this time, the PI did follow up with several families. In a follow up conversation, the newly enrolled family said they were very grateful for finally being connected with the USDB. As a result, they discovered their

8-year-old child needed a hearing aid in both ears; they commented that the second hearing aid has “changed her life.” Another family said that they hoped we would run another series next year.

Finally, the parent handbook created with the information from the speaker series and local resources was also a major accomplishment. This handbook will continue to serve as a resource of information for current and future Latino families.

### **Limitations, Lessons Learned, and Implications**

One of the often-mentioned challenges of CBPR projects is that they are complicated by having multiple stakeholders (Israel et al., 1998; Henderson et al., 2013). Even when all stakeholders share a common goal, each person/organization may have secondary goals that they would like to accomplish. We had heard from several USDB employees that the majority of Latino families do not attend USDB events and often miss even required meetings with teachers and other school staff. With the successful attendance rate of our first event, various USDB staff quickly approached us with requests they had for specific parents. These requests most often included things like passing along information; however, in one case the staff wanted us to help convince a family to make a major decision about their child’s education. This created conflict to the CBPR educational approach we were trying to implement. By adopting a CBPR model, the goal was to empower parents to become full partners with us so that we could learn from each other how to better serve the DHH children. I did not want our sessions to become substitutes for top-down meetings. Along with this, I worried that the families would become confused about the purpose of the sessions and that we would lose their trust. Their trust was crucial and not easy for the PI to gain, being an outsider to the DHH community.

The second major lesson learned was about the importance of a completely supportive infrastructure. In this case, having an already established working relationship between the PI and the Listening and Spoken Language director (community partner) helped get the project off the ground and move the project forward as challenges arose. The two of us shared a vision and primary goals for this project and we were both committed to working with this community. However, we should have established a clearer plan for communication with the staff involved in the project from the beginning to ensure everyone was on the same page. I assumed that everyone

we hired to help would support the university partnership and understand the benefits of the project; however, this was not necessarily the case. The places where support was lacking affected the team ambiance and also our publicity. The series lost momentum during the third session due to several logistical factors, including lack of publicity. Community partner projects are like delicate living organisms in that they can quickly fall apart when any of the logistical components fail.

Previous literature on projects working with Latino populations strongly urged the hiring of Latinos, especially native speakers of Spanish, in presenter and leadership roles (Israel et al., 1998; Hicks Peterson, 2018). Although every effort was made to hire native speakers of Spanish, the parents were just as receptive to non-native Spanish speakers. It did seem, however, that the audience favored presenters they knew over presenters they did not know, regardless of race or language background. For this group, it did not seem to make a difference if the presenter was a native speaker of Spanish. Parents were grateful for presentations given in Spanish, even the one with the help of an interpreter. I think the reason is that in this community, families are used to working primarily with English-speaking service providers, so there is no expectation of having a Spanish-speaking provider. Importantly, these families have had positive experiences working with their English-speaking Listening and Spoken Language director, preschool teachers, aides, and audiologists. Even though the presenters were not all native speakers of Spanish, many of the members of the leadership crew were, including the PI, planning committee parents, and two session moderators.

As other researchers who work with Latino populations have also mentioned (DeNemie, Medic, Castro, Vazquez, Rodriguez, & Kim, 2019), winter weather presented a challenge to attendance. The series was scheduled to run during the school year but ended up having to take a longer break (beyond the regular winter school break) for extreme weather. It was an unusually cold winter with earlier and heavier snowfall, which made driving difficult for everyone, especially since the families commute from across a large valley and even outside the valley. This break in the middle of the series affected our ability to establish a commitment from the families and hurt our community-building efforts. Despite the challenges that come with summer scheduling, it would be more effective to run the series from

March through October.

We were also originally expecting extended family, such as grandparents, to attend the sessions, but only parents attended. The original flyers announcing the series explicitly invited all family members, but the individual session flyers were not as clear on that point. The phone call reminders may have also communicated parents only; that would be an important issue to address with the callers if extended family members are invited.

The childcare service for younger children, including the DHH children, was planned for and expected to be necessary. This service was indeed very popular and grew with every session. The surprise was that older children and teenage siblings also came to help take care of their siblings. We learned that the majority of teens and older children are taking on the role of caretakers for their DHH siblings at home. In the future it would be beneficial to include a program designed specifically for them during the sessions, perhaps a support group with a professional counselor.

If we run a future series, we would include an exit survey or impact assessment for the families to evaluate the strengths and weaknesses of the program. In fact, if we organize another series, it would be possible to invite attendees of this series to provide similar feedback during the planning stage of the next one.

### Conclusion

The primary goal of this project was to help Spanish-speaking families of DHH children gain access to information they need to make informed decisions for their children.

This main goal was accomplished with the series and handbook. The project addressed health and cultural issues with materials, but more importantly, with an educational program created from within the academic/community partnership. The handbook compiled from this project was a major success and will continue to serve as a resource of information for future families. Due to having to cut the program short, the community-building goal was impacted. Despite the challenges, the project was worthwhile and the experience was valuable for everyone involved.

### Appendix A: English-Language Text of Flyer Announcing the Entire Speaker Series

This series is provided by a University of Utah community-based research grant.

#### COMMUNITY SPEAKER SERIES

For Spanish-Speaking Families with Deaf and Hard of Hearing Children — 5:30 to 7:30 p.m.

Dinner and childcare will be provided for families attending this event.

Located at the Utah School for the Deaf and Blind.

### Appendix B: Spanish-Language Text of Flyer Announcing One of the Sessions

Esta serie es patrocinada por la beca para investigaciones en la comunidad de la Universidad de Utah

24 DE OCTUBRE 2018

Presenter, del Programa Parent Infant de USDB nos hablará sobre la comunicacion con los niños, su desarrollo de idiomas, y las transiciones escolares de Programa Parent Infant a LSL a escuelas primarias. Esta es su oportunidad para aprender sobre las capacidades auditivas de sus niños y conocer a otras familias hispanas. Se proveerá cena y cuidado de niños, sin costo, para las familias que asistan a la charla\*. La presentación será conducida en español.

#### Schedule:

5:30 – Introducción y dejar a niños con maestras

5:40 - Cena

6:30 – Presentación

7:00 – Preguntas con presentadora

7:15 - Discusión en grupo

7:30 – Clausura y recoger a niños

En el Centro Educativo Openshaw (detras de la escuela Jean Massieu) Salt Lake City, Utah 84106

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## About the Author

Tanya L. Flores is an assistant professor of Spanish linguistics in the Department of World Languages and Cultures at the University of Utah.