

# Untreated severe-to-profound hearing loss and the cochlear implant situation: how policy and practice are disabling New Zealand society

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## ABSTRACT

As a signatory to Convention on the Rights of People with Disabilities, Aotearoa New Zealand aims to be a “non-disabling society—a place where disabled people have an equal opportunity to achieve their goals and aspirations”. Yet many adult New Zealanders with severe-to-profound hearing loss (SPHL) due to sensorineural deterioration over time are being denied timely access to publicly funded cochlear implants. This presents a serious inequity in Aotearoa New Zealand’s health system and contravenes disability and human rights principles. For Māori affected by SPHL, this brings additional challenges along with broader impacts on Māori health and development. These issues are investigated through a self-case study together with a review of relevant evidence-based research and public policy.

**H**earing is at least as equally important as vision. Unlike blindness, deafness is largely invisible, very misunderstood and its impacts underestimated. A key reason why there is enormous silence around deafness is that deaf people have less access to education, income, influence in public conversation (because of their deafness), and therefore have less access to societal power.

Nearly one in five New Zealanders experience hearing loss. The attrition of, and growing inequities between publicly funded hearing services across the country pose huge access challenges to many deaf and hearing-impaired New Zealanders in general. The most common reason why people are unable to access hearing-related services and equipment is that they simply cannot afford it.<sup>1</sup> This issue is exacerbated by the association between low-income and disability. For example, New Zealand’s

Deafness Notification Report shows the overwhelming majority of children and young people diagnosed with hearing loss live in high deprivation areas.<sup>2</sup>

While comparatively small in number, people with severe-to-profound hearing loss (SPHL) experience marked levels of social and economic marginalisation and attendant health inequities, due to the severity of their impairment. For people with SPHL caused by the degeneration of the hair cells in the cochlear (sensorineural hearing loss), cochlear implants have proven to be very reliable in restoring people’s ability to be well functioning and contributing members of society.<sup>3</sup> However, recent cost cutting in the health sector has once again made publicly funded cochlear implants very difficult to obtain. The cost of a cochlear implant (CI) for one ear in Aotearoa New Zealand is approximately \$50,000 NZD. Those with SPHL able to afford it generally

elect to receive privately funded CIs. Lack of publicly funded CIs exacerbates issues of access for Māori who generally have higher rates of hearing loss and unmet needs for technology and equipment when compared with non-Māori (while rates of higher hearing loss for Māori are particularly pronounced in the mild to moderate range, for those with SPHL, access to expensive hearing technology associated with CI is often pronounced relative to the rest of the population).<sup>4</sup> Due to the gendered nature of income disparities in New Zealand, we can also expect that women will have higher rates of unmet needs for hearing technology and equipment relative to men.

The total cost of hearing loss in New Zealand in 2016 was estimated as being 4.9 billion, comprising 957.3 million in financial costs and 3.9 billion in terms of loss of well-being.<sup>1</sup> Most of the financial costs are due to lost productivity. Hearing loss has been shown to have a considerable impact on a person's chances of employment leading to significant productivity, monetary and social losses. Research demonstrates that people with hearing loss suffer stigma from the hearing population, are often under-employed and experience reduced working opportunities.<sup>5,6</sup> People with hearing loss have been found to have a 10% reduction in the likelihood of employment, while those aged between 45–64 years of age with SPHL have a nearly 20% lower labour force participation rate.<sup>1</sup> These years are often a person's most productive. These impacts, as well as depression, cognitive decline and comorbidity as a result of the stress of untreated SPHL, are well documented in the deafness literature.<sup>1,7</sup>

As an oral-based society recovering from the impacts of colonisation and experiencing continued health disparities,<sup>8</sup> these issues have particular implications for Māori well-being and development to which Kaupapa Māori research methods are pivotal. Kaupapa Māori research demands *kanohi ki te kanohi* (face to face) interactions in a wide variety of often new encounters on and off marae, and other community and institutional settings. Kaupapa Māori research also demands researchers be attuned to the changing and nuanced relationships within *iwi*, *hapū* and *whānau*. While verbal communication is important in any commu-

nity-based researchers' day-to-day work, it is even more so for Māori as a largely oral culture in which *whakawhānaungatanga* (practices of relationship building and connection) are very important. Working knowledge of *Te Reo Māori* is also vital.

This article represents a revised version of a letter sent by the author to the Chief Human Rights Commissioner. The self-case study section is written in the first person as it describes the author's direct experience as a person with SPHL. In its entirety, the paper also draws on the author's professional expertise as an experienced social worker, past director of a population health promotion research centre, Associate Professor of Public Health, and current experience as a senior Māori researcher. Some of the data drawn on refers to the Northern Region Cochlear Implant program, as the author lives within its regional boundaries. It should be noted that access to timely CIs for those suffering SPHL living in the Southern Region (Taupō to Bluff) is even worse.

### Deafness and the cochlear implant situation in Aotearoa New Zealand

In New Zealand, SPHL people under 19 years of age deafened through sensorineural hearing loss generally receive two publicly funded CIs in a relatively short space of time. SPHL adults deafened through sensorineural hearing loss receive a maximum of one publicly funded CI (the bare minimum deemed to restore some functional level of hearing) and are placed on a lengthy waiting list (where they may be 'bumped down' because of more urgent cases presenting), with no advised date of surgery.<sup>1</sup> The average waiting time is around two years,<sup>1</sup> and up to four years for a considerable number of people, and on occasion six years.<sup>7,9</sup>

The Northern Region's base volume (guaranteed funding from central government) for the 2018–2019 financial year was set at 20 fully funded cochlear implants. On average there are eight new referrals per month. Currently there are 37 clients waiting with 10 of these waiting for more than two years.<sup>9</sup>

The actual time between needing a CI and receiving treatment is often in reality much longer than two years, as many adults are not being referred for assessment. Audiologists often consider referral to be fruitless in light

of New Zealand's stringent CI criteria and long wait list. Given this situation, potential CI recipients are often advised to go privately and/or self-refer to the private sector. For those who can afford it there is virtually no waiting time in the private sector.

Adults living with SPHL face increased difficulties with long wait times for cochlear implants, with many increasingly struggling to cope with everyday tasks. The longer the wait time, the less chance there is of recovery of the loss of auditory and neural functioning. Furthermore, significant social and economic loss frequently occurs in the lives of people with SPHL while waiting for help.<sup>1</sup>

Currently the candidacy guidelines for New Zealand adults are so stringent (audiometric thresholds of 90 db HL or above at 2 and 4 KHz) that many adults with poor access to speech are not being considered for publicly funded implants.<sup>10</sup> "This means that in New Zealand there is a clear difference between eligibility for funding and suitability for implantation".<sup>11</sup>

### Self-case study

I am a social scientist and senior Māori researcher in my 50s. I am an integral part of, and contributor to my whānau and many communities. Diagnosed with a progressive hearing loss 22 years ago while undertaking my PhD studies,<sup>12</sup> today I have SPHL in both ears. For many years I have had to negotiate and compete in a 'hearing' world and workforce with a very significant hearing (and therefore communication) disability.

As a Māori researcher, communication is the linchpin of my work. It entails providing senior research capacity on a wide-ranging number of research projects and demands verbal communication and negotiation with a wide variety of research stakeholders, including iwi and community members, policy makers, practitioners and other researchers.

My current untreated condition means that I am unable:

1. To have a telephone conversation with a colleague, the doctor, or family and friends;
2. Undertake professional training that relies on oral methods of communication and function;
3. To participate fully in Te Reo Māori

classes which are integral to my cultural identity and professional development;

4. To carry out focus-group and ethnographic research in community-based settings. For example, I have not been able to attend and observe a pakeke kōrero group (conversation group for people in their 50s upwards) held in a community café; an essential aspect of whakawhāungatanga, as per kanohi ki te kanohi, kaupapa Māori research methods;
5. To participate in virtual meetings that have more than one person—on occasions colleagues have texted me the meeting dialogue as a means of inclusion;
6. Participate fully in face-to-face team meetings, strategic planning and other events;
7. To negotiate new introductions and conversations with people without first explaining my deafness and asking them to face me, speak up and speak slowly. This makes attendance at strategic networking work events such as suppers, and 'meet and greet' stressful;
8. To chair a panel at a research conference, participate on boards and successfully hear and respond to questions from audiences on presentations that I make at national and international conferences;
9. Communicate with ease within my day-to-day living situation, and attend social events and everyday things; and,
10. Keep myself safe from bicycles, trains and motor cars.

I have spent thousands of dollars on hearing technology over the years to remain a part of the workforce and retain my social contributions and supports. With the progression of my deafness, I am now out of hearing assistive device options. However, the chances of getting a CI from the public health system in a timely manner are slim.

The average life expectancy for women in New Zealand is 81 years of age. Therefore, I can probably expect to live a further 24 years. A key public policy goal, in view

of our aging population, is that people maintain their social and economic independence for as long as they can. Independence is strongly linked to workforce and social participation and networks. Below I have laid out, in simple terms, the economic costs to society of providing me with and not providing me with a CI in a timely manner.

**Economic contribution with CI and ability to retain paid work**

Taxes paid:	\$34,296/annum
Kiwi Saver contribution:	\$13,861/annum
<b>Total contribution:</b>	<b>\$48,157/annum</b>

**Economic contribution with job loss as result of untreated need for cochlear implant**

State pays me a sickness benefit:	\$15,000
Extra healthcare costs as a result:	\$5,000
Loss of my taxes and RSP	\$48,157/annum
<b>Total cost to state (conservative estimate):</b>	<b>\$68,157.00/annum</b>

Total economic cost to state over two years \$136,315 (average wait list time) contrasted to \$50,000 for one CI.

**Discussion: domestic and international policy**

As a signatory to Convention on the Rights of People with Disabilities,<sup>13</sup> New Zealand aims to be a “non-disabling society—a place where disabled people have an equal opportunity to achieve their goals and aspirations”. In New Zealand the rights of people with disabilities are legislated for under the Bill of Rights Act 1990<sup>14</sup> and the Human Rights Act 1993.<sup>15</sup> The Human Rights Act (1993) covers a number of provisions including making discrimination unlawful against people with disabilities when it occurs in relation to access to public education and health services.

Had the author’s sensorineural hearing loss been acquired through an accident, she would very likely be eligible for ACC and able to receive an implant in the private

sector within a very short space of time. Secondly, those in New Zealand affected by other forms of physical disability wait no longer than four months for elective treatment interventions in public health system.<sup>16</sup> Clearly with SPHL, which occurs over time due to sensorineural hearing loss, discrimination is occurring regarding access to a public health service. This is arguably a ‘hangover’ from the stigma associated with deafness and other forms of disability, particularly those which appear to be innate to the individual rather than externally caused.

Both the Treaty of Waitangi,<sup>17</sup> New Zealand’s official founding constitutional document and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)<sup>18</sup> recognise the rights of Māori and Indigenous peoples to be free of discrimination, to retain and practice their Indigenous languages and cultural heritages (articles 2 and 3, Treaty of Waitangi, and articles 5, 8, 11, 13 and 14, UNDRIP). The well-known WAI 262 Treaty of Waitangi Claim<sup>19</sup> reinforced the status of Te Reo Māori as a ‘taonga’ and access to Te Reo Māori as an inalienable Māori right, that is integral to Māori identity and wellbeing. Despite this, rates of conversational Te Reo Māori among Māori have continued to decline in recent years.<sup>20</sup>

The New Zealand Government gave its official support to UNDRIP in 2010. The declaration holds considerable moral authority and is consistent with the aims of the Treaty of Waitangi. Article 22 1. UNDRIP states “Particular attention shall be paid to the rights and special needs of Indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration”. Given the author’s cultural identity, and profession as a Māori researcher whose job encompasses Māori health and development, her current lack of access to CI treatment (bear in mind that even for those who meet the CI criteria, the average waiting time is two years) appears to contravene the spirit and intent of both the Treaty of Waitangi and the UNDRIP.

Lack of access to CI treatment for the author and other similarly affected people, contravenes these public policies and/or principles in the following ways:

- Equal access to health services due to lack of parity with both elective surgery wait times and those who can access CI treatment through the ACC legislation;
- For Māori, the right to retain and practice their Māori cultural heritage through accessing Te Reo Māori classes, including the right to special provision of Indigenous persons with disabilities under section 22 of UNDRIP; and,
- For Māori, the right to access training opportunities necessary for Māori development work (for example knowledge of Te Reo Māori), and the right of hapū, iwi and Māori to benefit from those skills more generally in the interests of the protection of Māori rights as per the Treaty of Waitangi and UNDRIP.

### Summary

Overall, hearing loss is a vastly under-treated and underfunded public health issue that contributes to serious health disparities throughout New Zealand. For those with SPHL caused by sensorineural degeneration,

advancements in CI technology over the past 30 years means that it is now possible to give this cohort access to hearing in a real-world setting, with improved health and quality-of-life outcomes. Yet this life-changing technology is being under-utilised for New Zealand adults with often disastrous results. The social and economic benefits of providing a CI implant in a timely and effective manner clearly outweigh the societal costs in economic and social terms of withholding this treatment. For late deafened adults who have developed sensorineural hearing loss over time, discrimination is clearly occurring in terms of access to CIs contrasted to other forms of physical disability, or to those people who incur sensorineural hearing loss through accident or illness. The effects of the author's SPHL and current CI situation also impacts negatively on her ability to undertake Kaupapa Māori research. Given Māori health disparities and the endangered status of Te Reo Māori, untreated SPHL on a larger scale in Māori has some potentially serious implications for the protection of Māori cultural rights, health and development.

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Nil.

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