

CI in Low Resourced Countries

WELCOME, Leo De Raeve,
Chair, CIICA

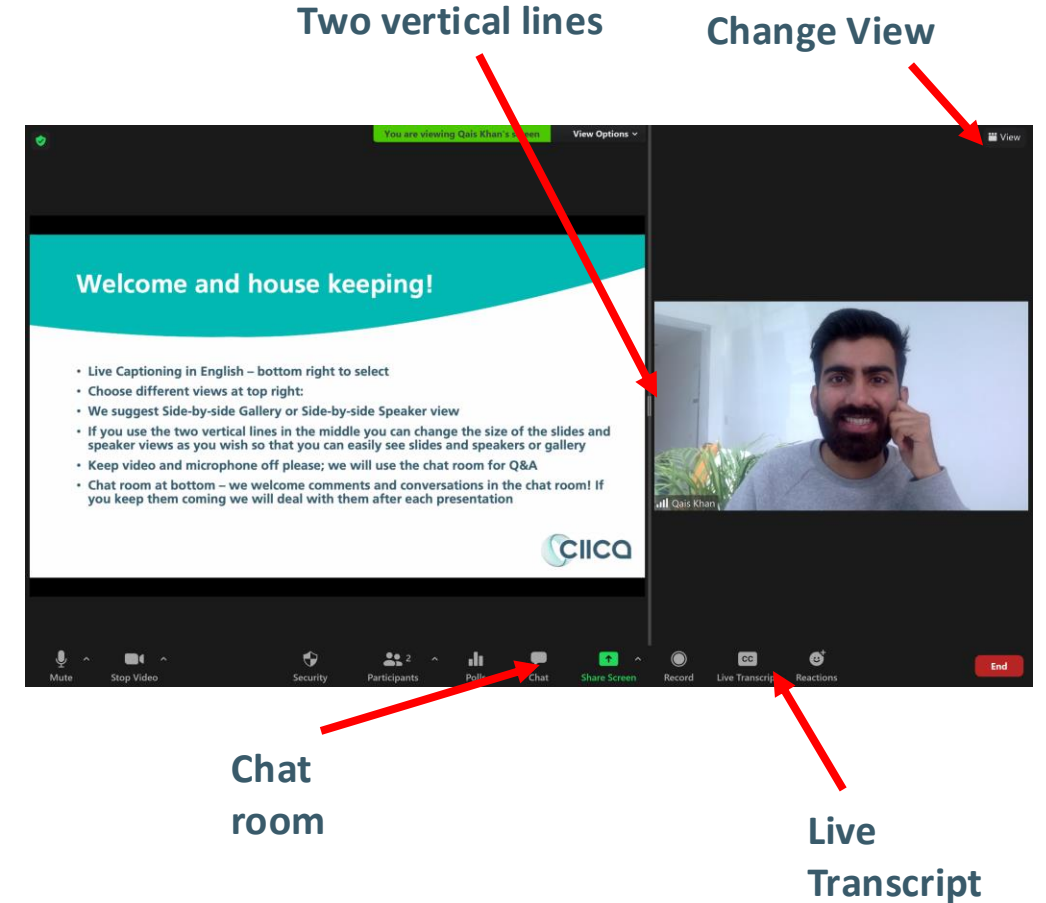
THURSDAY 26 September 2024

Welcome and house keeping!

- Choose different views at top right: We suggest Side -by-side Speaker view
- Use the two vertical lines in the middle to change the size of the slides and speaker views so that you can easily see slides and speakers at same time
- Camera and microphone off please; please use the chat room for comments and to say hi to everyone !
- The meeting will be recorded – by staying on you have agreed this.

Captioning

- For English : Turn on the live transcript in Zoom or use stream text link in the chat room to view subtitles in another window or device
- You can choose other languages
- Any questions, Robert will answer in the chat room



INTRODUCTION AND CHAIR

Eddie Mukaaya

Founder of Hear His Voice,
Uganda, and parent of a daughter
using CI, and member of the Board
of CIICA.



The Programme

Introduction	Eddie Mukaaya, Uganda
Bridging the Gap: Navigating the Challenges of Cochlear Implant Provision in Low-Resource Countries!	Steve Kittur, Kenya
Parental Challenges in Colombia	Marcela Varela, Colombia
Parents driving CI	Lusine Stepanyan, Armenia
Addressing Habilitation needs	Paige Stringer, Global
Delivering across the lifespan	Vahishtai Daboo, India
CI funding challenges	Jenny Perold, South Africa
Round Up	Brian Lamb



CAROLINA DER, WHO

CAROLINA SENDS HER APOLOGIES- SHE IS IN FLIGHT!

LAST TIME THIS WAS HER TITLE- AND
AVAILABLE AT: www.ciicanet.org/events

Carolina Der, MD, PhD, Technical officer, Ear and Hearing Care, World Health Organisation
Carolina is an ENT surgeon from Chile, specialising in CI.

Ear and Hearing Care for all!

**How can we make cochlear implants affordable and accessible?
A public health approach**

**Carolina Der, MD, PhD
Technical officer,
Ear and hearing care
World Health Organization**



**World Health
Organization**



STEVE KITTUR, KENYA

BRIDGING THE GAP: NAVIGATING THE CHALLENGES OF COCHLEAR IMPLANT PROVISION IN LOW- RESOURCED COUNTRIES

Steve is a parent of a child with CI – and is developing audiology services in Kenya against lots of challenges

Challenges of CI provision in Low-Resource Countries (Sub-Saharan Africa)

Bridging Sound and Opportunity!

Mr. Stephen Kittur

Introduction

Cochlear implants offer hope for severe hearing loss, but access in Sub-Saharan Africa is limited due to unique regional challenges.

Cost and Accessibility

- **High cost:** High cost: US\$20,000-\$30,000 per implant, unaffordable for most families.
- Average household **income** is around **\$1,800 USD** annually, means the cost of a CI is **many times higher** than a family's yearly income!
- **Lack of funding:** Limited govt and donor support for CI
- Financial **burden** on **families**.
- In some cases, **insurance** policies **exclude hearing implants** from their coverage.

Limited Specialized Centres

- **Geographical Barriers**-Limited or no facilities within reach:
e.g Only one CI facility in Kenya, located in Nairobi, serving 54 million people.
- Long travel distances for rural patients; delays in treatment due to high demand.
- Some centers represent one brand of CI manufacturers, limits options/choices for consumers

Shortage of Trained Personnel

- Lack of ENT specialists, audiologists, and speech therapists trained in CI surgery and rehabilitation.
- Average of only 1 CI specialist for every 1,000,000 people, compared to about 1:25,000 in the US!!

Awareness and Diagnosis

- **Low awareness** of CIs, especially in rural areas.
- **Late diagnosis**: Many children are identified after age 2, reducing CI effectiveness.

Post Implantation Challenges

- **Rehabilitation services:** Lack of rehabilitation services (audiological follow-up, mapping, speech therapy).
- **Device maintenance and replacement:** Difficulty in maintaining and replacing CI devices due to limited service access

Cultural and Social Barriers

- Cultural beliefs and stigma surrounding hearing loss and CIs.
- Resistance to surgery and technology due to fear or misunderstanding.

Policy and Governmental Support

- No national policy or framework for supporting CI programs.
- Limited integration of hearing health into healthcare infrastructure.
- Govt still imposing tax on CI products and accessories, making them more expensive

Potential Solutions and Approaches

COUNTY GOVERNMENT OF NANDI

WORLD HEARING DAY

Hearing for Life. Don't let hearing loss limit you.

Join us as we mark the World Hearing Day

3RD MARCH 2024 9:00 AM

ACTIVITIES

1. Walk from Namgai through town to Sports Grounds
2. Free Screening of Speech & Hearing Loss.
3. Education on Early Detection and Interventions
4. Advice on Treatment Options-Hearing Aids and Cochlear Implants.

For more information or enquiries call **1548**

childrenshearingfoundation@gmail.com | www.whdenya.com

WORLD HEARING DAY 2024

HEARING FOR LIFE
Don't let hearing loss limit you

04 MARCH 2024

KIPCHOKE STADIUM GROUNDS, KAPSABET

Join us as we mark the World Hearing Day and you can benefit from:

- ✓ **FREE TESTING AND SCREENING**
- ✓ **EDUCATION ON EARLY DETECTION**
- ✓ **ADVICE ON TREATMENT OPTIONS**

Prevention
Education on causes of hearing impediments and loss

Intervention
Facilitate early and continuous testing

Treatment
Provide interventions such as hearing aids cochlear implants



1. High Cost of Cochlear Implants and Surgery

- Subsidize CI services through government, NGO, and donor partnerships..
- **National Health Insurance Inclusion:** Include CI services in national insurance schemes (e.g., NHIF).
- **Corporate Sponsorships:** Secure corporate sponsorships for CI surgeries.

2. Lack of Trained Professionals

- **Training:** Establish training programs for CI surgeons, audiologists, special education teachers and speech therapists.
- **Fellowships and Workshops:** Provide fellowships and mentorship opportunities for local professionals.

3. Limited Access to Cochlear Implant Centres

- **Regional CI Centers:** Set up regional CI centers outside capital cities.
- **Telemedicine and Remote Support:** Implement telemedicine for remote CI support.
- Reverse medical tourism (where specialists come to treat and tour in SSA)

4. Lack of Awareness

- **Awareness Campaigns:** Launch public awareness campaigns and community outreach programs. Use all media platforms
- **School Outreach:** Partnering with schools to educate on hearing loss and CI benefits-children are better ambassadors and can influence parents.

5. Sustainability of CI Programs

- **Government Support:** Advocate for government support and integrate CIs within EHDI programs.
- Ensure long-term rehabilitation services (speech therapy, audiological follow-up).
- Demonstrate and provide cost-benefit analysis to stakeholders.

6. Cultural and Social Acceptance

- **Support Group:** Establish strong parent support groups for families undergoing CI procedures.
- **Community Engagement:** to address cultural barriers and stigma.

7. Research and Policy Development

- **Policy Advocacy:** Collaborate with government to include CIs in national health strategies
- **Data Collection and Research:** Collect data on CI outcomes to advocate for policy changes.

Conclusion

While challenges may seem daunting, we draw inspiration from the African proverb: "The best time to plant a tree was twenty years ago; the second best time is now." This wisdom encourages us to take action today, regardless of the obstacles we face, to foster meaningful change. Together, we can make a difference!



Thank You!



MARCELA VARELA, COLOMBIA

PARENTAL CHALLENGES IN COLOMBIA

Marcela is a proud mother of a CI user and a business woman!

Marcela Varela Mother of Nicolas Salazar

"The hearing solution has had a huge impact on Nico, as it allowed him to become a hearing child again and has enhanced his unique ability to learn every day without any limitations, just like any other hearing child."

His story:

Nicolás was born with normal hearing and used to speak with his grandmother on the phone daily. At two and a half years old, his preschool noticed that he wasn't following instructions, and at home, he no longer reacted to the shout of "GOAL" during the 2018 World Cup. When he was taken for a hearing test, a 30% hearing loss was discovered, despite a previous normal diagnosis. After several tests, ventilation tubes were placed, and he began using hearing aids. However, his hearing continued to deteriorate rapidly. During a consultation with the ENT specialist, significant hearing loss was confirmed in his right ear, and a cochlear implant was recommended. He received the implant in June 2019. Today, five years later, Nicolás hears again and lives a normal life, which has been a miracle and a blessing.



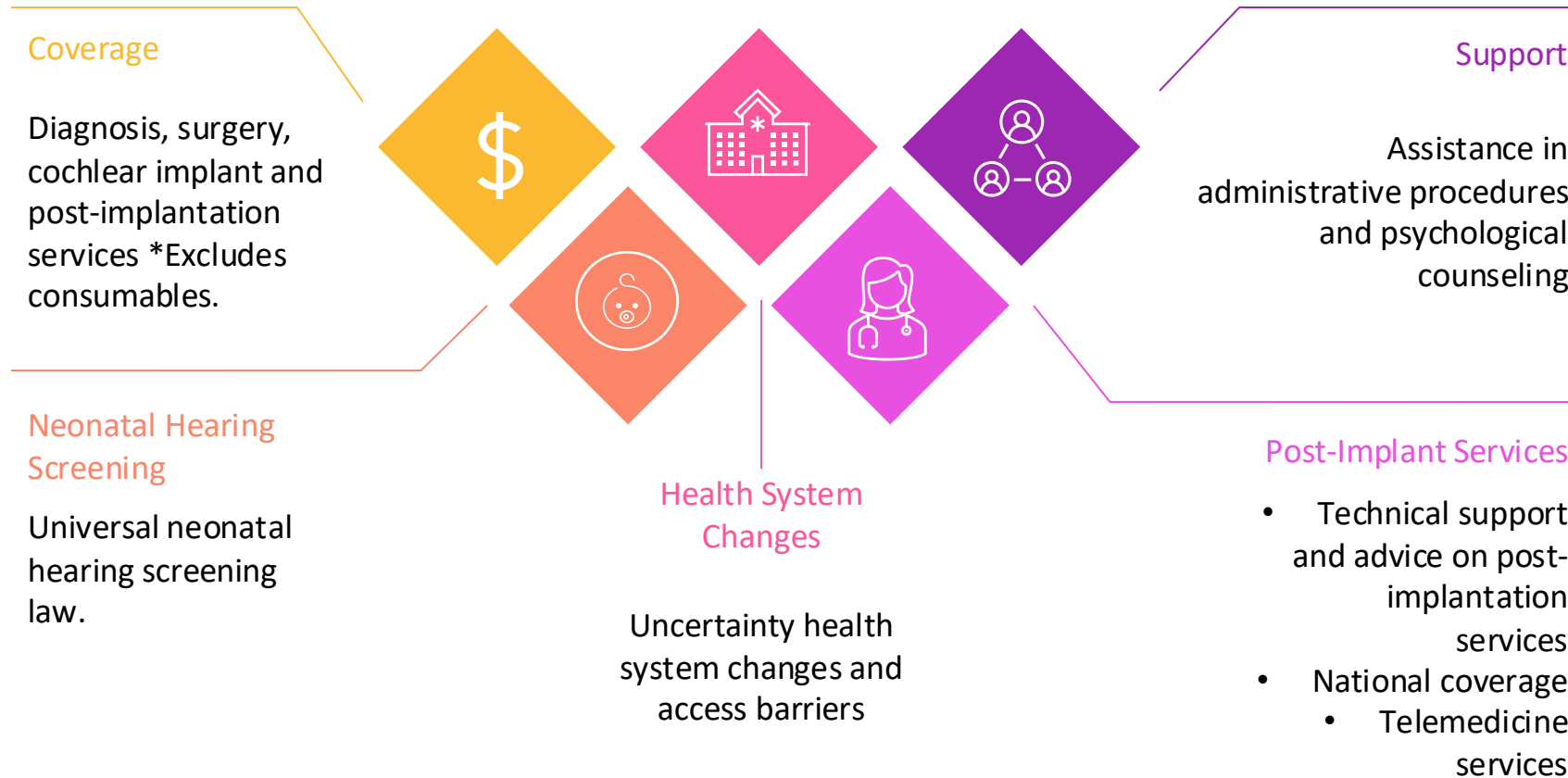
"My bionic ear has given me the joy of hearing the sounds around me, and it has given me the confidence and security to face any obstacle in life. It's true that, with perseverance, anything is possible".



Colombia

- Population: 50 million people
- Language: Spanish
- Landmark: Amazon jungle, Bogota, The Coffee triangle.
- Famous for: Colombian Coffee, Colombian Arts and Artists, Diversity of Flora and Fauna and Emeralds

Health Services in Colombia



Principal challenges and barriers in Colombia

Diagnostic Barriers

- Limited access to diagnostic tests
- Insufficient trained personnel

Economic Barriers

- Inequality in access
- Costs such as travel to specialized centers in remote areas

Administrative Barriers

- Waiting times for paperwork and authorizations.
- Unknown regulations by health care providers.



Information and Education Barriers

Insufficient information to patients, their families and educators.

Technical and Medical Barriers

- Availability of specialized centers
 - Device maintenance

Barriers During Post-Implant Rehabilitation

- Access to hearing rehabilitation therapies
 - Continuity of rehabilitation
- Low levels of family and social support

Psychological and Social Barriers

- Stigmatization
 - Emotional adaptation
- Social and schooling inclusion

Cochlear Implant User Rights



Health awareness as a fundamental right



Cochlear implant users have the right to file a tutela action, a legal recourse to demand immediate access to health services.



Collaboration with patient associations that offer support, legal guidance, and education for the community.



Participation with patient organizations to strengthen the collective voice and help make problems visible to health authorities.

Thank you

Marcela Varela



LUSINE STEPANYAN, ARMENIA

PARENTS DRIVING CI

Lusine has been a driving force for cochlear implants in Armenia against all the odds.

LOW RESOURCED COUNTRIES AND COCHLEAR IMPLANTATION OPPORTUNITIES

Armenian case study





WHEN DID IT START IN ARMENIA?

2004

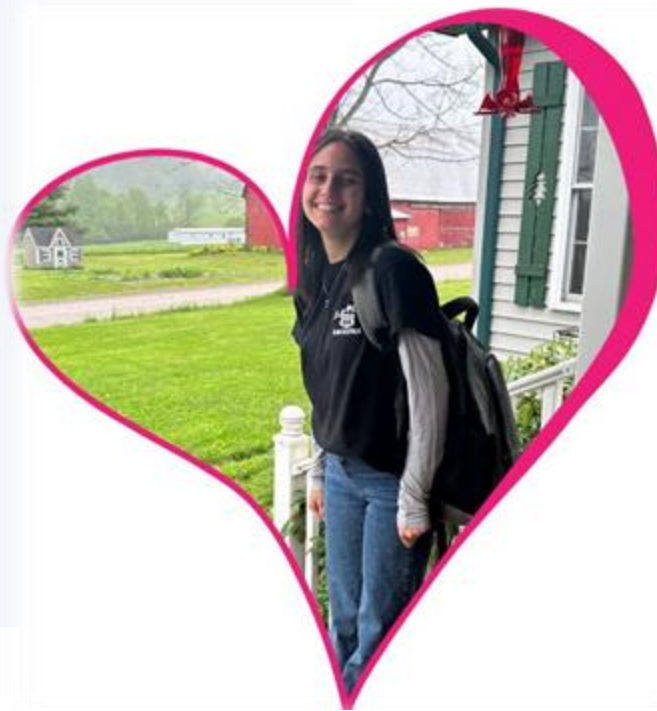
The Cochlear Implantation started in Armenia.
The project was founded by Armenian International Medical Foundation

**2004
2024**

More than 200 children and adult were operated

2019

Armenian State support program begun



OUR ACHIEVEMENTS

2017

Ministry
of Social Affairs and
the
Ministry of Health

2019

The Governance decided
to include Cochlear
Implant recipients to the
state support Program

2018

We started
negotiation with the
Ministry
of Social Affairs

2019

Ministry
of Social Affairs and
started to provide 5
equipment to cochlear
implant recipients

OLD SPEECH PROCESSORS UPGRADE



This year we send a letter to the Ministry of Social Affairs and ask them to start upgrading the old speech processors. We are still waiting for their decision.



We also send a letter to State Revenue Committee. We pay high taxes when the equipment, speech processors and implants are imported to Armenia. So we have asked for a tax exemption.



The Armenian government has made a decision to provide support for speech therapy to the children with speech delay starting from 2026. Again we are going to ask the to include children with CI to this program.



PAIGE STRINGER, GLOBAL ADDRESSING HABILITATION NEEDS

Paige Stringer is a CI user and Founder and Executive Director of the Global Foundation For Children With Hearing Loss.

Addressing Habilitation Needs

Prepared for:
CIICA LIVE

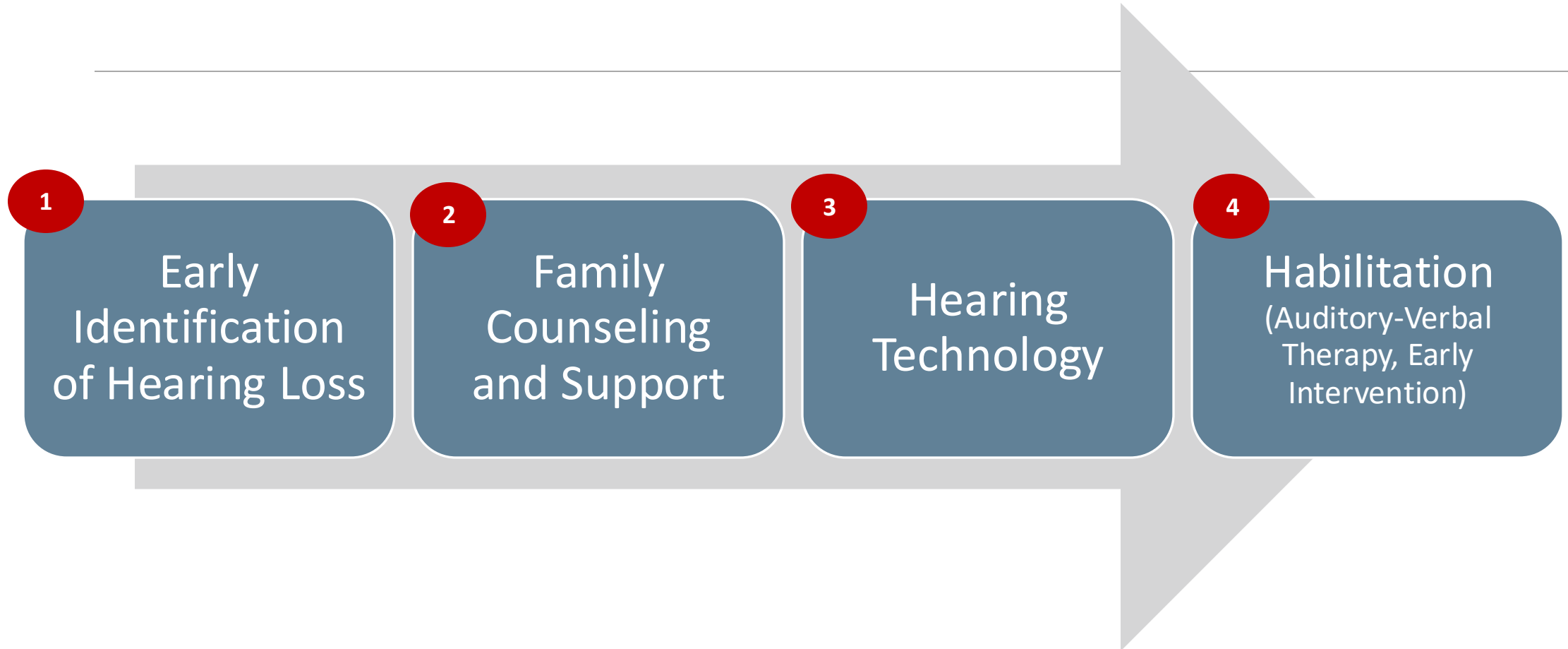


PAIGE STRINGER, MA, MPH
FOUNDER AND EXECUTIVE DIRECTOR



**Global
Foundation
For Children
With Hearing Loss**

Continuum of Care



Some Habilitation Challenges

- Earlier identification of hearing loss results in younger patients with unique needs
 - Habilitation is different from Rehabilitation, which focuses on improving communication skills in those who already have spoken language.
 - Auditory-Verbal Therapy helps babies and young children with hearing technology develop audition, speech and language.
- Limited number of professionals with expertise to coach families, support children
- Lack of family understanding of the importance of AV Therapy and their role in it
- Short duration of complementary AV Therapy in CI packages
- Cost of AV Therapy services

Global Foundation For Children With Hearing Loss: Training and Task Shifting to Address Therapy Gaps in Nepal





What Can WE Do?





VAHISHTAI DABOO, INDIA

DELIVERING ACROSS THE LIFESPAN

Vahishtai is a parent of a young adult with CI, Jehan, and
Mental Health Practitioner, Emotional Freedom Technique
Practitioner and Speech Therapist
Her organisation is called INTEGRATED.

Delivering Across the Lifespan

By

Vahishtai J Daboo

B.Sc., B.Ed.(HI), PGCCAVT, LSLS Cert. AVT

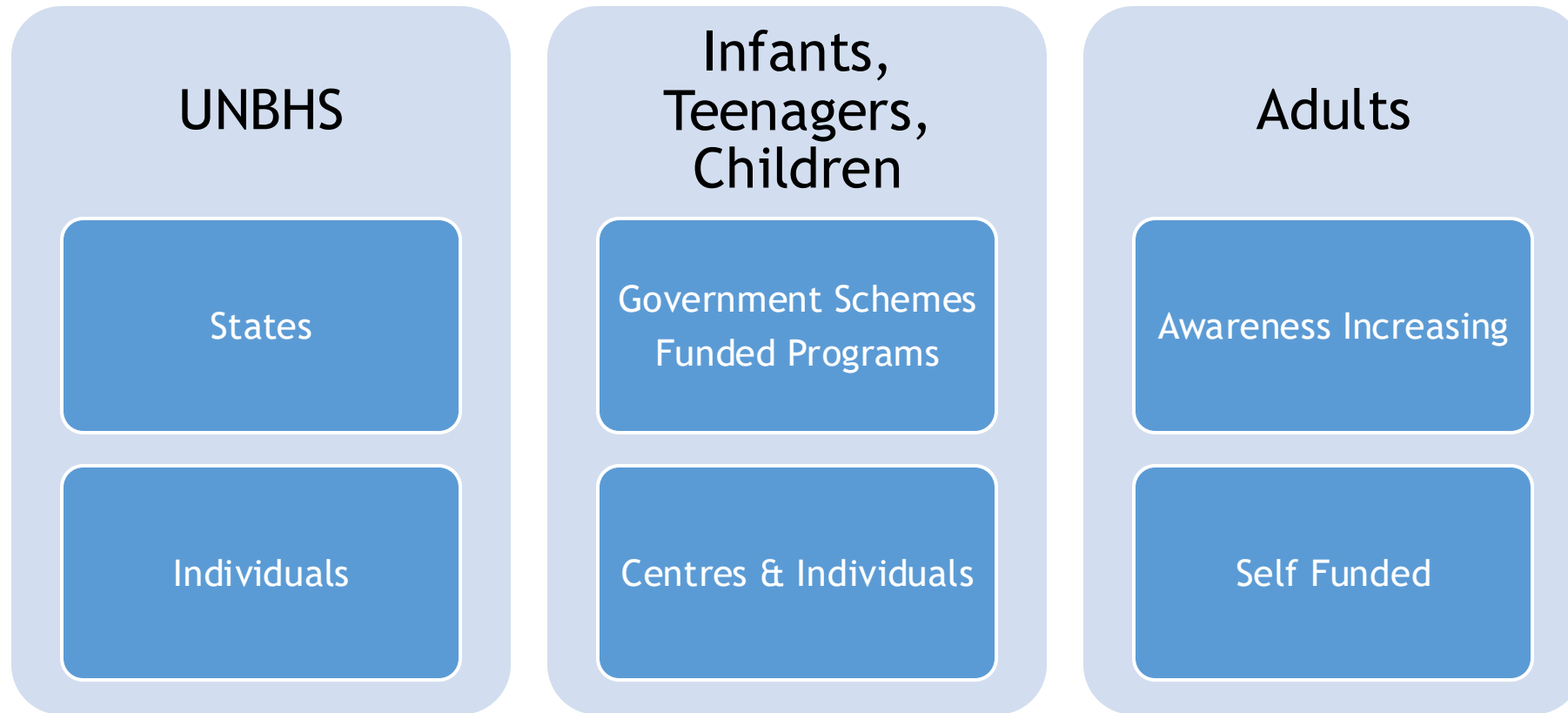
integrated  Services for Listening
& Spoken Language

India story...

- ▶ Population: 1.451 Billion which is 17.78% of the world's population
- ▶ New Born Hearing Screening
- ▶ Awareness impact of Hearing Loss
- ▶ Early Intervention
- ▶ Support across the lifetime
- ▶ Costs involved for maintenance and upgrades



Status:



Services

Government & Funded Programs

- Age criteria
- Mapping
- Therapy

Individuals Programs

- Age criteria....
- Mapping
- Therapy

Adults

- Pre & Post lingual
- Mapping
- Therapy

Our Programmes Delivering Services Across the Life Span

NBHS Programme

Programme 1:

OAE

- ▶ Conducted at the Government Hospital in collaboration with the Indian Academy of Pediatrics

BERA

- ▶ Conducted at our centre

Programme 2:

Both OAE & BERA done at our centre



Working with infants, toddlers and their families

- ▶ Pre implant counseling & Hearing Aid trials
- ▶ Coaching and Guiding the Families
- ▶ Developing Listening and Language - using functional language, Daily Routines, Songs, rhymes, Stories and Book Sharing, Craft, Festivals
- ▶ Developing Self Advocacy and Early Literacy Skills
- ▶ Guidance and preparation towards mainstreaming



Working with late implanted children and their families

- ▶ Awareness about Speech therapy vs Listening and Spoken Language
- ▶ Awareness about what are good outcomes
- ▶ Awareness, guidance and counselling about ‘Listening and Spoken Language’ and how this can be achieved
- ▶ Guidance and counselling about **realistic outcomes**
- ▶ Understanding the need for a bridge programme prior to mainstreaming
- ▶ Getting the whole family on board to help the child progress



Multiple Languages Challenge

- ▶ Home Language vs English
- ▶ Families aspiring their children to study in English medium schools
- ▶ Most schools in India are English medium schools or semi English
- ▶ Difficulty to comprehend in higher classes
- ▶ Huge gap between comprehension level and the grade the child is in



Higher Language Skills in Teenagers

- ▶ Social emotional language
- ▶ Higher level cognitive language
- ▶ Higher level concepts are missed
- ▶ We work with some families who see the need to develop this in their children's higher language skills by using different approaches:
 - Individual
 - Group
 - Assisted learning program



Adults

- ▶ Awareness through camps
- ▶ Audiological Assessments
- ▶ Guidance & Counselling for CI
- ▶ Meeting other recipients
- ▶ Regular Mapping
- ▶ Auditory Skills Training
- ▶ Counselling
- ▶ Meeting other families in their CI journeys





JENNY PEROLD, SOUTH AFRICA

CI FUNDING CHALLENGES

Jenny is Coordinator and Chief Audiologist: Cochlear Implant Programme, Speech Therapy & Audiology Department Tygerberg Hospital, South Africa.

She is used to the challenges of running a CI programme there.



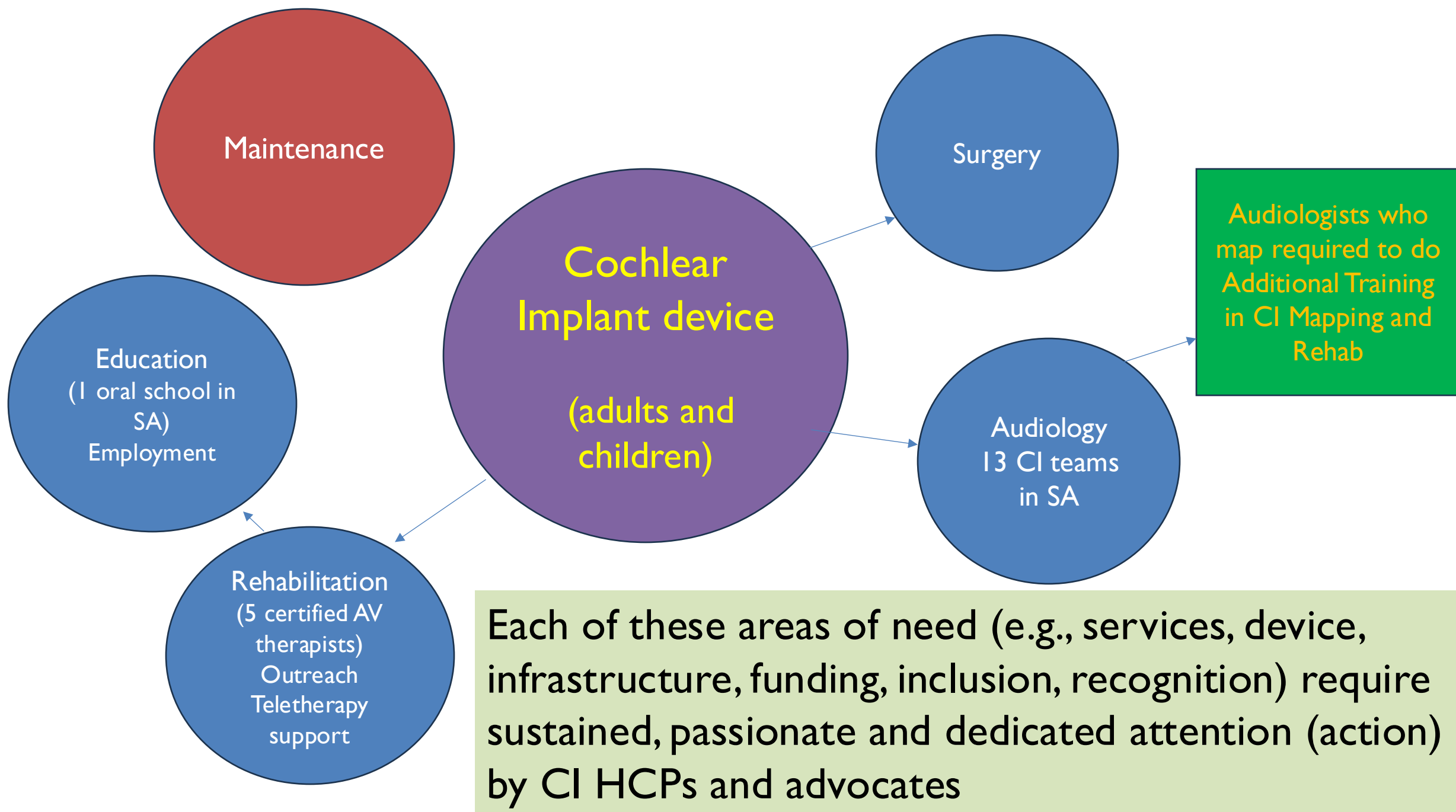
FUNDING COCHLEAR IMPLANTATION AND SERVICES IN SOUTH AFRICA

JENNY PEROLD

TYGERBERG HOSPITAL-STELLENBOSCH UNIVERSITY COCHLEAR IMPLANT PROGRAMME

26 SEPTEMBER 2024





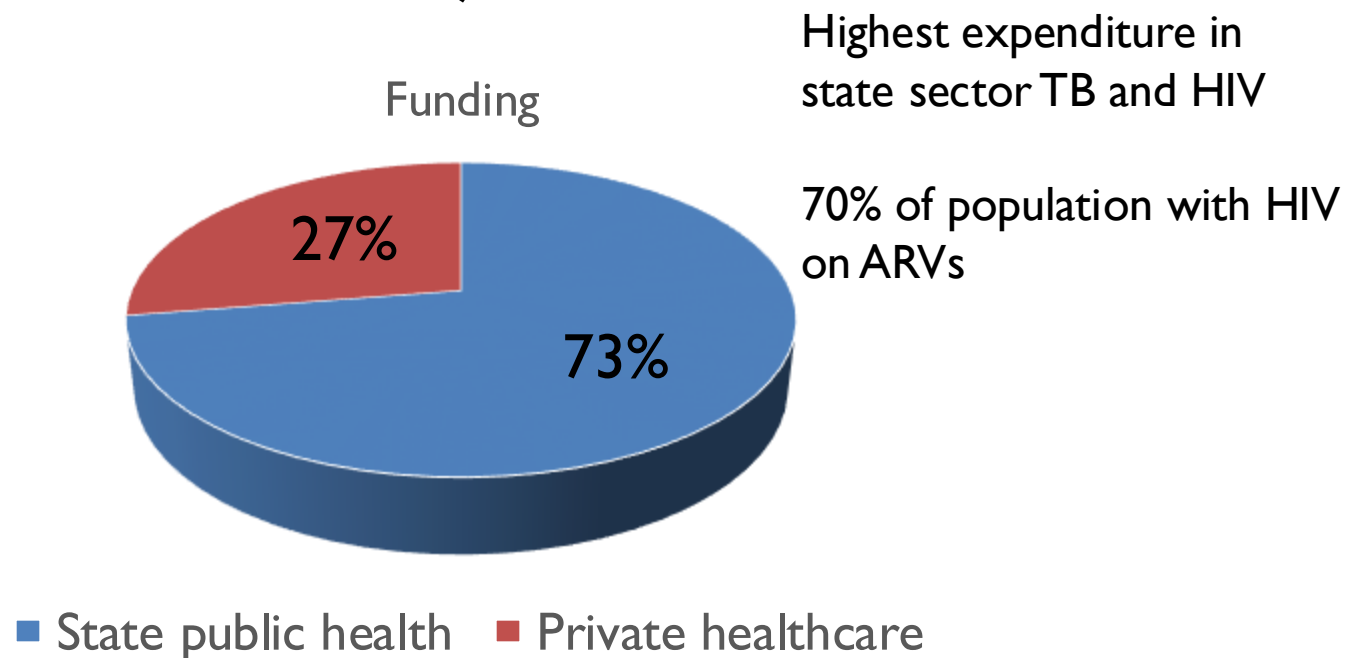


HEALTHCARE PRIORITIES WITHIN SA CONTEXT

- **Poverty** 18m (26%) living in extreme poverty, 45% on social grants
- **Unemployment** (33.5%: 60.8% 18-25y; 41.7 25-43y)
- **Crime** rate ranks 1st in Africa



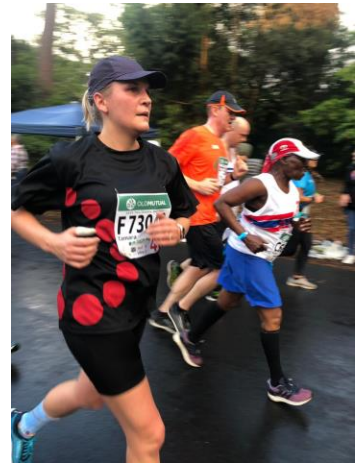
- Healthcare challenges (priorities)
- Two-tiered (state and private sectors)



FUNDING COCHLEAR IMPLANTATION

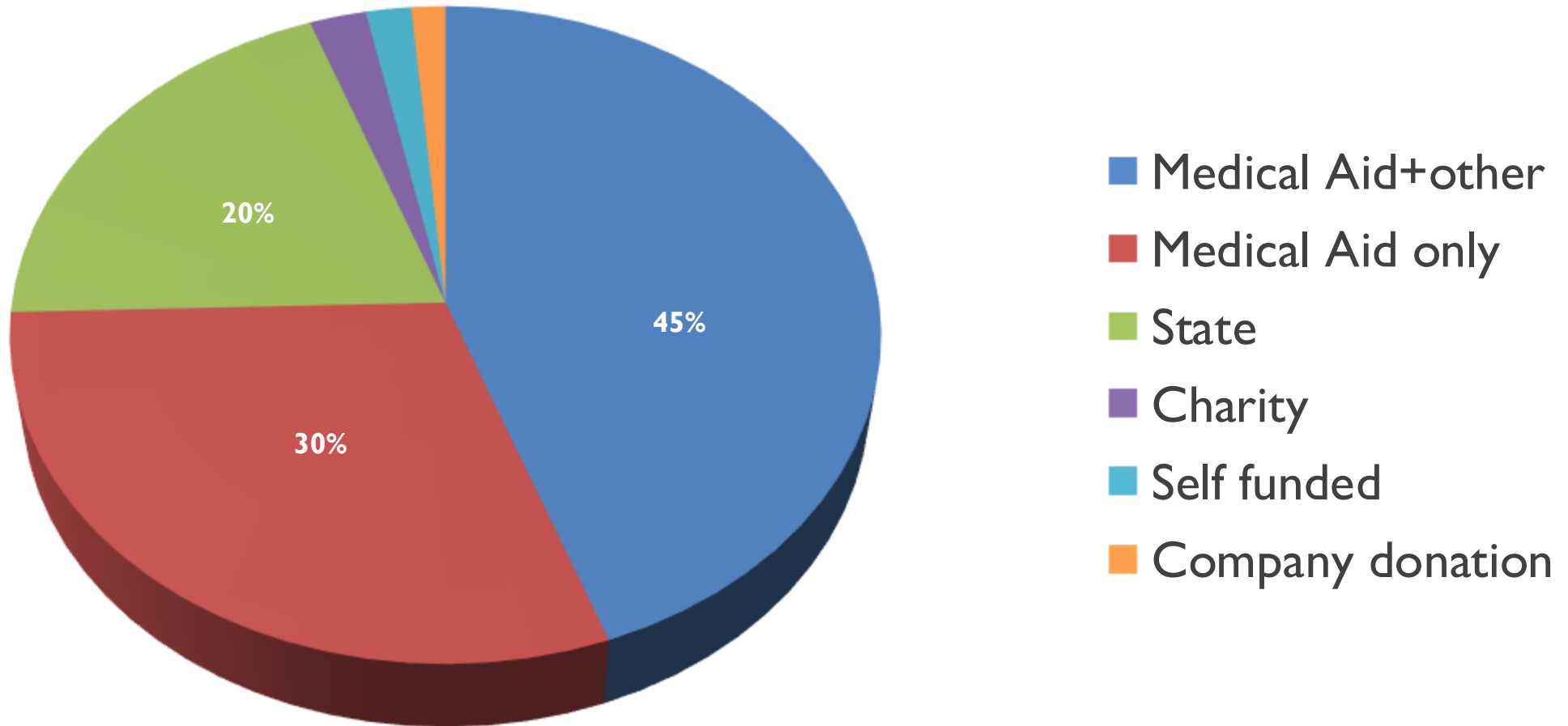


- **Private** sector (majority) – varied levels of cover for CI according to the specific health insurance, do not usually include repairs and parts (self-funded), limited rehabilitation cover
- **State** – varied levels of support in 6 of the 13 programmes
- Funding implant systems only
- Funding of implant systems + limited # upgrades
- Funding of implant systems, some upgrades and some maintenance (2 of 13)
- **Charity organisations** and Foundations to assist patients with **fundraising** (e.g. Hear Always Foundation Trust, HearUs, Foundation for children with hearing loss, Netcare Foundation)



Funding of CI systems in SA (Bhamjee, 2021)

Funding of CI 1986-2019



Selection of candidates for CI

This background has necessitated an expansion of the usual considerations for selection of patients for CI, particularly in the state sector



Considerations for selection criteria (especially state patients)

ADULTS:

- skill / desire to enable re-entry to workforce
- access to CI services

CHILDREN:

- age
- adequate family support and commitment
- parent/s employed (financially able)
- accessible, appropriate educational and audiological facilities (1 oral school for deaf)
- The (potential) ability to financially maintain the device (lifelong: repairs, replacements, insurance)
- Since 1986 ±4000 recipients (4 million deaf in SA, 600 000 SASL users)



Biggest challenges for funding



- Allocation of healthcare resources (private and state)
- Unemployment and poverty
- Government level awareness and prioritisation of hearing healthcare, including NBHS
- Keeping patients "on the air", especially "state" patients
- Patients paying "out of pocket" for mapping, parts, rehabilitation
- The responsibility of appropriate patient selection
- Ongoing communication to funders about cost effectiveness – a good spend ("spend to save") with fewer landing up on social grant system, higher employment (tax revenue) and improved educational levels



What have we /can be done to increase funding and awareness?



- **Inclusion of funders in national meetings and conferences, ongoing communication**
- SACIG conference 2019, 2024: invited private and state funders to **present on their funding** models - **sessions on “funding” and cost effectiveness**
- CI teams gained insights into the challenges faced by funders
- Funders understood more about cost effectiveness and that CI is a “good spend”
- Resulted in increased allocation of funds (private and state) and more awareness
- **Annual newsletter** of patient stories provided to funders (the good story)
- **Meetings and communications** with funders and public awareness
- Donations, appeals (radio), fundraisers
- **Rely on donations of parts from patients who upgrade (“pay it forward”)**

Is “hearing / access to sound” not a basic human right?



Miss South Africa 2024



- “as a deaf woman with a cochlear implant, I represent a community that often goes unheard”.
- “I am here to prove that, despite being differently-abled, it has not affected me in terms of what I am capable of”.
- “I aspire to eventually help provide cochlear implants to those who cannot afford it and give the same gift my community has given me”
- “Teach the included how to be inclusive towards the excluded”

ROUND UP...

**BRIAN LAMB,
Public Policy
Advisor, CIICA**



Meanwhile, **ACTIONS** for **YOU**:

- Join CIICA if you haven't already and tell people about us
- Tell us what you are doing – send us advocacy news to share on the website
- Have a look on our website - www.ciicanet.org



Thank you to our speakers and CIICA organisers. Keep up by checking the CIICA website to learn about global efforts and to share your local work, challenges and accomplishments

With our individual and united efforts, we can make a difference in the availability and uptake of better hearing healthcare