Hear me, here for you – The elephant in the room and the dispersed village

Tanya Lehmann

Family journeys are pivotal in identifying challenges and opportunities for newborn screening

Why did you become an audiologist or allied field?

What interested you about working with the smallest and most vulnerable people in the community?

Personal journey

Disclaimer:

- You have your own cultural and life experiences/’baggage’, just as I have mine
- I am hearing and not deaf
- I have friends and family both in Australia and overseas who have adopted AVT, signed communication, or a combination of both and switched what ‘worked’ for them
- Ideally, my son would tell his story, but due to his age, that isn’t possible.
- Parents/caregivers is also are interchangeable in this context.

Terminology begins at the first appointment

- Deaf, hearing loss, and similar descriptions in this context are often interchangeable/age of a resource

Teacher of the Deaf stance

- ‘deaf and hard of hearing’ (DHH) is used to refer to all hearing loss, from mild to profound
- ‘Deaf’ (capital ‘D’) is used to refer to culturally Deaf people who communicate in Auslan (Australian Sign Language) and identify with the Deaf community
- The term ‘hard of hearing’ refers to people who communicate in English and Auslan
- DHH individuals should not be identified as hearing impaired as this term has negative connotations.

(NAATD, 2016)

Lived Experience as a hearing parent

Autobiographical research draws on and interprets lived experiences and connects personal insights:

- Qualitative research method
- Uses personal experience to describe, critique cultural beliefs, practices and experiences
- Acknowledges and values relationships with others
- Uses self-reflection to examine intersections between self and society
- Shows people as part of the lived experience and the ripples of impact on people around them
- Includes deep thinking, emotional responses and creativity
- Often strives for social justice and improved quality of life for a group of people or individuals.

(Poulos, 2021)

Lived Experience

My ‘literature review’ is life experience

- Living research
- To enable my child and others like him to have the ‘best’ opportunities and ‘quality’ of life, we as parents/caregivers as well as professional services can provide; ‘happy’ isn’t enough
- In the context of newborns, we are making decisions that will have lifelong impacts on someone who is incapable of doing so
- Living in a community with people, not in isolation.

No glasshouse in the village approach - who is "in" and who is "out" segregation

- Facebook Groups with a focus on deaf people (ongoing)
- Deaf Mentors (ongoing)
- NDIS feedback such as Foundational supports children, and their families, carers and kin (ongoing)
- Deaf Connect research groups (various and ongoing)
- Newborn hearing evaluation/survey (2016)
- PhD research participant (2017-2018)
- The Bionics Institute of Australia, fNIRS and language development in children – Melbourne (2018)
- *Eloquent Hands* Raining Poetry Adelaide, Street Art (2021)
- Audiology Association feedback (2022)
- Access all Areas Symposium (2023)
- Consultation on the State Disability Inclusion Plan, SA (2023)
- West Torrens Council (2023) – requesting changes to access/safety

- Disability Advocacy and Complaints Service of SA (2023)
- Inclusive and Emerging Tourism, Topic Development (2023)
- Cochlear Nucleus Smart App research (2024)
- Ticketing and Inclusion Roundtable Workshop
  - Hon Nat Cook Minister for Human Services (2024)
- Feedback draft model of care for the WCHN Cochlear Implant Service (2024)
- The AusChildDeafness-CAG/ Australian National Childhood Hearing Health Outcomes Registry (ANCHOR) (2024)
- Integrated Transport Strategy, City of Adelaide (2024)
- SA Education Network Meeting with Deaf Australia (2024)
- Subscribe to World Federation for the Deaf (2024 - ongoing)
- Cochlear Implant International Community Action Member (2024)
- Lions Hearing Dogs – Foster Carer/Socialiser (2024-2025)
- Cathleen O’Grady, *Science* journalist deafness & language development (2025)
- Conversations with allied health professionals, Teachers of the Deaf, CarersSA and read A LOT

Newborn screening

Australia has one of the best systems for identifying babies born with atypical hearing BUT there is no guarantee that all children will receive the 'right' kind of support. How can you, as part of newborn hearing programs improve this?

What works, what is lacking?

(Deafness Forum Australia, 2023)

Goal of the screening?

- Why parents/caregivers participate?
- What do they hope it achieves?
- Want what is ‘best’ for their child and do the ‘right’ thing?
- To enable both children (hearing and deaf) to grow into adults who can participate in community life, whatever that community looks like
- If they choose, they can have fulfilling and meaningful employment, live independently, have close friendships, feel they are valued and can make meaningful contributions.

This journey starts with the newborn hearing test

The tone of the marathon begins with you!

1 month

Child and Family Health Service (CaFHS)
families in SA children birth to 5 years

Refer

GP/immunisations

Obstetrician

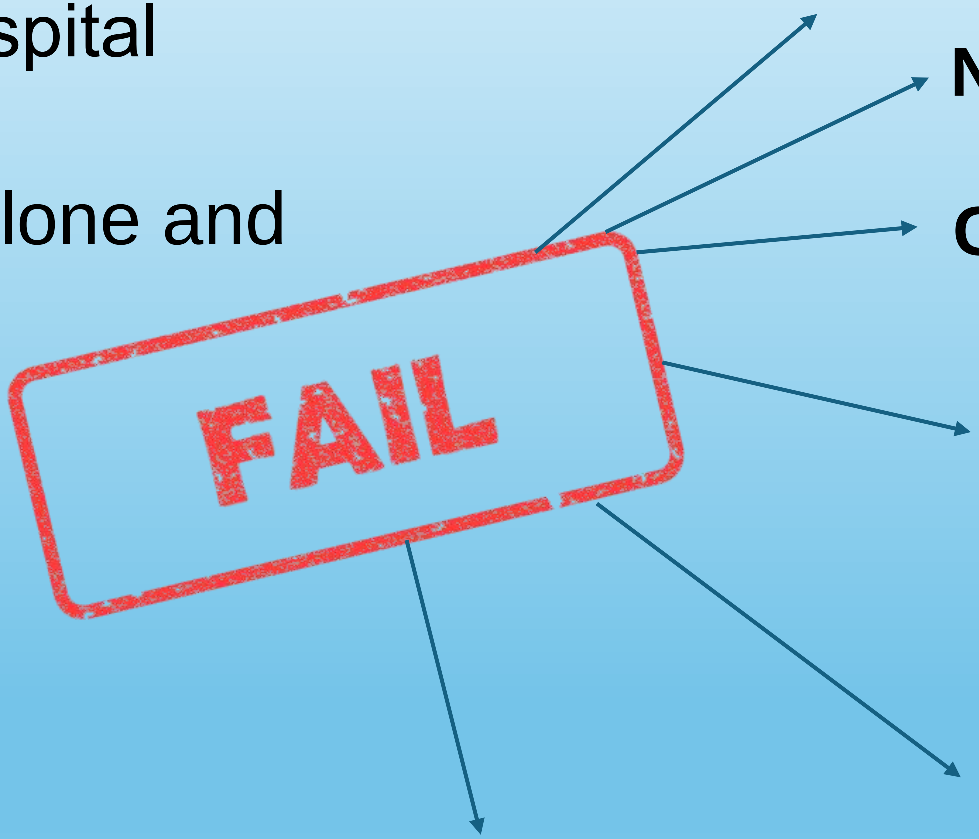
Cranial ultrasound/imaging

Paediatrician

Pathology urine and bloods

Women’s and
Children’s Hospital
Audiology

Went to the alone and uninformed



Speech Pathologist

NDIS

Centrelink

Private vs and or Public Hospitals and allied health (what do they cover, speech, surgery?)

GP Chronic Disease Management Plan (Is my child sick?)

Hearing Australia

2 months

What does this cycle of hope, despair or failure do from
a psychological perspective?
What friends and family members say? Peer pressure?

How does the result challenge how we see ourselves,
our relationship with our child (and other family members) and their/our identity?

It is more than a hearing test; communication mode/s are more than a language; it is a choice about who will interact with people and how they will identify themselves.

Where do they start to form their sense of place in the world?
These all start from the results of the first hearing test.

(Hamilton, 2024)

Letter to my employer – 6 weeks old

- We won’t know the results of the genetic testing
- for another 3 months
- It is difficult to know what exactly to tell people other than he has hearing loss, we had an ECG Tuesday and assume no news is good news, sometimes hearing issues can be connected to other syndromes etc. Urine sample set off yesterday as again, kidney failure is another possible syndrome complication
- We have chosen a provider for speech…they want to start almost immediately but we are waiting on forms and funding
- Hopefully, the hearing aid appointment is a bit more straight forward

3 months (return to work) and beyond

Physiotherapist/Hydro

ENT

Audiologist

Cardiologist

Pathologist

Teacher of the Deaf

Neurologist

GP - referrals

Paediatrician

Gastroenterologist

Conductive Therapist

Occupational Therapist

Ophthalmologist

Child Development Unit

Barriers to understanding - Simplified pathways

Newborn hearing screening

Birth

Diagnosis

1 ½ years

1 month

Amplification

2 Months

Access

Decline, change of services

Early Intervention

(Joint Committee on Infant Hearing, 2019, pp. 1-34)

Enablers and Barriers for Parents/Caregiver and children

Family support

Having questions answered

Multidisciplinary meetings

Combining medical and social model

No preparation for deaf diagnosis

Appointments some face to face unnecessary

Lack of staff with any Auslan skills

Cost, availability of interpreters and Auslan courses that the whole family can access

(Terry, 2023)

3 months
(return to work) & beyond

- The practical aspects of keeping aids and are still counting feed and wake times
- Very poor community understanding of what causes deaf/hearing loss in the community, stares, questions etc.
- Overwhelming new terminology

Hearing aids - 6 moulds in just over 12 months which is at least 12 appointments

First year of life, they had approximately 150 hearing/ associated appointments some 2 or 3 times a day

Not the only child in the family

Sibling perspective – Age 4

The process, production line?

- False expectations and luring us into an

  unhelpful situation (pregnancy scans)

- It may have come back at the second, or third testing

  as “fine”, what if it doesn’t?

Specialist views in conflict or supporting early intervention

  - What you don’t do now is lost ‘forever’ or the wait and pivot approach

- Timing of diagnosis just before Christmas and New year
  - ‘can’t’ register for NDIS
  - The position of community liaison is now vacant – so you want for a call that never comes.

The Village
– where do you fit?

“It takes a village to raise a child” recognises that many people (or teams) are needed to provide children with a safe, healthy environment in which to develop, flourish, and realise their hopes and dreams.

As Audiologists, Speech Pathologists, Midwives, Paediatricians, General Practitioners, Teachers of the Deaf and Parents/Caregivers, you are part of this team – starting with the very first newborn screening.

(Reupert, Straussner, Weimand & Maybery, 2022)

What other parents and families are communicating

Early profound hearing loss diagnosis

Maybe it is a surprise we have brought up our children
to consider their cochlear implants NOT as a sign of
disability, but as a superpower. It is an ability others don’t have.

We want them to feel proud of the fact that they are Deaf

We focus on the “can do” not the can’t, and for those we pivot (music lessons).

(Miles, 2022)

A parent’s story – a common story

The screener reassured us that a ‘fail’ was common for the

first screen that there was “**nothing to worry about**”.

They told us things like, **“He’s probably still got fluid in his ears” and “We’ve just updated our machine this morning.” And we were continually told “Not to worry.”**

He “failed”.

My world stopped.

(Oliva, 2024)

Parent’s story – a common story

... because this world wasn't 'designed' for Deaf kids

... daily fight for equality

... our kids experience lifelong challenges, prejudice and ignorance

(Raising Bilinguals, n.d.)

Hayley’s Story

Context: Went to the screening alone,
assured everything is ‘fine’.

“this amazing [member of staff] … battered the door open, pushed this newborn hearing screening lady out the way who was standing there going ‘oh I'm really sorry’, and just scooped me up in her arms, and just literally hugged me and didn't let me go for about ten minutes”.

Parent/caregiver needs will change, how do you respond to that?

-So many contributing factors, genetics, first child or subsequent, prior knowledge of Auslan or assistive technology, first language, born in Australia or elsewhere?

(Terry, 2023)

The dispersed village – allied health and other medical professionals and paid support people

What does the research show?

The Model – Conflict within the village

Changing practices is difficult, because they are grounded in education, laws and regulations, health policy and funding models.

The language and priorities seem to differ, even at a degree or higher course level.

(Reupert, Straussner, Weimand & Maybery, 2022)

Parents’ perspective of early diagnosis

- Accurate, unbiased based on current research is a ‘non-negotiable’ to enable parents/caregivers to make informed decisions
- Professionals must consider the emotional needs of the parent/caregiver during a potentially overwhelming time, early intervention is important but why the rush?
- Family-centred care is essential and includes not only information but that emotional needs are met and all support services are working collaboratively
- What does your waiting room and/or office space communicate about what communication you support?
- What commitment to you have towards dialogue with different deaf groups?

(Scarinci, Erbasi, Moore, Ching, Marnane, 2018)

US Model Speech/ Audiology combined Registration	**Undergraduate course Hearing Disorders (Association?)**	**Master of Disability Studies/Standards for Teachers of Deaf (Registration)**	**Master of (Clinical) Audiology (Paediatric) (Association)**
Key words in course outlines	Focus on hearing issues/necessity of speech. When very behind sign language introduced > language deprivation	Deaf Gain, antonym for *hearing loss*, referring to Deaf people as having a “cultural and linguistic difference” rather than being “defective”, and needing to be fixed”. Focuses on benefits of deafness, challenging deafness as a disability.	Focus on rehabilitation and deafness as a disability. When child is very behind sign language introduced > language deprivation
Social or medical model	The social model of deafness as a disability.	Deaf cultural model values deaf people as a cultural and linguistic group who use a signed language and are proud of deaf heritage. Family-centered approach.	The social model of deafness sees it as a disability.
Access for minority groups/ leakage	Unknown	Efforts made to employ people with lived experience, particularly for families with a new diagnosis and those needing mentors. What funding is available, retention of staff? Unknown scholarship?	Scholarships for Aboriginal/Torres Strait Islanders. Retention of graduates?
Sources	Joy, Ledger, Duncan, 2024	Terry, 2023 Humes & Bess, 2013	Humphries, Mathur, Napoli, 2024, p.18. Flinders University 2024, Charles Darwin University, 2024

Conclusion

- Children born with ‘different’ hearing are beyond, the pass, fail or being ‘fixed’.
- Children are more than their hearing and the achievements and life journey is not suppressed, defined, predetermined or less than a child with ‘full’ hearing; but each child is unique, special and valued.

Do you agree or disagree?
Do you ‘box’ clients?
What are your stereotypes?
How does dispersed differ from dysfunctional?

Do families perceive you as:

- a lifelong professional learner - cross pollination of ideas/collaboration. Sharing genuine and timely information between stakeholders, strengthen village networks
- having an open mindset, flexible and willingness to learn and open to change if needed
- Informative, at times say “I don’t know, but can find out” or help parents/caregivers learn how to “self-discover”
- part of a client focused journey respecting difference and individual pathways?
- respectful, parents/caregivers have skills, abilities and valid perceptions. They don’t come to you as ‘empty’, built on what they know or have already experienced.

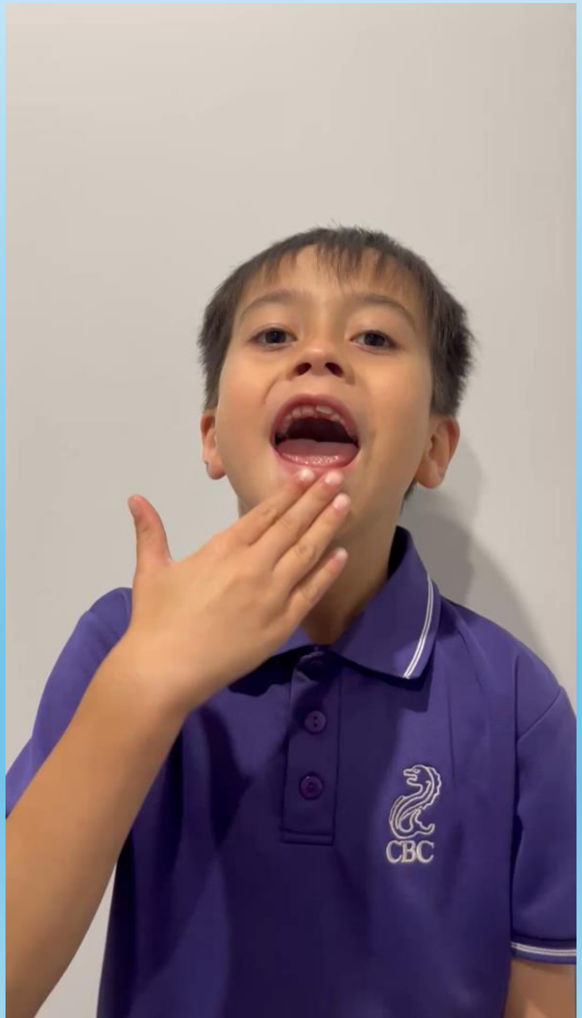
A ‘true’ holistic approach will provide **options** that work for individuals with different needs and considerations.

Newborn screening is only the start
– how can you prepare families and communities for life?

The change starts with you; your next client, your next family interaction.

(Tluczek, Ersig, Lee, 2022, p. 53)

Thank you



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