



466 M  
80% LMIC



3%



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# Disclosures

- Sarah Radlinski is an employee of the Auditory-Verbal Center, Inc. (AVC). AVC received funding from Hear the World to support the Hear Panama project.
- Carina Rodriguez is an employee of Advanced Bionics, a subsidiary of Sonova who founded Hear the World Foundation.



# Learning Objectives

- List 3 barriers and limitations to consider with the donation of implantable technology in developing countries without a well-established pediatric cochlear implant program.
- Identify strategies and solutions for ensuring that a cochlear implant donation has a meaningful and sustainable impact on the lives of implant recipients.

# BETTER HEARING FOR A BETTER FUTURE

By supporting the charitable Hear the World Foundation, Sonova is campaigning for equal opportunities and a better quality of life for people with hearing loss.

HEAR  
THE WORLD  
FOUNDATION

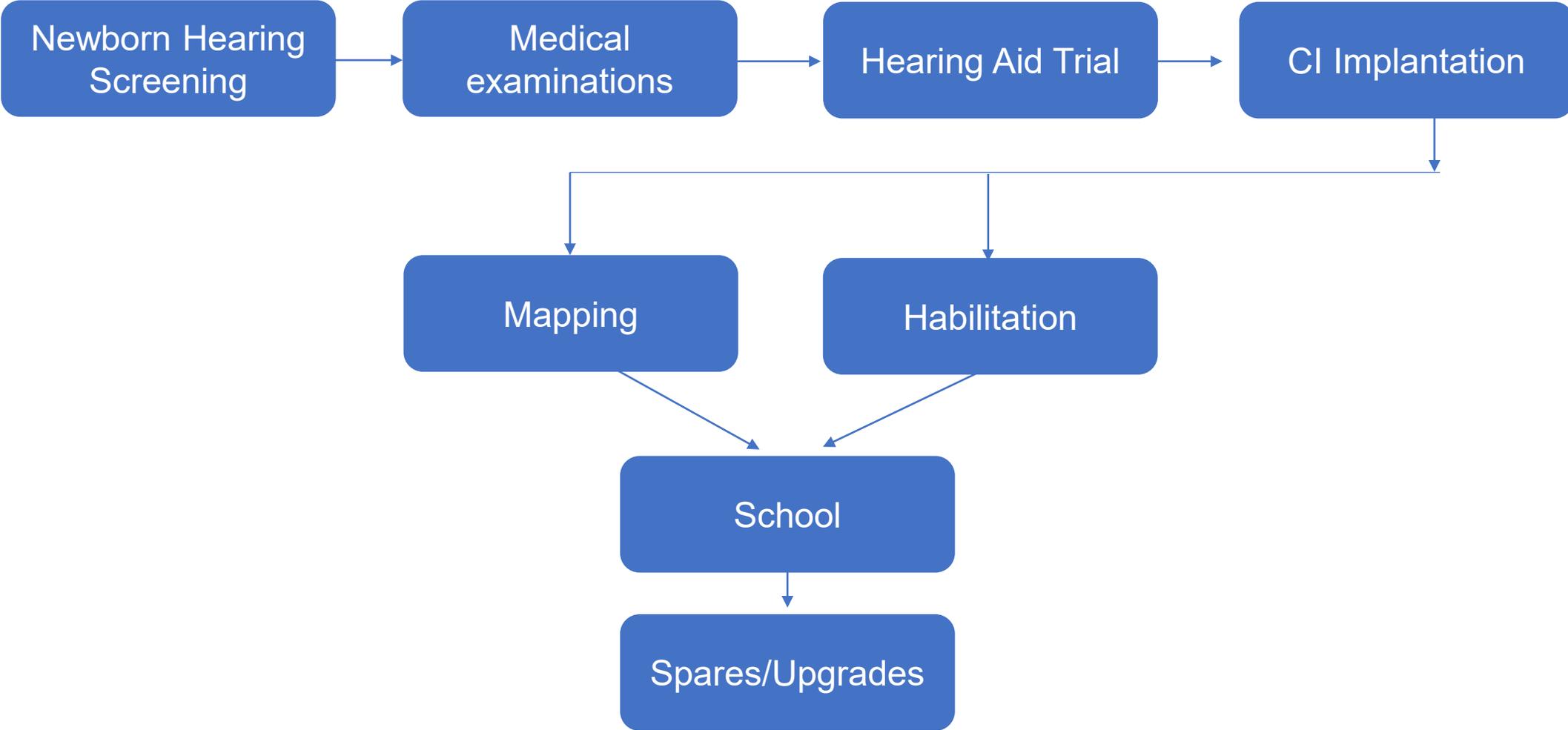
*a Sonova Group initiative*

**Hear the World** is an independent charitable foundation established by Sonova in 2006.

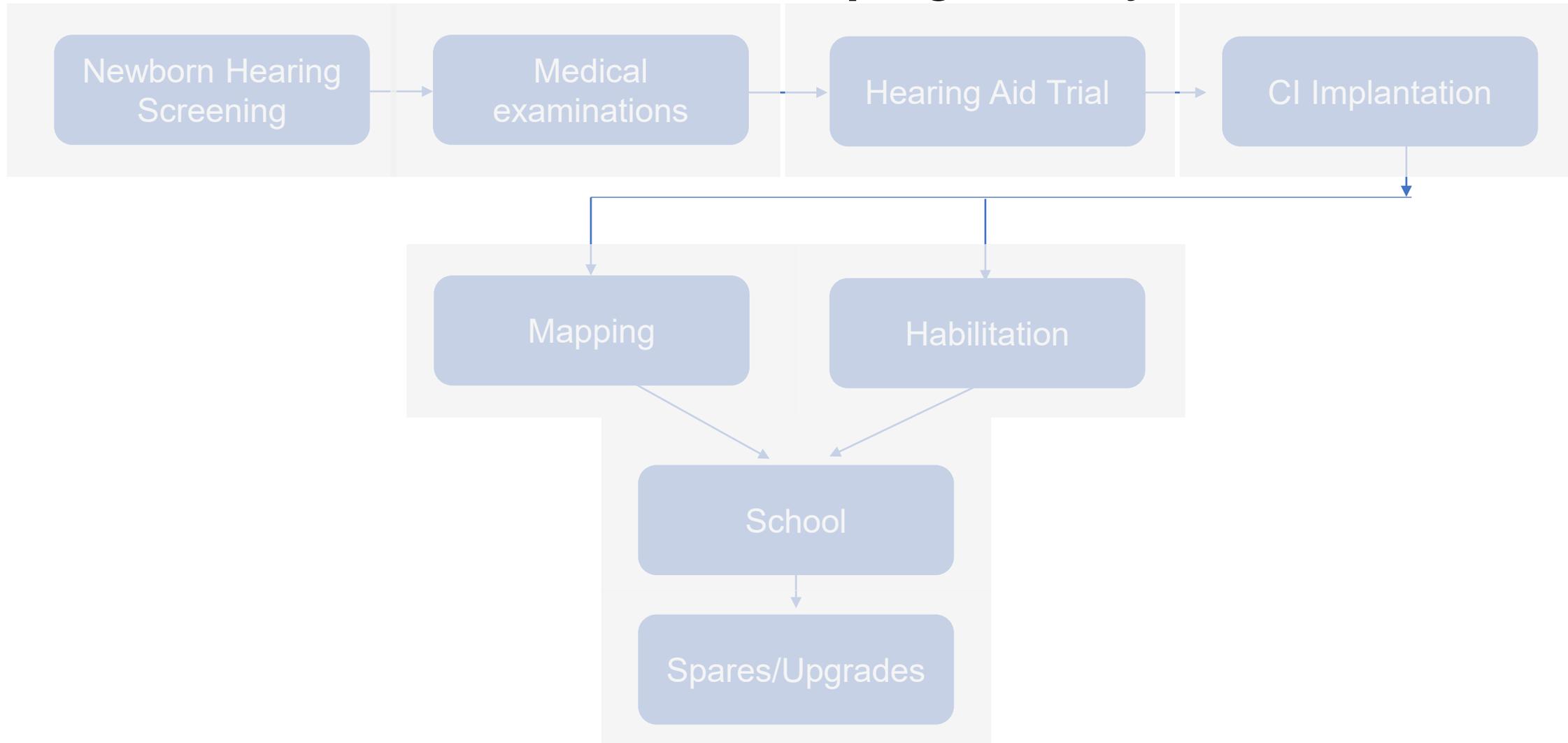
The Foundation's **GOAL** is to work for equal opportunities and better quality of life for people with hearing loss.

In many low-to-middle income countries, there is no insurance coverage or state subsidization for cochlear implants. This makes the implants, the associated operations, the long-term audiological follow-up care and the costs of device maintenance unaffordable for many families.

# Overview of the Cochlear Implant Journey for a Child a Developed Country

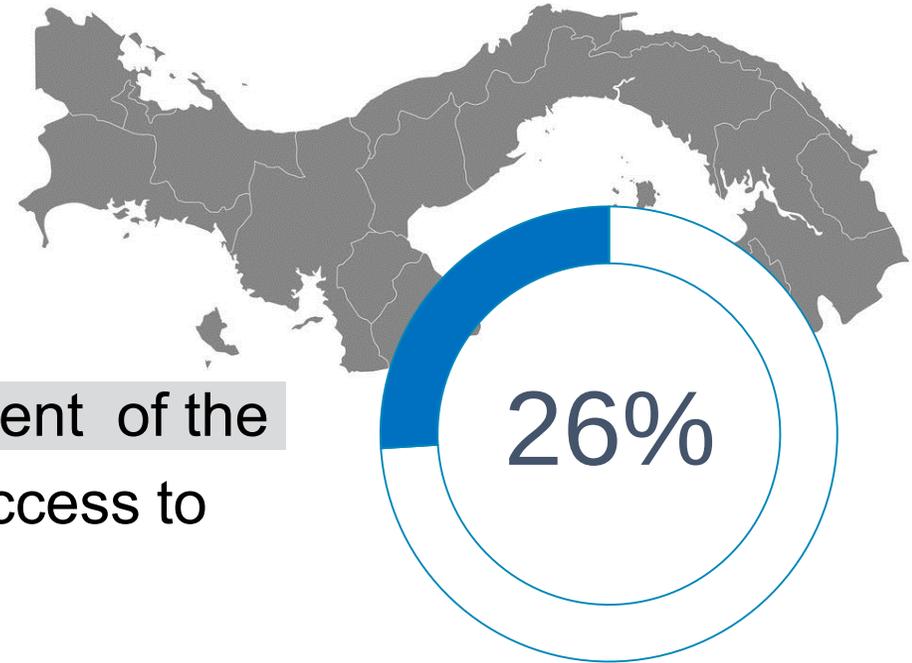


# Overview of the Cochlear Implant Journey for a Child in a Developing Country



## Panamá landscape

- Although Panama is ranked the second most competitive economy in Latin America, 26 percent of the population is living in poverty, and is lacking access to audiological care. Particularly for children.
- Although the health sector is making major progress in terms of its audiological care infrastructure, the state-run healthcare system can only cover the costs of hearing aids and speech therapy for a handful of those living in poverty.
- Local foundations are allocating funds to close this gap by providing free examinations and professional audiological care.



# FIRST COCHLEAR IMPLANT DONATION FOR CHILDREN

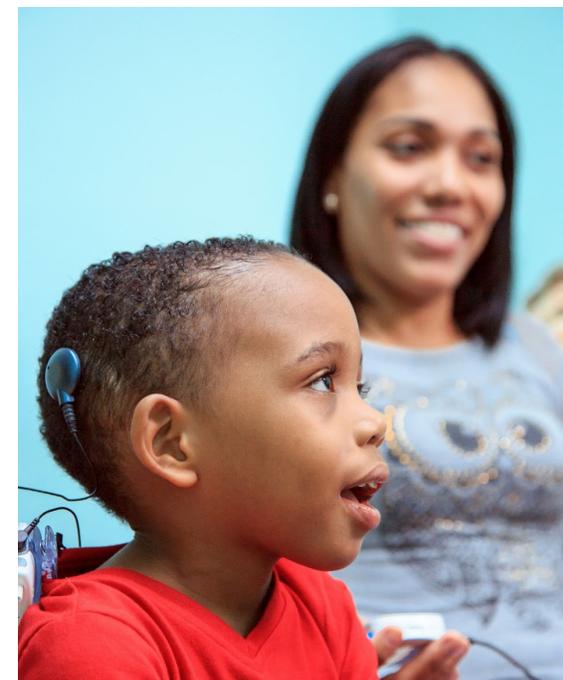
Project Partner: **Funproi** (Fundación Pro Integración)

Foundation working in Panama since 1983

HTW has been supporting FUNPROI with funding, expertise, and hearing aids since 2013

For the first time in 2016 HTW decided to support FUNPROI with cochlear implants (CIs), donated by the Sonova subsidiary Advanced Bionics, in addition to the funding, expertise, and hearing aids it had provided up until then.

Pilot project: **Hear Panama**



A Milestone...Hear Panama

# Hear Panama – overview/approach



Partner with Local Foundation



- Understand the community
- Understand the family background
- Infrastructure around the family



Partnership CI manufacture



- Expert in hearing technology implementation
- Continue technical support, updated knowledge
- Trainer on fitting, care, troubleshooting



Local HCPs



- Pre-surgery, Surgery and Post-surgery management
- Use professional connections to help (surgical support, training, Mentorship, long term medical follow up)



Follow up & support



- Continue support on medical & surgical; audiological; technical; hearing & language rehabilitation; social & phsicological, etc



Long term financial support



- Continue support external costs
- Replacement externals and upgrades over 15 years

# Phase 1 Key actions

## Candidate selection & coordination of care

- Working with local professionals, candidates were identified and evaluated (4 candidates/3 implanted)
  - Counseling sessions were provided

2016



## Speech therapy & Parents Educational events

- Provision of speech therapy
- Training of families providing information and resources to support the hearing journey

2017



2017

## Local Partner training & Hearing habilitation

- Training on CI technology & Audiological Follow up
- Surgeries, Post-op activations, routine mapping were performed.



## Phase 2 Key actions

### Second round of implantations

- new candidates (**4 implanted**)

2018



2018

### Professional training & monitoring

- Professional follow-up care.
- Regular audiological monitoring of the CI and mapping optimization
- Limited progress noted; decision made to seek external AV professional to bring in

### Outcomes assessment Evaluation Phase 1&2

- Sarah conducts auditory & language assessments.
  - Limitations and barriers involved in the process.

2019



February  
2019:  
My first trip

- Assessment of:
  - Local therapist's skill level
  - Children's auditory, speech, and language levels
  - Parents' understanding of their role
  - School/childcare situation
  - Local resources

# Barriers



Age of implantation



Additional disabilities—  
one acquired due to  
seizures



Ability/training of local  
therapist



Parent coaching; home  
carryover



Environment  
throughout day

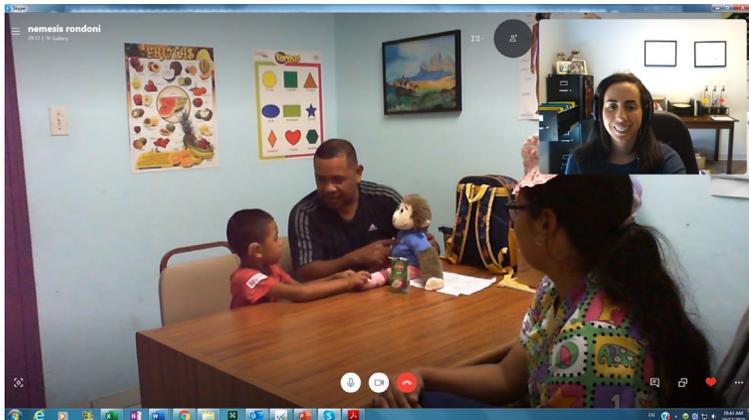


Resources

Barrier: Providing continuity of care and consistent intervention and training of local therapist

Three trips isn't enough!

How can we bridge the time between in-person visits?

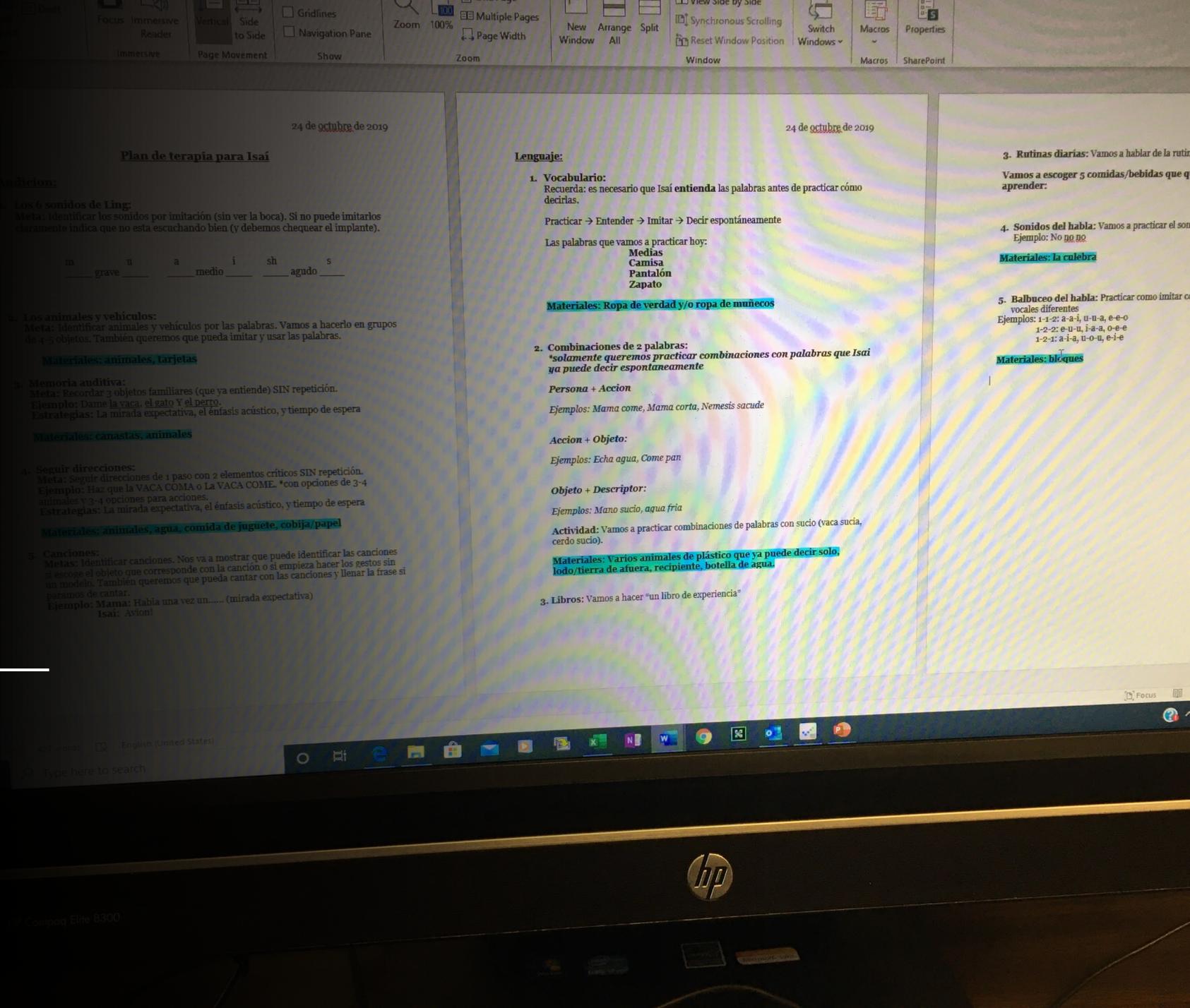


Solution:  
Remote support via tele-therapy

# Therapy Plans

I sent plans initially then therapist sent me plans

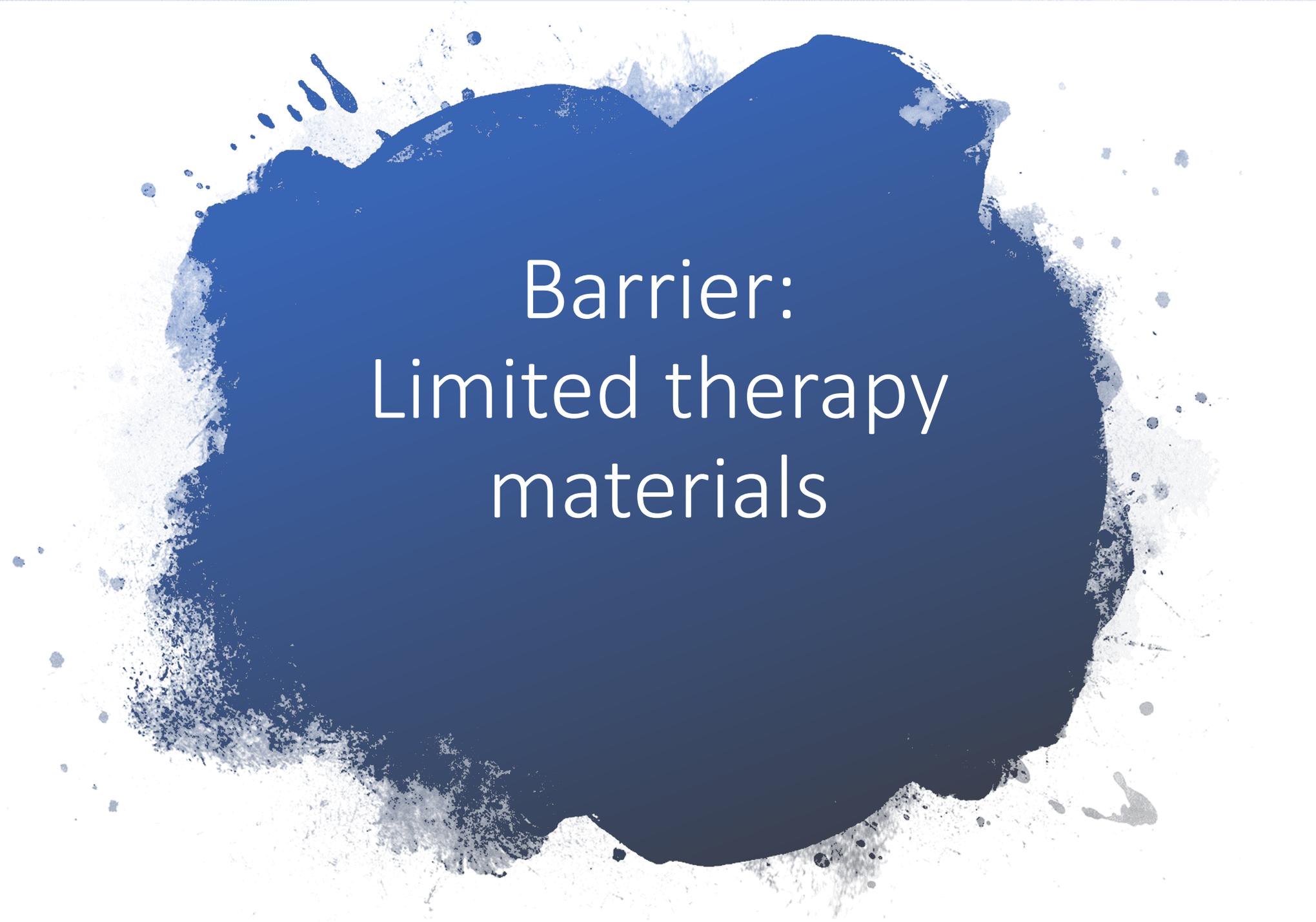
Individualized for each child



## Continued Barrier: Distance/transportation

- Tele-therapy from families' home not option because of internet (and also goal of teaching local professional)
- Alejandro's story



A dark blue, irregularly shaped graphic with a splatter effect, containing white text. The graphic is centered on a white background and has a rough, ink-like border. The text is centered within the graphic and reads "Barrier: Limited therapy materials".

Barrier:  
Limited therapy  
materials



# Solution: Routines-based intervention

Coach families on strategies to build language around routines they are already doing!



Hojaldres: Power of using routines that are culturally relevant to family

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# Lime juice

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# Pineapple and papaya



Use what is relevant to local families. May be different for different projects!

# Tips

- Talk me through things you do everyday
- Many universal routines– but the **“how”** and **“what”** may be different
- Let the family be the expert in their own routines/culture
- Their routines may be different than your own. You don't have to learn/memorize routines.
- Say: Show me how to do it.
- Your job is to coach families on strategies to enhance outcomes.
- Build the language around what they are already doing!

Barrier:  
Cultural differences



Therapy Solution:  
Culturally-  
relevant  
intervention

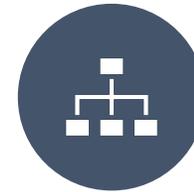
# Other Cultural Differences



Depth of application/reports



How things are organized



Hierarchy of staff at the local foundation

# Language barriers

- Finding volunteers who speak the language
- Local foundation communicating with HTW in Switzerland



## Differences across dialect

- Cerdo
- Puerco
- Chancho
- Marrano
- Cochino
- Cuche
- Cocho
- Gorrino

# How to approach families/local therapist

1

Be up front about goal:  
we want the child to  
speak like his  
FAMILY/local  
community

2

Give permission/ask  
them to correct you

3

Be clear that **THEY** are  
the experts in their  
language

# Overall communication

- Not only about Spanish language itself
  - Body language
  - Implicit messaging
- Needed to be more direct

# Adapting therapy



# Selection of vocabulary targets: Do NOT just translate early developing word lists from English



Length/difficulty  
of word



Poor translation  
equivalent



Multiple  
words/concept



Frequency of use  
in language



## *Did you know?*

Onomatopoeia sounds are different across the world!

- Animal, vehicle, and other beginning sounds are different across languages
- Spanish-speaking families often do not naturally use the “classic” (i.e English) sounds



Woof  
woof



Mung-  
mung



iGuau  
guau!



Bau-bau

Adapt, don't  
translate  
songs,  
rhymes, and  
music



# Experience books



# One year later...

## Child progress

- All improved but varying rates

## Therapist progress

- Much improved but still in process

## Family outcomes

- Improved home carryover
- Need for continued guidance

# Expectations for a pilot program

- Don't undersell but also need realistic expectations
  - Aim high but also fair
- Outcomes may be different for different families



Lessons learned

Don't make  
assumptions



Literacy level



Local therapist knowledge



Skill level of child



- Repetition is key
  - Videos with strategies
  - Have therapist/family explain idea back
- Less can be more
  - Arrived with huge binders for each child
  - Too much information at once



# Be flexible and creative!

Scheduling

Materials/equipment



## Summary:

# Questions to consider when pursuing a cochlear implant donation

1

### Infrastructure

Can the existing infrastructure support the child **easily and conveniently?**

**If so where (capital, large cities, etc)**

2

### Surgical support

Before and post implantation. Do the local professionals are able to **provide surgical support** and long term follow up, identify, mitigate and manage surgical complications ?

3

### Maintenance cost

How to minimizing the **“burden” of a free cochlear implant on families** . Convenient and free access to mapping/habilitation  
Externals warranty expiration

# Questions to consider when pursuing a cochlear implant donation



## Candidate selection

How can we identify right candidates?  
Is there any multidisciplinary group working locally on hearing screening? Or we need to think about creating one?



## Family support

Family support is paramount to ensure success.  
How we will evaluate these key elements in families?  
How can we support continue education for families?



## Schooling post CI

Do we have local CI experienced schools?  
Mainstream, blended, self-contained?  
Streaming technology (Roger). D/HH

# Questions to consider when pursuing a cochlear implant donation

7

## Language/cultural differences

Can we meet the language needs of population? How can we provide culturally relevant intervention?

8

## Professional training

How can we train local professionals? Can we build a local professional care network with continuing education?

9

## Sustainability

Do we have the ability and conditions for the project to have a long-lasting impact.



Questions?

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