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PARENTS OF DEAF CHILDREN
Supporting families for over 60 years

8th December 2023

Dear Children's Commissioner,

I am writing on behalf of Parents of Deaf Children (PODC) with grave concerns regarding the recent cochlear implant disaster initially discovered in South Australia, and now also affecting children in Queensland and possibly other states. Our organisation has been in close contact with affected families and has become increasingly alarmed by the lack of understanding surrounding language acquisition and the profound impact of language deprivation on these deaf and hard of hearing children.

Language deprivation puts deaf children at risk for cognitive delays, mental health difficulties, lower quality of life, a higher level of trauma, and limited health literacy.
Gulati, S. (2014). Language Deprivation Syndrome. ASL Lecture Series

It has come to our attention that these families are unaware of the critical nature of language acquisition and the severe consequences of language deprivation for their children. They have been informed that they must navigate their children's future needs with the NDIS and the Department of Education, yet they lack a fundamental understanding of how language deprivation will significantly impact their children's lives. Additionally, some have already reported issues with the NDIS, including a decrease in their NDIS package and inadequate communication of the situation to relevant people in these institutions.

The absence of essential language resources and information accessibility for culturally and linguistically diverse (CALD) families embroiled in the cochlear implant situation exacerbates an already devastating situation. These families, facing the aftermath of the implant disaster, are grappling with a profound lack of support and accessible information which intensifies the challenges they face in navigating this complex issue, hindering their ability to fully comprehend the situation and access appropriate assistance.

Australia is one of the most culturally and linguistically diverse countries in the world. However, some people from culturally and linguistically diverse (CALD) backgrounds face greater challenges when dealing with the health and welfare system. Language barriers, lower health literacy, and difficulties navigating an unfamiliar system put them at greater risk of poorer quality health care, service delivery and poorer health outcomes compared with other Australians.
Culturally and Linguistically Diverse Australians 2022: Australian Institute of Health and Welfare

While a payment of up to $50,000 has been provided to acknowledge the stress and financial burden experienced by these parents throughout this distressing process, there has been an alarming absence of compensation directly addressing the potential life-altering impact of language deprivation on the affected children - $50,000 is nowhere near adequate to fund the ongoing and lifelong educational, psychosocial needs of these families and children as a result of this failure of the cochlear implant services to perform their jobs correctly.

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We strongly believe that the children embroiled in this situation are at grave risk of missing urgently needed interventions and having their present and future support needs grossly underestimated due to the insufficient and poor quality information and advice given to their caregivers. This has been exacerbated by the absence of guidance from qualified language specialists who could assess these children and provide crucial reports on the extent of their language development deficit, and thus enable a more informed assessment of the short-term and long-term impacts on their cognitive and psycho-social development.

It is deeply concerning that in Australia, there are only three language specialists specialising in the impact of language deprivation in deaf and hard of hearing children, and so far, these professionals have had no involvement with the affected children. This glaring absence of specialised expertise is a significant barrier to mitigating the profound harms suffered by these children.

We implore the Children's Commissioner to urgently intervene and ensure that:

1. Adequate compensation and support are provided directly for the affected children to address the potential life-altering impact of language deprivation. Establishing a trust fund and implementing a future-oriented plan are imperative to oversee and support the ongoing development and well-being of these children.

2. Specialised language specialists are engaged immediately to assess these children and provide comprehensive reports on the extent of their language development deficit. Dr Karin O'Reilly, Dr Christine Clarke, and Dr Louise de Beuzeville are the three language specialists skilled in this area in Australia.

3. Comprehensive education and guidance are extended to affected families regarding the critical importance of language acquisition and strategies to mitigate the impact of language deprivation. These families urgently require a dedicated forum facilitated by professionals with suitable expertise, offering a safe space to collectively navigate and address the profound impact and devastation stemming from this situation.

4. Organisations and professionals providing services to deaf and hard of hearing children and their families are challenged on their current unimodal approach. This is especially important for those associated with the provision of cochlear implants. These organisations and professionals should be required to adopt robust frameworks and strategies to mitigate the risk of language deprivation in deaf and hard of hearing children. This must involve early bimodal bilingual approaches, integrating Auslan (Australian sign language) and spoken language. Research suggests this is the best way to enable a rich linguistic environment, crucial for cognitive and psycho-social development in deaf and hard of hearing children. This will help mitigate the risk of language deprivation through a failure of implant hardware or software, or the ability of a child to adapt to it.

5. Families, educators, and healthcare professionals are empowered with resources and training supports, enabling informed decisions and enhanced language diversity, access and exposure for the deaf and hard of hearing children in their care. Collaborative efforts among

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government, education, and advocacy groups are essential to establish policies that recognise and implement this approach as a standard practice, significantly reducing the risk of language deprivation.

6. The Australian Government should conduct a comprehensive, long-term study on the effects of language deprivation on affected deaf and hard of hearing children. This critical research will serve as a guiding resource in shaping future policies regarding language accessibility, encompassing both spoken language and Auslan.

The well-being and future prospects of these children hang precariously in the balance. Immediate action is imperative to safeguard their rights and ensure that they receive the necessary support and expertise to navigate this profoundly challenging situation.

Thank you for your urgent attention to this matter.

Sincerely,
Suzanne Robertson
President
Parents of Deaf Children

ATTACHED – Key Terms definitions and list of relevant readings.

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KEY TERMS

Critical Period of Language Acquisition: The early childhood years when children can acquire language naturally through exposure, after which it is much more difficult.

Deaf/deaf: When we write "Deaf," it refers to the Deaf community or a person's cultural identity. When it's not capitalised, it is an adjective describing hearing loss, from total deafness to lower than normal hearing ability.

Language Deprivation: Occurs when someone has insufficient exposure to language during the critical time of language learning.

Language Input: Language input is how much someone is exposed to language they can understand.

Language Modality: Language modality is the means though which language is expressed, such as spoken, written, or signed.

Auditory-Oral: Auditory-Oral is a way of teaching deaf and hard of hearing children that focuses on spoken language as the main or only form of communication.

Cochlear Implant (CI): A cochlear implant is a device implanted in the ear to help people with significant hearing loss. Instead of relying on regular hearing, it uses electric signals to stimulate the hearing nerve. With practice, someone with a cochlear implant may learn to understand these signals as sound and speech.

Bimodal Bilingual: Bimodal bilingual for deaf children means they use two modes of communication, usually sign language and written/spoken language, to understand and express themselves.

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READING LIST

Australia & International – reports:

Media release from the Premier of South Australia
Government overhauls WCH cochlear implant program, supports families impacted since 2006 | Premier of South Australia

Culturally and linguistically diverse Australians Report 2022
Culturally and linguistically diverse Australians Overview - Australian Institute of Health and Welfare (aihw.gov.au)

Establishing the costs of hearing loss in Australia
https://deafaustralia.org.au/statements-papers/our-culture-our-value-the-costs-of-hearing-loss-in-australia/

Exploring the benefits of Auslan in Early Intervention approaches for deaf children
https://deafaustralia.org.au/statements-papers/exploring-the-benefits-of-auslan-in-early-intervention-approaches-for-deaf-children/

World Federation of the Deaf - Declaration on the Rights of Deaf Children
https://wfdeaf.org/rightsdeafchildren/

The right to language
https://pubmed.ncbi.nlm.nih.gov/24446945/

The rights of deaf children
https://www.researchgate.net/publication/373170399

The fundamental framework for deaf/hard-of-hearing children: a model from the child's perspective
https://www.researchgate.net/publication/373489301

Language deprivation:

Avoiding linguistic neglect of deaf children
https://www.researchgate.net/publication/311215976

Responsibility in the current epidemic of language deprivation (1990-Present)
https://doi.org/10.1007/s10995-020-02989-1

What You Don't Know Can Hurt You: The Risk of Language Deprivation by Impairing Sign Language Development in Deaf Children
What you don't know can hurt you: The risk of language deprivation by impairing sign language development in deaf children - PMC (nih.gov)

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Language Deprivation Syndrome: A Possible Neurodevelopmental Disorder with Sociocultural Origins
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5469702/

Understanding Language Deprivation and Its Role in Deaf Mental Health
https://www.jstor.org/stable/26983957#:~:text=The%20book's%20content%20provides%20in,LDS%20affect%20the%20deaf%20population.

Effects of Early Language Deprivation on Brain Connectivity: Language Pathways in Deaf Native and Late First-Language Learners of American Sign Language
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6761297/

Responsibility in the Current Epidemic of Language Deprivation (1990-Present)
https://pubmed.ncbi.nlm.nih.gov/32761503/

Should All Deaf Children Learn Sign Language?
https://pubmed.ncbi.nlm.nih.gov/26077481/

Language Deprivation Syndrome: A Possible Neurodevelopmental Disorder with Sociocultural Origins
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5469702/

Sign Bilingualism or Language Deprivation
https://www.researchgate.net/publication/344350940

Auditory deprivation does not impair Executive Function, but language deprivation might: Evidence from a parent-report measure in deaf native signing children
https://www.researchgate.net/publication/308079184

Early Intervention/Language Development:

Early Intervention Protocols: Proposing a Default Bimodal Bilingual Approach for Deaf Children
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7477485/

How Bilingualism contributes to healthy development in deaf children: a public health perspective
https://doi.org/10.1007/s10995-020-02976-6

Language acquisition for deaf children: Reducing the harms of zero tolerance to the use of alternative approaches.
https://harmreductionjournal.biomedcentral.com/articles/10.1186/1477-7517-9-16

Education and health of children with hearing loss: the necessity of signed languages
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6796673/

Successful communication does not drive language development: Evidence from adult home sign.
https://pubmed.ncbi.nlm.nih.gov/27771538/

Deaf Children of Hearing Parents Have Age-Level Vocabulary Growth When Exposed to American Sign Language by 6 Months of Age
https://www.jpeds.com/article/S0022-3476(21)00036-6/fulltext

Language development in deaf bilinguals: deaf middle school students co-activate written English and American Sign Language during lexical processing
https://doi.org/10.1016/j.cognition.2021.104642

The Design and Validation of a Parent-Report Questionnaire for Assessing the Characteristics and Quality of Early Intervention Over Time
https://academic.oup.com/jdsde/article/14/4/422/491307

Acquisition of Sign Languages
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8570554/

Describe, don't prescribe. The practice and politics of translanguaging in the context of deaf signers
https://pure.hw.ac.uk/ws/portalfiles/portal/24265674/Describe_don_t_prescribe_The_practice_and_politics_of_translanguaging_in_the_context_of_deaf_signers.pdf

Education and health of children with hearing loss: the necessity of signed languages
https://pubmed.ncbi.nlm.nih.gov/31656336/

The effects of sign language on spoken language acquisition in children with hearing loss: a systematic review protocol
https://pubmed.ncbi.nlm.nih.gov/24314335/

Critical period for first language: the crucial role of language input during the first year of life
https://pubmed.ncbi.nlm.nih.gov/26111432/

Early Sign Language Exposure and Cochlear Implantation Benefits
https://pubmed.ncbi.nlm.nih.gov/28759398/

Deaf Children Need Rich Language Input from the Start: Support in Advising Parents
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9688581/

Language Choices for Deaf Infants: Advice for Parents Regarding Sign Languages
https://pubmed.ncbi.nlm.nih.gov/26603583/

Language and Communication of Deaf and Hard of Hearing Children
https://www.asha.org/practice-portal/professional-issues/language-communication-deaf-hard-of-hearing-children/

What we can learn from hearing parents of deaf children
https://journals.cambridge.org/abstracts_S1030011214000190

Systems that support hearing families with deaf children: A scoping review
https://doi.org/10.1371/journal.pone.0288771

Using Family-Centered practices to increase language access for multilingual deaf or hard of hearing children
https://www.researchgate.net/publication/357495486

Examining the influencing factors on deaf children in treatment procedure and family environment
http://dx.doi.org/10.32598/irj.20.3.1637.1

Rethinking the language development of deaf and hard of hearing children
https://www.researchgate.net/publication/367083230

The benefit of the "And" for considerations of language modality for deaf and hard-of-hearing children
https://pubs.asha.org/104.227.68.18

Language not auditory experience is related to parent-reported executive functioning in preschool-aged deaf and hard-of-hearing children
http://doi.org/10.1111/cdev.13677

The benefits of sign language for deaf children with and without cochlear implant(s)
https://www.researchgate.net/publication/263082827

Early language intervention in deaf children of hearing parents
https://www.researchgate.net/publication/354768787

Long-Term Implications:

Discourses of prejudice in the professions: the case of sign languages
https://pubmed.ncbi.nlm.nih.gov/28280057/

Ensuring language acquisition for deaf children: What linguists can do
https://gallaudet.edu/deafhealth/ensuring-language-acquisition-for-deaf-children-what-linguists-can-do/

The Language Experience and Proficiency Questionnaire (LEAP-Q): assessing language profiles in bilinguals and multilinguals.
https://pubmed.ncbi.nlm.nih.gov/17675598/

Early Language Acquisition and Adult Language Ability: What Sign Language Reveals About the Critical Period for Language
https://academic.oup.com/edited-volume/28159/chapter-abstract/212970837?redirectedFrom=fulltext

Age constraints on first versus second language acquisition: evidence for linguistic plasticity and epigenesis
https://pubmed.ncbi.nlm.nih.gov/14642540/

Neurolinguistic processing when the brain matures without language.
https://pubmed.ncbi.nlm.nih.gov/29406150/

Age of acquisition effects on the functional organization of language in the adult brain
https://pubmed.ncbi.nlm.nih.gov/21705060/

Dinner Table Syndrome: A Phenomenological Study of Deaf Individuals' Experiences with Inaccessible Communication
https://www.researchgate.net/publication/342623540_Dinner_Table_Syndrome_A_Phenomenological_Study_of_Deaf_Individuals'_Experiences_with_Inaccessible_Communication

Rethinking the critical period for language: New insights into an old question from American Sign Language
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6818964/

Ten things you should know about Sign Languages
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What Medical education can do to ensure robust language development in deaf children
https://www.researchgate.net/publication/267025999

Deaf children's non-verbal working memory is impacted by their language experience
https://www.researchgate.net/publication/276510816

Theory of mind in deaf adults: The role of verbal ability and interpersonal experiences from early years
https://www.researchgate.net/publication/318492030

Does early exposure to spoken and sign language affect reading fluency in deaf and hard-of-hearing adult signers?
https://www.researchgate.net/publication/374054048

The influence of language deprivation in early childhood on L2 processing: an ERP comparison of deaf native signers and deaf signers with a delayed language acquisition
http://www.biomedcentral.com/1471-2202/13/44

Adverse childhood communication experiences associated with an increased risk of chronic diseases in adults who are deaf
https://doi.org/10.1016/j.amepre.2020.04.016

American Sign Language syntax and analogical reasoning skills are influenced by early acquisition and age of entry to signing schools for the Deaf
https://doi.org/10.3389/fpsyg.2016.01982

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https://www.researchgate.net/publication/317276464

Deafness and early language deprivation influence arithmetic performances
https://doi.org/10.3389/fnhum.2022.1000598

Mental health experiences of deaf in New Zealand – interviews with twelve Deaf with mental illness
https://www.researchgate.net/publication/354399865