



LISTENING SESSIONS – PROJECT GUIDE

IDD Diversity & Inclusion Task Force

What is a Listening Session?

A *Listening Session* is similar to a ‘focus group’ in marketing/business. Participants in a Listening Session are asked to talk about their experiences and sometimes answer specific questions about a topic. Generally, the goal is to understand the opportunities and challenges surrounding a topic as families themselves perceive them. As providers, we use the information participants share to determine what changes or actions we need to take. In a health care system where families often have limited means to give feedback, Listening Sessions are a tool to collect valuable information on the patient experience!

Logistics:

- Listening Sessions typically last between an hour to an hour and a half
- Groups of 5-8 participants are ideal, ensuring everyone has time to talk
- Participants should have personal or first-hand experience with the topic of discussion
- Organizers should consider: family transportation, childcare and/or work schedules when determining the time/location to make it as convenient as possible
- Facilitators should be skilled in validating and redirecting participants

HELPFUL RESOURCES:

Start here>> Waisman Center [“Launching Inclusive Efforts through Community Conversations”](#)
[Georgetown Center for Cultural and Linguistic Competence](#)
[Institute for Patient and Family Centered Care](#)
“Listening Sessions” folder on the Task Force box

Establish the purpose of your Listening Session:

Participants must be invested in the topic of your Listening Session if they are going to show up and give honest feedback. Consider how your topic/goal is motivating and meaningful for families.

- Tips: keep it simple (what’s your *one main goal*), emphasize the change you hope to create, make it have a direct impact on kids, offer an incentive (item, skill, or resource)

Conduct informational interviews with key stakeholders:

Unless you already have significant experience with your target group, a helpful first-step is talking to representatives of the community. Cultural brokers, family representatives, etc. will have ideas about what to incorporate, where/when to hold your session, and how to motivate participants to attend.

Members of the Task Force who have experience with Listening Sessions:

Daria Ettinger (Research Associate, IDD)

- Conducted focus groups on clinic space for “Life Span” clinics, wrote up the results for the Dean of the School of Medicine

Shauna Signorini & Tamara Bakewell (Oregon Family to Family Health Information Center)

- Conduct Listening Sessions with Family to Family participants yearly

Paulina Larenas (LEND Trainee, FACT Oregon)

- Worked with Daria, and Breanne/Hannah to lead Listening Sessions in Spanish for IDD/CDRC, has extensive experience facilitating parent groups through her work with FACT Oregon

Lindsay Sauv  (Research Associate, UCEDD)

- Helped analyze and present data from previous UCEDD Listening Sessions in rural communities.

Identify your target participants:

The way you recruit will depend on the target audience and scope of your Listening Session. The less PHI you have to collect from participants, the more likely your project will be “Quality Improvement.” If you need to contact/recruit specific participants, you will likely need IRB oversight. You will need a clear idea of your recruitment method before you submit your IRB application.

Possible methods of recruitment:

- Pass out fliers to participants of a specific clinic (more specific group)
- Post fliers in the IDD/CDRC and/or specific community centers/locations (more general group)
- Partner with a non-profit or other group that will ‘recruit’ for you (some ideas below)
 - [Oregon Family 2 Family Health Information Network](#)
 - [FACT Oregon](#)
 - OHSU [Patient and Family Advisors](#)
 - [United Cerebral Palsy of Oregon](#)
 - [Autism Society of Oregon](#)
 - [Northwest Down Syndrome Association](#)

Submit a “Request for Determination”:

Your Listening Session may qualify as a *Quality Improvement* project, which does not need IRB oversight. To determine if you qualify for this status, you’ll need to summarize the intent of your Listening Session (goals, questions, recruitment, data collection, publication) in a [Request for Determination](#) form.

- Tips: for quality improvement, avoid collection of PHI. It’s ok to audio record data/dialogue that doesn’t include participant names or PHI.
- *If you plan to publish your research later, it may be better to have IRB oversight as most research journals will require this for publication.*

Complete an Information Sheet/Consent to Participate Form:

If project is *Quality Improvement*, the Information Sheet summarizes your study and is a tool for participants if they have questions or want to contact you after the Listening Session. If you have IRB oversight, the Consent Form will be part of your IRB proposal, and will take time to complete during your Listening Session.

Advertising:

Access the pre-designed OHSU templates for rack cards, trifold brochures and fliers on the [Template Portal](#) (O2>Communications>Templates, Logos and More). You can save your completed templates as PDF files or submit them for printing.

- Tips: If you’re partnering with a non-profit or other group, ask if they can post/send-out your flier, or otherwise recruit participants (Facebook groups, emails, etc.). Your community stakeholders will also have ideas about advertising.

Plan your Listening Session:

See the sample outline for a 90 minute Listening Session in the resources below.

- Introduction: set the purpose of your session, review the IRB information sheet and logistics

- Discussion: consider how much time you'll need for your particular mix of open-ended questions, directed questions, activities, etc.
 - If you expect a comfortable/talkative group, starting with a positively-framed open-ended question may be best.
 - If you expect you'll need to 'get people talking' consider opening with an activity or more directed/specific questions that set the stage for the dialogue you hope to have.
- Facilitator tips: your facilitator will need to be skilled at verbally summarizing, validating, and re-directing participants. Before you begin, consider addressing the time limitations, and warn participants that you may need to redirect the dialogue to make sure all topics are addressed (*see "Tips for Facilitators" handout below*)
- Conclusion: Leave 5-10 minutes at the end of the session to summarize input, review next-steps and remind participants how their valuable input will be used!

Make Sure to Bring:

- Copies of the Information Sheet or Consent Forms
- At least 2 audio recording devices (check these work before you go)
- Paper/pens or a laptop to take notes (also back-up if recording fails)
- Donations (food, beverages, etc.) if applicable

Set yourself up for easy data analysis:

- Recording: as noted above, consider using multiple audio-recorders so you have back-up. In the space, determine the best placement (away from windows/fans/background noise) and/or test your recorder beforehand. The clearer the recording quality, the easier transcription will be.
- Note-Taking: determine a note-taker (or two), other than the facilitator who will attend the Listening Session. It is helpful to write the first word or line of each participant turn so you can clearly delineate speakers when you transcribe.
- Transcription: As a rule of thumb, it will take around an hour to transcribe every 20 minutes of the Listening Session. This will likely take longer if you need to transcribe and translate into another language, so plan accordingly.

Distribution:

How you choose to distribute your results will vary depending on your scope/topic. Regardless, you will likely need to share and summarize what you learned.

- Food for thought: consider including complete quotes/talk-points *in the participants own words* (and/or with accompanying translation) so that their perspectives and sentiments are minimally altered.
- Example Summaries: in the "Listening Session" folder on box, you can find example summaries from previous UCEDD and task-force listening sessions. *Screenshots in the resources below.*

SAMPLE TIMELINE

SEPT-OCT:

Research Listening Sessions

Determine a topic/theme for your session
Talk to key stakeholders
Identify possible groups for recruitment

NOV-DEC:

Outline your plan in a “**Request for Determination**” (If determined to be Quality Improvement, this will turn-around ~2 weeks)
Create your Information Sheet or Consent for Participation form

JAN:

Reach-out to prospective groups to see if they are interested in hosting
And/or finalize your recruitment/advertising plan

FEB-MAR:

Determine/finalize the date/location
Create a flier on the OHSU marketing portal to **advertise your event** (if needed)
Disseminate your flier or begin other advertising

APRIL:

Reach out to local grocery stores with *at least 30 days notice* to request a **donation of food/beverages**
Depending on the event, you may also request donations of clothing, toys or books
Arrange for access/use of recording devices, if needed

MAY:

Finalize your event outline (see sample)
If you are doing guided activities (butcher paper/post-it notes), written surveys, etc. assemble materials as needed
Conduct your Listening Session!

JUNE-JULY:

Thank your recruitment partners/participants
Transcribe data, and **code** for themes as determined in your research protocol

AUG:

Compile your findings into a summary (info-graphic, PPT presentation, report, one-pager, etc.)
Present your findings to the Task Force
Share any resources created in the “Listening Session” folder on box.

Quick Reference Guide: Quality Improvement or Research?

In the era of quality improvement, questions about the line between QI and research come up frequently. This guide is a supplement to HRP-421 WORKSHEET – Human Research.

Definition of Research

A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. ([45 CFR 46.102\(d\)](#))

General Characteristics of Quality Improvement vs. Research

Quality Improvement

- Implement change according to mandates of hospital's Clinical QI program
- Improve process or delivery of care with established/accepted methods
- Implement systematic monitoring to ensure existing quality standards are met
- All participants receive standard of care
- Improve performance in a specific program

Research

- May be funded by an external research agency
- Answer a research question/tests a hypothesis
- Uses research design: Group comparisons, randomization, control groups, prospective comparison, cross-sectional, case-control, etc.
- Develops new paradigms or untested methods, establishes a new clinical practice standard
- Follows a protocol that overrides clinical decision-making
- Develop or contribute to generalizable knowledge

Examples

Quality Improvement

Developing an outreach process to facilitate scheduling follow-up appointments for patients with blood pressure readings above goal, and measuring the percentage of follow-up visits scheduled before and after the intervention.

Research

Randomizing patients who have blood pressure readings above goal at a primary care visit to receive either an email reminder or a phone call reminder in order to determine which method results in a higher percentage of patients scheduling a follow-up appointment.

Quality Improvement

Hospital implements a procedure known to reduce pharmacy prescription error rates and collects prescription information from medical records to assess adherence to the procedure and determine if error rates have decreased as expected.

Research

Investigators conduct focus groups and individual interviews with pharmacists at various hospitals in order to analyze likely causes of prescription errors in different types of hospital settings.

FAQs about Quality Improvement Projects

If we want to publish our QI project, is that research?

Sometimes.

Usually, when you systematically collect information with intent to generalize the results to those outside your local environment, the project is research. The intent to publish can be an indicator that you intend to develop or contribute to generalizable knowledge. However, it is possible to conduct a QI project that is specific to a local or very limited context and publish the results as an example for others to learn from without the project meeting the definition of research. It is also possible that a project is research even if there is no intent to publish.

What if I started a QI project, then the results were really interesting, and now I think the knowledge we are gaining might be generalizable, so I want to publish? I didn't have IRB approval when I started. What should I do?

Stop working on the project and evaluate whether your goal has changed from a local improvement project to a generalizable systematic evaluation (in other words – it's now research). If so, you need IRB approval before continuing with the project and need to submit a New Study to the IRB.

If you are unsure of whether you need IRB approval, submit a Request for Determination. The IRB will determine whether your project qualifies as human subjects research, and if so what level of review/oversight is required. Once this is completed, you can proceed with the project.

See Also: FAQs about Quality Improvement Activities from the Office for Human Research Protections (OHRP): <http://answers.hhs.gov/ohrp/categories/1569>.

SAMPLE OUTLINE

DRAFT: Listening Session Outline – Spanish-Speaking Family Perspectives on Diversity & Inclusion

<u>Time:</u>	<u>Purpose:</u>	<u>Script/Potential Questions:</u>
5 minutes	INTRODUCTION: Purpose of the Listening Session and what we will do with this information	We are coming to families to get feedback instead of guessing what is helpful. Their feedback helps us to improve our programming for Spanish speaking families.
5 minutes	INFORMATION SHEET/DEMOGRAPHICS: Distribute mandatory IRB/research info sheet to inform participants	Participation in this project is optional. Conversation will be open-ended, participants are not required to answer any specific questions. All information collected will be anonymous.
30 minutes	OPEN ENDED QUESTIONS: Alert participants to the beginning of audio-recording	What do we do that we should continue? (strengths) What could we do better? (challenges) How is your child's disability viewed in your family? Do you feel your doctor/provider has appropriate expectations for your child? What are the priorities of your community? What are some challenges facing children with disabilities in your community?
10 minutes	DIRECTED TOPIC: Visit Logistics	What information is helpful before a visit to clinic? When you arrive at the hospital, what is helpful (signs, brochures, maps, parking, etc.)? Is there anything you would change about the physical space at the hospital (waiting rooms, bathrooms, food, etc.)? After the visit, how do you like to receive feedback about your child?
10 minutes	DIRECTED TOPIC: Interpreters/Translation	How has your experience been working with interpreters? Have they worked well with your child? Do you like to receive information translated into Spanish? How do you use this information? What information is most important to have translated?
10 minutes	DIRECTED TOPIC: Feedback	How do you give feedback to your doctor/provider about your experience? Have you used a survey, comment card, or other resource to give feedback before? Why did you choose this method? How can we help families with limited literacy give feedback to providers? What should providers know about working with and giving feedback to Spanish speaking families?
20 minutes	WRAP-UP/ PARTICIPANT QUESTIONS Summarize input End audio-recording	Opportunity to rank ideas/ priorities (sticky notes/interactive poster) Open up to participant questions about community resources

TIPS FOR FACILITATORS:

Author: Paulina Larenas (IDD Task Force/FACT Oregon)

Introductions:

- Introduce yourself and give time for other team members to introduce themselves
- Ask families to introduce themselves (according to demographic information in your IRB proposal) Consider asking something fun about them (e.g., what did they do earlier that day?).
- Explain the difference between the CDRC, OHSU or Doernbecher if relevant for your topic.
- Introduce the project: Why are we doing this? What's the outcome? What will you talk about?
- If the session will be audio-recorded, let families know. Explain names will not be recorded nor personal information disclosed. Start audio-recording after the family introductions.
- Consider setting some agreements/group norms before the session begins.
- Check for questions or concerns before you start.

During the session:

- There will be times you need to take initiative, sometimes families are not sure what to answer or what the questions is about. If this is the case, try a short personal example.
 - After this, consider asking person by person around the group.
- Be confident and redirect as needed (it's easy for discussion to get out of track).
 - Say something like "yes, thank you so much for sharing that, does anyone have an experience about...? (repeat the question)"
- Interrupt *only when necessary* or if someone is taking too much time sharing. You can say something like, "I am sorry about your experience..." and then redirect to someone else.
- Smile throughout the session. Try not to take up much time sharing your experiences, only if it is necessary to redirect or guide the conversation.
- A little bit of humor is always good, it makes the participants feel more comfortable and tends to ease the tension.
- If some families are not talking, encourage them to talk by asking more specific questions, or by looking to them and saying something like "what about your experience...."
- Be respectful, remember that families are talking about their children and lived experiences. This can be uncomfortable with strangers, difficult to share, and emotional for them.
- Families need to feel safe, especially in the current political climate. Repeat/assure them their information will be kept confidential.
- Remain positive at all times, even if the conversation starts to turn negative. Validate and acknowledge negative experiences, but try to help them see the positives.

End of the session:

- Thank everyone for participating! Make sure families know how important and valuable their time is, especially to the team holding the Listening Session
- Ask if they have any questions or feedback they can give about the Listening Session experience.

SAMPLE ABSTRACT:

LEND RESEARCH PROJECT: FINAL ABSTRACT

Study Title: Spanish-Speaking Family Perspectives on Developmental Disabilities

Trainee Name: Breanne Toney, M.S., CF-SLP (Principal Investigator)

Mentor Name: Hannah Sanford-Keller M.A., CCC-SLP

Background: The IDD Diversity & Inclusion Task-Force seeks to better meet the needs of culturally and linguistically diverse families who access services at IDD. To date, both the UCEDD and Family to Family Health Information Network have undertaken “listening sessions” to elicit family perspectives on community strengths and challenges. In contribution to this body of evidence, this project recruited Spanish-speaking families to share the unique perspectives of their cultural and linguistic community.

Objective: Conduct a “listening session” enlisting Spanish-speaking families in a discussion about their experiences with healthcare. Results will help determine whether identified Task-Force activities are aligned with family needs and values.

Method:

- a) **Participants:** A total of thirteen participants, one Spanish-speaking facilitator, and two CDRC staff participated. Of the thirteen family members, eight had children experiencing disability, four were currently receiving private/school therapy, and one had attended a CDRC clinic. Developmental disabilities represented included: autism, speech/language disorder, attention/learning disorders and hearing loss.
- b) **Setting:** The adult education space at WL Henry Elementary School in Hillsboro, OR.
- c) **Design:** A semi-structured roundtable discussion conducted in Spanish by a native-speaking facilitator. Participants were asked open-ended questions about: disability experience, clinic logistics, working with interpreters, and cultural expectations. Many questions were adapted from previous sessions for cross-comparison of responses.
- d) **Procedures:** Participants were recruited through non-profit Adelante Mujeres. The listening session was held during a weekly parent education program. Recruitment fliers were sent to all families participating in their early childhood programming. Project was determined exempt from IRB oversight and coded as “Quality Improvement.”
- e) **Analyses:** The listening session was audio-recorded for later transcription. Participants were assigned a number and responses were tracked by number for later analysis. To date, the transcript has been outlined and “loosely translated” into English by the primary investigator. The native speaker who served as session facilitator in undergoing final transcription in Spanish-English.

Results: Participants endorsed feelings of disbelief and inattention from their medical providers. They described concerns being dismissed as “normal,” in addition to frustration about access, insurance, and long wait times. Another major theme was concern about accurate interpretation, both in the room and print translation. Regarding cultural considerations, they described fear of retribution for filling out comment cards, intimidation when providers don’t speak Spanish, and surprise when providers address their children instead of speaking to them directly.

Conclusion:

Participants endorsed the need for current Task-Force activities including training for interpreters and providers working with interpreters. As a research team, we would like to replicate the study with families who specifically receive care at OHSU, to compare with the themes identified in this session. |

SAMPLE SUMMARY (partial)

Community Listening: Diversity & Disability

OHSU University Center for Excellence in Developmental Disabilities

OHSU UCEDD, 707 SW Gaines St, Portland, Or 97239 <http://www.ohsu.edu/ucedd> ucedd@ohsu.edu

Why Community Listening?

The University Center for Excellence in Developmental Disabilities (UCEDD) at Oregon Health & Science University, as a member of PODD*, in partnership with three Regional Health Equity Coalitions (RHEC) conducted three listening sessions in various regions in rural Oregon during the month of June.

The intent of the Listening Sessions was to provide PODD's agencies' representatives the opportunity to make meaningful connections and build relationships with diverse populations (Latino and Native American) in rural communities in Oregon. The sessions were not intended for PODD members to offer fixes, suggestions or advice.

The Sessions provided PODD members with an increased understanding of diverse populations' and what is/are:

- their perspective on disability,
- culturally relevant and important to them,
- the strengths of their communities,
- their community's gaps or barriers,
- their perspectives on how agencies can be more welcoming and responsive,
- ways agencies can better partner and support diverse communities.

*Partners in Oregon on Diversity and Disability (PODD), serves all of Oregon, and includes Oregon's two University Centers on Excellence and Developmental Disabilities (UCEDDs), Disability Rights Oregon, and the Oregon Developmental Disabilities Council.

Listening in Hood River

The third of the three Listening Sessions took place in Hood River. There were approximately 30 attendees who joined together to discuss disability and culture in their community. Dinner, interpreters and child care were provided and community members were asked to participate in both facilitated large group and small group discussions. The evening began with attendees being invited to share their opinions about their community's top three strengths and top three challenges via the "Strengths and Challenges Posting Activity".

See chart on page 2

Inside This Report

- 1 Community Listening
- 1 Listening in Hood River
- 2 Hood River Strengths and Challenges
- 3 Strengths and Challenges cont'd
- 4 Dream BIG
- 4 What's Happening Now!
- 4 Next Steps

"Listening Sessions provide opportunities to learn from, and build trust with, a community."



SAMPLE SUMMARY (partial)



Event:

-Tuesday, May 8, 2018
WL Henry Elementary School,
Hillsboro, OR
-Principal Investigator:
Breanne Toney, M.S. CF-SLP
-Co-Investigator: Hannah
Sanford-Keller, M.S. CCC-SLP
-Facilitated and Translated
by: Paulina Larenas

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.

SAMPLE PPT SLIDES (partial)

Spanish-Speaking Family Perspectives on Developmental Disabilities

Trainee Name: Breanne Toney, M.S., CF-SLP
Mentor Name: Hannah Sanford-Keller, M.S., CCC-SLP

Rationale

IDD Diversity & Inclusion Task-Force

Diversity Action Plan **objective**:

- "Improve access to healthcare for diverse families and populations"

Identified **activity**:

- "Interview 3 family representatives from FACT to identify themes in access to healthcare at the CDRC"

My goal: elicit Latino/Spanish-speaking family perspectives to determine family priorities and values

Listening Session

THANKS TO:

Tamara Bakewell (EPH HIN)
Daria Ettinger (ICD)
Paulina Laranas (FACT)
Lauren Cyoak (U of O)

Resources provided by:
Undsay Sauve (UCEDD)
Shauna Signorini (EPHIN)

- Invest families in the impact of your project
- Provide childcare if possible
- Provide an incentive to participate
- Work with trusted community partners for recruitment
- Aim for 6-10 participants
- Plan for 60-90 minutes conversation
- Consider participant literacy if collecting information/filling forms

Community Partner

"Women Rise Up/Move Forward"



ADDELANTE MUJERES

- Adult Education
- Early Childhood Education
- "Chicas" Youth Development
- ESPERE/School of Forgiveness
- Sustainable Agriculture
- Empress Small Business Development
- Forest Grove Farmers Market

Adelante Mujeres educates and empowers Latina women and their families through holistic programs that ensure their full participation and active leadership in the community.

Research Questions

Disability Experience

- What are the health priorities of your community?
- What are some challenges facing children with disabilities in your community?

Visit Logistics

- What information is helpful before a visit to clinic?

Working with Interpreters

- How has your experience been working with interpreters?

Giving and Getting Feedback

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


Analyses

So far...

- Audio-recorded
- Participant responses were tracked by number
- Translated in Spanish/English by native speaker

In progress...

- Code for themes, recruit second rater
- Summarize for Task-Force



Feeling dismissed by medical professionals

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

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

The "normal normal" problem

El [mi esposa] escuchó la palabra [normal] de la doctora y me dice «¡ya le dijo la doctora que es siete, el niño no tiene mal!» pero la siento no es normal, mi hijo tiene un problema y necesito averiguar.

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.

Mother of a child diagnosed with Autism at age 12