The HearMe Project

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EXECUTIVE SUMMARY & RECOMMENDATIONS

Soundfair's HearMe Project grew organically from the evidence-rich stories collected during six months of deep community engagement and collaboration across the academia, business, industry, policy and health sectors.

The ten priorities identified in the HearMe Report are both interconnected and interdependent; and demonstrate that hearing is not only a health issue. Hearing is a social issue and the one-in-six of us living with hearing conditions often have to navigate society with needs that are invisible, sometimes misunderstood and often ignored.

The individuals whose stories and voices are highlighted throughout this report have set the HearMe agenda with their lived experience. This approach is truly human-centred design, starting not with systems, funding models or regulation, but with stories of how people with hearing conditions experience our society and their lives. The HearMe Report sets out how we, as a society, can all take collective responsibility for not just providing accessibility and health services, but more importantly creating social inclusion and with it a sense of belonging so that every Australian can thrive.

By 2050, an estimated quarter of all Australians will be living with a hearing condition – now is the time to listen to lived experience and create a fairer future for people with hearing conditions:

The HearMe Report's priorities for society-wide action are:

1. **Centre the lived experience of hearing conditions and embed this in decision-making and design processes.**
2. **Put consumers at the centre of hearing service delivery, and provide greater choice, accountability and address their needs beyond devices.**
3. **In line with the Roadmap for Hearing Health, invest in ongoing public health initiatives that embed the social determinants of health, and engage in research to inform future decisions.**
4. **Make hearing and acoustics standards mainstream alongside education for the design sector and awareness raising.**
5. **Invest in initiatives that focus on inclusion, not just 'awareness', to create a society that accepts and welcomes diversity in hearing.**
6. **Encourage the evolution of technology that is informed by the consumer experience and increases their control over their experience of hearing.**
7. **Make the captioning of all free-to-air television broadcasting and emergency announcements mandatory and establish enforceable minimum standards for content providers, broadcasters and platforms.**
8. **Formally recognise Auslan with official national language status.**
9. **Increase funding for tinnitus services and research.**
10. **Invest in specific, targeted and co-created programs for minority and disadvantaged populations to ensure hearing health equity across society.**

EMPOWERING. HEARING. EQUALITY.

FOREWORD

Soundfair's primary goal is to create a society where having a hearing condition is not a barrier to living a connected, healthy and successful life. This is a valuable purpose and one the Australian Government shares.

More than 3.6 million Australians currently experience hearing loss. That figure is expected to more than double by 2060 to 7.8 million Australians struggling to hear without assistance.

I have hearing loss myself and am proud to be a "Pionear" for Soundfair. I know that for too many Australians, hearing loss can lead to emotional, psychological and social damage, as well as economic loss. As the Federal Minister responsible for hearing services, I am working hard to change this and ensure all Australians with hearing loss get world-class health services and devices.

Soundfair's HearMe Project puts the lived experience of people with hearing conditions at the centre of developing ideas and policies. It is primarily about systemic and community change to lift the barriers facing people with hearing loss, including social attitudes. It complements the work being done right now by the Australian Government and the work we are doing with other governments and stakeholders.

We developed Australia's first Roadmap for Hearing Health, and we are now implementing key priorities in our areas of responsibility, with a $21.2 million hearing package in the 2020 Budget.

I will continue to work closely with the hearing sector as we implement the Roadmap, and as new technologies and strategies are explored to improve the lives of Australians who are hard of hearing.

This HearMe Report is an important contribution to the ideas and discussion about how we can improve the experience of all people with hearing loss, and move closer to hearing equality.

Thank you to everyone who has contributed.

THE HON MARK COULTON MP

Minister for Regional Health

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ACKNOWLEDGEMENT OF COUNTRY

Acknowledge the traditional owners of the land on which we conduct our business and pay our respect to Elders past, present and emerging.

A NOTE ON TERMINOLOGY USED IN THIS REPORT

Hearing conditions, like people, come in many different forms, from balance disorders to tinnitus; from profound deafness to mild hearing loss. Equally, each person relates to their hearing condition in their own way – each perspective on lived experience is valid and should be respected. This report uses 'hearing conditions' to encompass all the variety of lived experiences and uses hard of hearing (HoH), deaf, Deaf and d/Deaf, as appropriate, to distinguish between people who use Auslan as their primary language (and/or consider themselves to be part of the Auslan community) and those people who live with or identify as having a hearing loss.

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INTRODUCTION

With hearing conditions – if we don't have an inclusive society – the impacts are not just physiological, the impacts are emotional, they're psychological, they're social and we need to take this into account when designing strategies to support people to navigate it.
– Maxine P

Half of us will have a hearing condition after we reach the age of 60. Owing to an ageing population, by 2050, a quarter of Australians, more than nine million of us, will be living with a hearing condition.

Despite their ubiquity, hearing conditions are often approached dismissively as something to be overcome or treated with a simple intervention, most often a hearing aid or device. However, this approach overlooks the fact that health is influenced by many determinants, including physiological, psychological and social factors.

Models of disability exist as a way of thinking about, analysing and assessing where disability comes from, what we should do about it, and what it means for society.[1] These models are powerful because they direct our attention to specific aspects of experience and thereby shape the psychological, political and economic outcomes associated with disability.[2,3,4] In this regard, the fundamental differentiation that has received the most attention is the contrast between the medical and social models of disability.[5,6,7]

The medical model says that disability is located in the individual's body and is subject to treatment and/or intervention. Approaching a hearing condition as something to be moderated with a hearing aid or device, as is common in our society, is reflective of the medical model of disability. On the other hand, the social model of disability locates disability in the environment that surrounds the individual with an impairment and so calls for society to remove the systemic barriers, derogatory attitudes and social exclusion that are disabling.

By applying the social model of disability to hearing conditions, we can see that the difficulties people with hearing conditions experience are the result of the interaction between them and an environment filled with physical, attitudinal, communication and social barriers. Essentially, we can see that people are more than just ears; and that hearing care is about more than just devices.

Soundfair's purpose is to transform the experience and wellbeing of people with hearing conditions by amplifying their diverse voices, focusing on the whole person and catalysing change across the system and society. Therefore, our approach to advocacy is deeply rooted in individual stories. And while every story is different, reflecting the circumstances of each individual's unique life journey, there are striking points of commonality – the shared experience of living in a society that is both actively and passively disabling.

In the course of this consultation, we identified ten areas of shared

experience that require society-wide action, starting with the need to embed the centrality and multiplicity of lived experience within all interventions, we move outwards to reconfiguring the hearing system and the value of addressing hearing within a public health framework; then further out to the individual's disabling experience of the built environment and the social factors that seed discrimination. We then look at society-wide interventions that would help bring equality closer – investing in and providing assistive technologies; embedding the provision of captioning and Auslan in society – before addressing tinnitus as a heavy and unaddressed public health burden and, finally, returning to the centrality of lived experience by exploring how aspects of an individual's position within society intersect with their hearing condition to create needs that are unmet by our current medical model of hearing care.

This report aims to provide an overview of these ten priority areas to bring a fair world for people with hearing conditions closer. Acknowledging the complexities of the whole-of-society approach and systems thinking that is required to deliver needs-based solutions, while also recognising the many initiatives currently in place, this document aims to capture and reflect not only the diversity of people living with hearing conditions, but also the diversity of expertise that has thus far contributed to the project and the gaps where there is still much work to do.

The Commonwealth government's Roadmap for Hearing Health, together with the quantity and quality of research that proves social determinants are closely associated with good hearing health outcomes, provides us with an invaluable opportunity to learn more and do more. We believe that these are valuable signposts for us to come together and radically reimagine what we can do to promote a fair world for people with hearing conditions.

The HearMe Project is built on the foundations of lived experience and brings together the multidisciplinary expertise from government, community, medicine, allied health, business and academia. We are encouraging the necessary discussions relating to the most pressing challenges, as identified by people with hearing conditions, while encouraging collaboration and partnerships to deliver effective change without duplicating efforts already being made. It's about reimagining what our world can be.

This report aims to provide an overview of our ten priority areas of focus to bring hearing equality closer. It is intended that the HearMe project will take its place beside other initiatives to ensure that hearing equality remains on the agenda. Soundfair extends thanks and deep gratitude to the individuals and organisations that have contributed their lived experience and expertise to the HearMe Project and this report.

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1. CENTRING LIVED EXPERIENCE

I think people automatically assume people with hearing conditions are those who are completely Deaf and use sign language. And even that stereotype is of 'Deaf' as ignorant (deaf and dumb). I hate it.

We need to show that people who are deaf, HoH or Deaf are not ignorant, but valuable members of society. But that stereotype also pushes away people who are not Deaf or part of the Deaf community or use sign language. Other people with hearing conditions feel invisible and left out by both the Deaf and hearing worlds.

People with hearing loss who might identify as HoH or hearing impaired feel 'torn between two worlds'. Their experiences are not covered enough. For example, it's mostly about how well they do in audiology or with a cochlear implant, but not their diverse experiences. Some might feel close to their Deaf identity, some might not.
– Ayah

I was told – by teachers, by audiologists – how to be Deaf, but their perspective could never define my experience. My disability changed every time I got a new hearing aid and I had to relearn how to be. I say: don't force me to be like hearing people – I'm Deaf.
– Catherine

It is widely recognised that policy making which includes people with lived experience is not only beneficial to the policy outcome; the process itself can have an impact on social inclusion – uniting and empowering everyone involved in the project.[8] Put simply, developing policies and programs without reference to lived experience is poor practice and results in poor outcomes.

Drawing on systems change practice and an extension of Socio-technical Transition Theory[9], Fraser and Glass have developed a lived-experience-informed methodology for creating social change that is termed the 'power shift framework' (Figure 1).[10]

Fraser and Glass' power-shift framework differs from other social-change models because it adds a new, foundational level defined by lived experience. The work done at this level is relational and includes shifting mindsets, perceptions, cultural practices, habits and values through storytelling and representation.

At its simplest, and most profound, storytelling is 'the element of self-expression in all human activities.'[11] It is how we understand both ourselves and the world around us. Therefore, listening to other people's stories gives us insight into the world as they experience it, which can be radically different to our own world of experience. Accounts of living with a hearing condition, for instance, are rich in 'both a specific form of knowledge (first-hand stories from everyday life) and a unique way of knowing (reflecting and telling from insider perspectives)'.[12]

The insider perspectives of living with a hearing condition in a hearing world allow us to change that world – to move beyond personal responsibility for accommodations (the medical model of disability) towards a society-wide responsibility (social model) for creating equality of access and opportunity for inclusion. Within the sphere of the delivery of healthcare, learning to listen to stories of lived experience increases the healthcare practitioner's 'capacities for attention, representation, and affiliation'.[13]

According to Fraser and Glass, working at a deep-roots system level by valuing lived experience can de-centre dominant power structures and create change by strengthening the traditionally 'marginalised'. Once strong, these voices can emerge as sources of expertise and propose solutions that operate on their own terms and are responsive to their own needs rather than those of the dominant system. This is the thinking

We're not getting the complete message out as to what it means to have hearing loss. It's not just 'whack in the hearing aid and you can hear perfectly'. I often get asked 'why can't you hear if you have hearing aids?' People don't realise that hearing aids don't make you hear perfectly.
– Jane

I am profoundly hearing impaired and have gone from a full hearing world to one of muffled distortion and can't understand speech. I do not sign nor identify with the Auslan community. Hearing people believe I cannot be THAT deaf or else I would use Auslan. I have chosen not to get implants as I even hate the mechanical robotic sounds that come from my hearing aids.
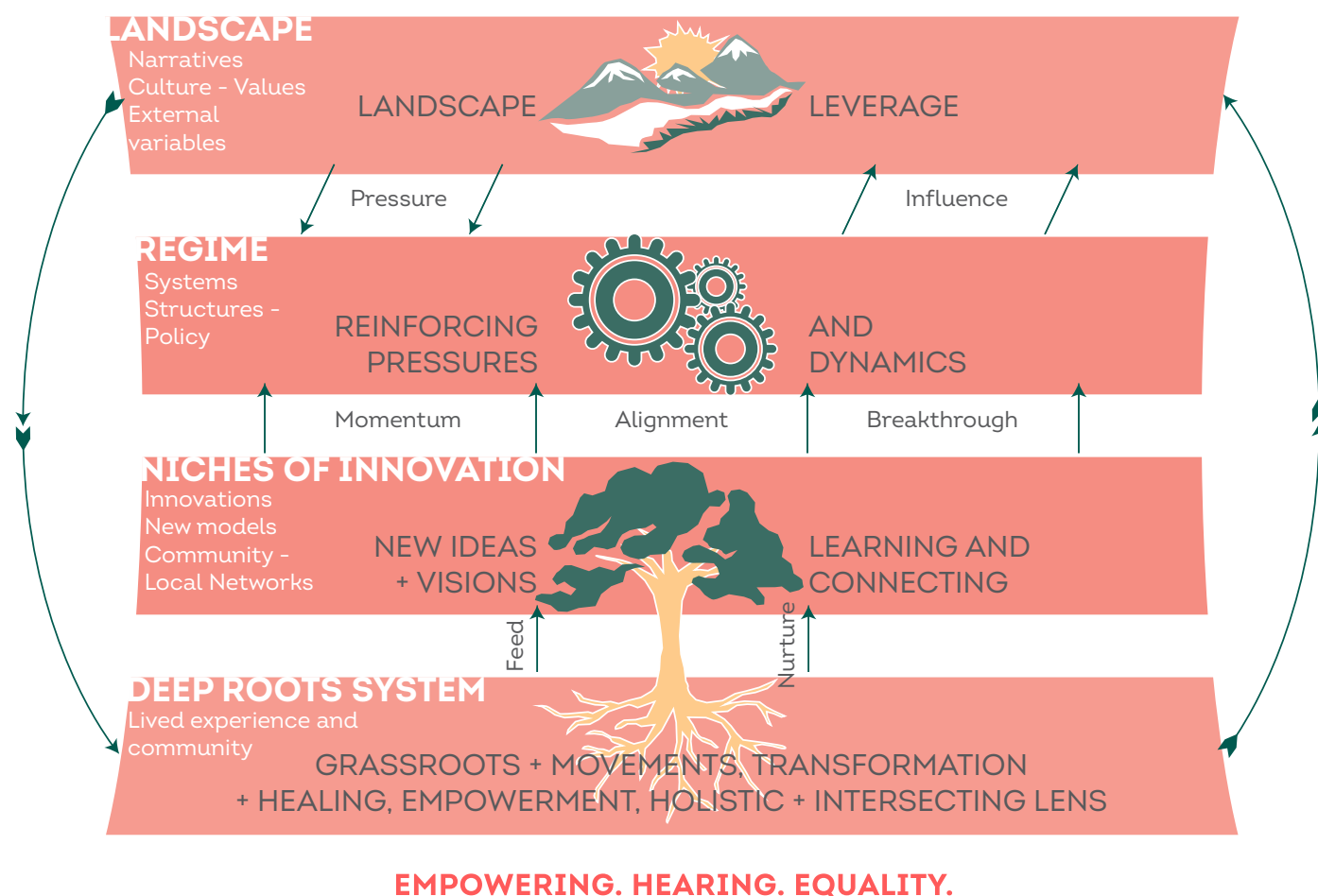– Christine

and methodology that underpins the HearMe Project and from which it draws its strength.

At Soundfair, we truly believe that power can be built from authentic connections between people with lived experience and groups working together and in alignment. By providing a platform for storytelling and story sharing, Soundfair is engaging in a deep process of therapeutic individual and social change by creating a space for empowerment, recognition and diversity.[8] We also believe that without this profound shift to centre lived experience, systemic changes may not be sustainable – as they are not considering the core needs of those most impacted by the social problems at hand. Therefore, many pathways for people with lived experience to be involved in policy development need to be created. This work will require commitment and investment across society. Finally, and we return to this in chapter ten, the diversity of lived experience and perspectives cannot be separated from the diversity of people's lives – the cultural construction of hearing health in their community, their access to services and the extent that supports are available to them.

Figure 1. Embedding lived experience in models of social change.
Adapted from Fraser F, Glass J.[10]

LANDSCAPE
Narratives
Culture – Values
External variables

LANDSCAPE   LEVERAGE

Pressure   Influence

REGIME
Systems
Structures –
Policy

REINFORCING   AND
PRESSURES   DYNAMICS

Momentum   Alignment   Breakthrough

NICHES OF INNOVATION
Innovations
New models
Community –
Local Networks

NEW IDEAS   LEARNING AND
+ VISIONS   CONNECTING

Feed   Nurture

DEEP ROOTS SYSTEM
Lived experience and community

GRASSROOTS + MOVEMENTS, TRANSFORMATION
+ HEALING, EMPOWERMENT, HOLISTIC + INTERSECTING LENS

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2. RECONFIGURING THE HEARING SYSTEM

Consultation partner Prof Anthony Hogan

I didn't know where to go for help there wasn't anything staring me in the face. I wasn't channelled through the system in terms of you know speaking to this person speak to this particular type of coach speak to this particular type of audiologist or therapist or health professional. I wasn't given any of that information, so for me it was all around self-advocacy and self-empowerment and that took a long time. I have to say it took probably a lot longer than I think it should have taken, had I been given the professional help from the beginning. So, yes, I definitely shied away. I definitely socially isolated and, you know, it even became an issue with relationships because, for example, my husband would want to go do things and instantly I would just knock it on the head and say no, not doing it. So it would impact relationships as well.
– Maxine P

The devices lived in my mum's drawer. I asked her why she didn't like them, and she said that the person who gave them to her spoke to her like she was an idiot and just told her that these were the ones for her. She didn't really have much say. She didn't feel comfortable going back to the provider for any adjustments so she just put them away.
– Anne

Given the recent work around the Roadmap for Hearing Health and the wealth of research around the social determinants and associations with good hearing health outcomes, it is timely that government funding for hearing health services, currently the Hearing Services Program, be reviewed and rebalanced to match the objectives in a broader sense. While the Hearing Services Program is not the only funding mechanism to access hearing health care, it is the most substantial, and across its decades-long history can be said to have shaped the hearing system as it stands today. The current hearing care system fits within the medical model, is device-centric and consistently misses opportunities to meet the diverse needs of people in Australia living with hearing conditions.

The hearing system is Australia is ripe for an overhaul. Substantial Australian-based research[14, 15] has documented that:

- People take 7–10 years to action their concerns regarding their hearing.
- When people do seek help, they join a conveyor belt of services that do not allow for individual preferences and needs, and in most cases includes provision of hearing aids.
- Even in the Government funded-system, people with hearing conditions are subjected to sales and manipulation techniques, often in the absence of appropriate information or time to make decisions.
- Of people who own hearing aids, 40% do not wear them and more report that hearing aids do not fully address their concerns.
- There is currently very little funding for, and subsequently few offerings that provide, services or support beyond hearing devices (psychosocial support), despite much of the daily impacts of hearing conditions being psychosocial in nature.
- The lack of data on outcomes (especially longitudinal) limits ability to inform targeted health promotion and improvement of interventions to overcome these challenges.

Clearly, there are several opportunities to reconfigure the hearing system such that it is genuinely person-centred and achieves appropriate outcomes for people with hearing conditions, funders and society. Four key areas to address are:
1. Consumer choice and control
2. Bio-psychosocial approach
3. Accountability and data
4. Access and equity

When I first had my hearing loss diagnosed, the whole process was very mechanical – I was diagnosed with a mechanical issue that needed a mechanical solution. Having a discussion 20 years ago about the fact that this was something I was going to live with for the rest of my life and the impacts it would have around communication and self-image would've changed my life. If I would've known that early on, I would've been better prepared.
– Jack

Consumer choice and control. These principles, which underpin the NDIS, are core to offering a person-centred system for support. For hearing loss, a common yet invisible and stigmatised condition, good outcomes will only be achieved through person-centred care. For consumer choice and control to occur, we need to address the absence of trusted information sources, be that a separation of the person who makes recommendations and builds a plan with the consumer from the salesperson, or, visible and accessible information hubs that are not linked to commercial entities. Additionally, consumers need to be able to control and have choices when it comes to the solutions they access. For example, have the option of devices, education and training around communication, personal-adjustment, modifications to their environment, perhaps workplace or family education, so they are able to, with the support of professionals, build a solution profile that specifically meets their needs.

Bio-psychosocial approach. Inextricably linked to 'choice and control' is the need to appropriately fund and therefore offer supports and services that go beyond biomedical (in this case, devices). This includes initiatives

Figure 2. No wrong door – a reconfigured system to prioritise person-centred hearing care.
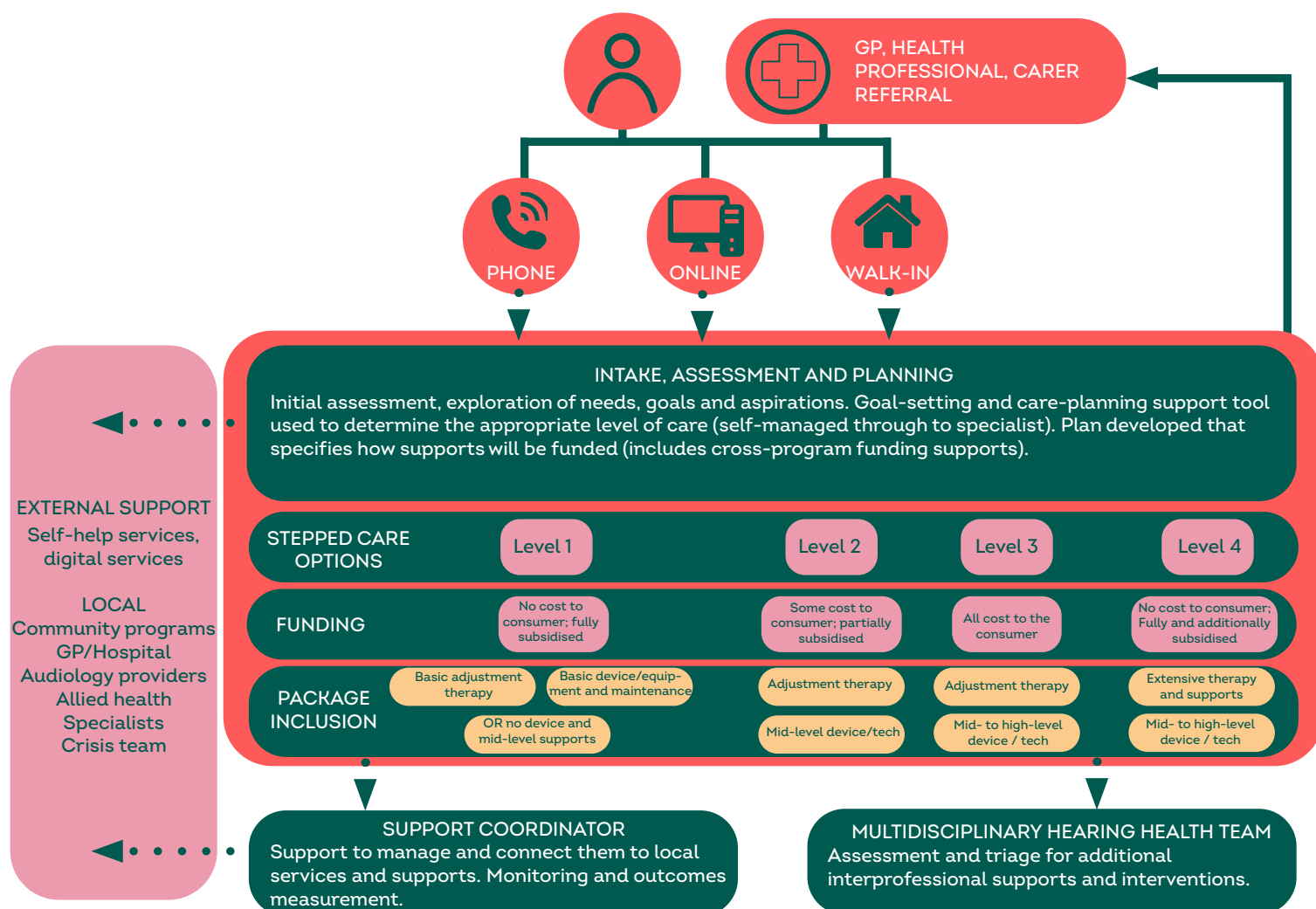
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I have found that the hearing aid industry as such often rips older people off with prices at shopping malls. They double the prices of a reputable dealer and/or con people into buying bad equipment.

They take advantage that it takes us a week to ten days to get used to the hearing aids. That's got to stop. We don't have the luxury of having many shops to choose from and it's stressful enough as it is.
– Frank

The hearing health system isn't working. It is confusing, expensive, cumbersome. People are not receiving the care and consideration they deserve when it comes to hearing health. Millions of people in Australia are suffering and their lives are falling apart due to unaddressed, unsupported, unaffordable hearing health care and rehabilitation. The situation is dire.
– Victoria

It's not just about going to the audiologist and having a hearing test, it's about having the right hearing aid to use; having people around you that can support you.
– Dale

that value peer-to-peer support, social groups, mental health (e.g. to support transition to life with hearing loss) and referrals for people with complex needs to psychological programs. Much of this work can and should be done by people, organisations and professionals who sit outside the traditional 'hearing sector', meaning that much greater collaboration and communication is required. Unlike other chronic diseases such as diabetes, there is nothing available for people who have hearing problems in terms of interactive e-education forums to support self-management.

Accountability and data. Data collection (specifically around outcomes) is critical for transparency and quality assurance. Gathered, stored and used appropriately, data is an essential ingredient in the creation of a person-centred model where consumers' powers and rights are substantial in keeping service providers accountable. Presently, providers, funders and organisations have minimal obligations to measure nor report on their outcomes, meaning there is little incentive, in a business sense, to ensure outcomes are favourable for consumers.

Access and equity. Funding accessibility for people with hearing conditions is complex and inherently inequitable in that it is exclusive in who it serves and the exclusivity is not clearly linked to who needs the service the most. For instance, many pensioners whose daily lives are only slightly impacted by their hearing conditions are eligible to receive devices that are consequently not used. However, working-age people who are substantially impacted by their hearing condition, but may not be eligible for NDIS, are ineligible and forced to self-fund or leave the workforce.

Hearing services (especially devices) are expensive relative to other health management options. However, there are a substantial number of people who do not and cannot benefit from funded hearing services. Greater clarity, coordination and clearer expectations of Commonwealth and State-funded hearing services would ultimately benefit the people living in Australia who currently, or may in the future, experience hearing conditions. If this is achieved, the Australian community will benefit through greater participation in the workforce, increased productivity, and reduced healthcare expenses at older age.

Of course, the provision of hearing health support is situated within the broader health system and here it is important to note that a whole-of-system approach should involve key partners, including, but not limited to: primary health care, community health centres, pharmacies and the aged care sector.

Taken together, hearing equality requires substantial and sweeping changes to the hearing sector that can begin to be instigated through the mechanisms of the Roadmap for Hearing Health. Soundfair highlights that changes can only be effective if lived experience is at the centre, and if stakeholders beyond the traditional power brokers are at the table and enabled to catalyse change.

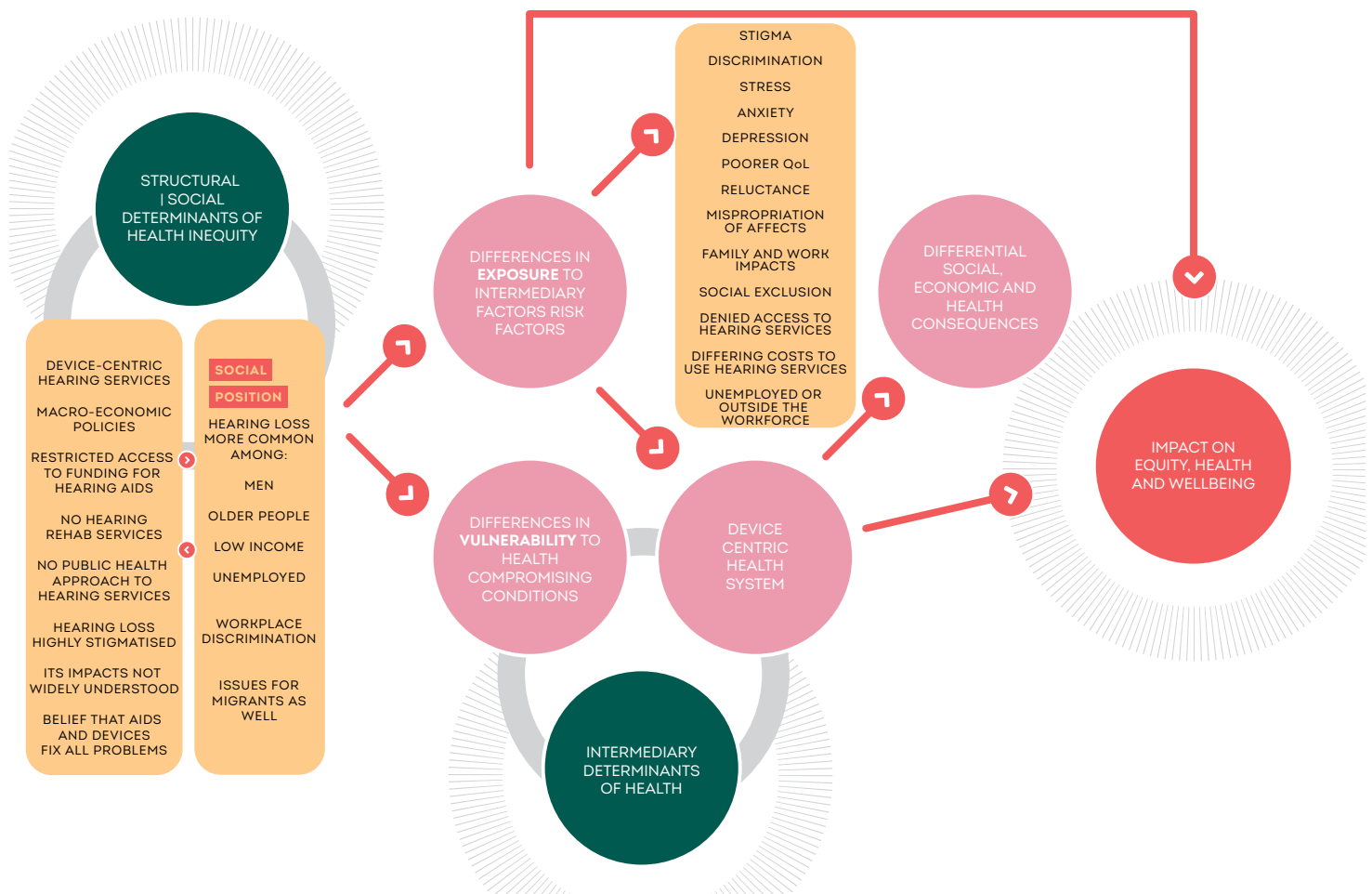# 3. HEARING CONDITIONS THROUGH A PUBLIC HEALTH LENS

Consultation partner Prof Anthony Hogan

The social determinants of health have rapidly become a central concept in population and public health, leading to the emergence of new theoretical models and frameworks.[16] The social determinants of health can be understood as the 'causes of the causes' and include factors such as education, occupation, income, social networks and housing. The World Health Organization states that these are, in fact, the most important factors that govern good or ill health.

Public health draws on knowledge from a broad range of disciplines, including medicine, sociology, psychology, education and economics, as well as from different sectors, including government, social justice and

Figure 3. A social determinants approach to hearing health.[14, 15]
Adapted from Solar O, Irwin A.[17]

STRUCTURAL | SOCIAL DETERMINANTS OF HEALTH INEQUITY

DEVICE-CENTRIC HEARING SERVICES

MACRO-ECONOMIC POLICIES

RESTRICTED ACCESS TO FUNDING FOR HEARING AIDS

NO HEARING REHAB SERVICES

NO PUBLIC HEALTH APPROACH TO HEARING SERVICES

HEARING LOSS HIGHLY STIGMATISED

ITS IMPACTS NOT WIDELY UNDERSTOOD

BELIEF THAT AIDS AND DEVICES FIX ALL PROBLEMS

SOCIAL POSITION

HEARING LOSS MORE COMMON AMONG:

MEN

OLDER PEOPLE

LOW INCOME

UNEMPLOYED

WORKPLACE DISCRIMINATION

ISSUES FOR MIGRANTS AS WELL

DIFFERENCES IN **EXPOSURE** TO INTERMEDIARY FACTORS RISK FACTORS

STIGMA
DISCRIMINATION
STRESS
ANXIETY
DEPRESSION
POORER QoL
RELUCTANCE
MISPROPRIATION OF AFFECTS
FAMILY AND WORK IMPACTS
SOCIAL EXCLUSION
DENIED ACCESS TO HEARING SERVICES
DIFFERING COSTS TO USE HEARING SERVICES
UNEMPLOYED OR OUTSIDE THE WORKFORCE

DIFFERENTIAL SOCIAL, ECONOMIC AND HEALTH CONSEQUENCES

IMPACT ON EQUITY, HEALTH AND WELLBEING

DIFFERENCES IN **VULNERABILITY** TO HEALTH COMPROMISING CONDITIONS

DEVICE CENTRIC HEALTH SYSTEM

INTERMEDIARY DETERMINANTS OF HEALTH

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I feel like there is a lot of responsibility on the individual to solve the problems of inaccessible and non-inclusive design to meet the needs of people with hearing loss as readily as it meets the needs of people without hearing loss.

Communication is a two-way street. I have control over one side of the conversation (mine) and the biases and assumptions I assume my audience has in receiving and processing information. But I'm amazed at the amount of time I spend advocating and educating to gain access to the same information that is readily provided to everyone else.
– Gillian

health. This broad knowledge base has allowed the field of public health to respond successfully to a range of health conditions.

At its core, a public health approach involves 'defining and measuring the problem, determining the cause or risk factors for the problem, determining how to prevent or ameliorate the problem, and implementing effective strategies on a larger scale and evaluating the impact'.[18] In order to eliminate disparities in hearing health outcomes, a public health approach must take place in the context of an integrated community health system, 'which includes health promotion, disease prevention and early detection, moving towards universal access to health care'.[19]

Australia is fortunate to have the Roadmap for Hearing Health[20], released in August 2019, that explicitly uses a public health approach to identify priority areas for action:
1. A public awareness campaign
2. An integrated national approach to ear health checks of children
3. The availability of Auslan services is increased
4. The quality of hearing health and care in aged care facilities is lifted
5. A comprehensive audit of the workforce delivering hearing health services
6. Supports in the education system are increased
7. There is a smooth transition for clients from the Hearing Services Program (HSP) to the NDIS
8. Additional support for people on low incomes

This marks the very beginning of a shifting away from a biomedical model, and towards a bio-psychosocial and socio-cultural model that brings together the strengths of the audiological expertise and of the community more broadly. However, as it only considers hearing conditions within the medical system, it is merely the first step towards making social inclusion a reality for people living with hearing conditions.

By ensuring our society – families, friends, workplaces, educators, event planners, urban planners and architects, to name a few – plays a role in hearing equality, the burden is lifted from government-funded services directly and a more consumer-centred and whole-person offering is delivered. Ultimately, this also lifts the burden of self-advocacy and system navigation from individuals with hearing conditions and their families to make it the responsibility of society as a whole. To achieve this, we need to commit to public health approaches and initiatives that go beyond the hearing sector, bringing in societal, behaviour change and inclusion-focused approaches while, at the same time, investing in research that brings together experts from the hearing sector with those from outside it.

4. BUILT ENVIRONMENTS AND URBAN DESIGN

Consultation partner Arup

When we are talking about physical accessibility, putting a ramp into a building is something that people get. They understand that if there is one step, the person in the wheelchair will not be able to get in. But where is the consideration in terms of communication access?
– Sarah

So I know, for me, an adjustment happened in my brain to handle the sensory inputs and things like that, but it's absolutely exhausting; by the end of the day my head is in a spin and the tinnitus is heightened. I think it would be wonderful if there was some regulation around healthy hearing decibels for public spaces. If there was some regulation around what is a healthy hearing environment that would be most helpful not just for people with hearing loss, but also to help prevent further hearing loss. Noisy environments can be a real challenge for deaf and hard of hearing people. Environments can be altered to suit and they're not just going to suit a person with hearing loss, they're going to suit a very, very wide range of people.
– Maxine P

The spaces we inhabit – our homes, workplaces, social settings and the infrastructure that allows us to move between them – shape our lives in ways both obvious and subtle. Navigating a noisy world with a hearing condition can be a frustrating and exhausting business, leading many to withdraw from, or self-restrict, activities that require such navigation.

There have been moves to architecturally design specifically for expression of d/Deaf cultural identity based around sign language. DeafSpace is perhaps the most complete and best known a set of architectural principles in this regard.[21, 22] However, while DeafSpace proponents argue that its design principles are not applicable only to d/Deaf people, questions remain about the type of spaces DeafSpace creates, most notably whether they lead to the creation of particularist spaces or reflect a set of design principles which can be embedded across a range of different environments.[23]

Universal design (UX), in contrast, takes as its starting point designing so that the greatest number of people possible will be able to access and participate without encountering barriers.[24, 25] Created during the social movements of the 1960s, it is now something of an architectural and design orthodoxy. However, UX as it is practised is often not as informed by lived experience as it proclaims itself to be: 'users tend to be held at arm's length and are only allowed in as abstractions (through functional concerns) or as ideals (through notions of authentic living).'[26] Worse still, for people living with hearing conditions, 'so far […] studies on inclusive design in architecture have paid little attention to hearing. They tend to focus on physical accessibility of buildings and spaces, but rarely address their acoustic.'[27] Often, UX approaches fall short, either because the visual aesthetic is considered more important than aural comfort or because of a lack of understanding – a mis-perception that it is a 'nice to have' rather than an imperative.

When designing spaces to create good listening conditions, the following are addressed: control of background noise and occupational noise within the space; control of noise coming into the space from elsewhere (which can also impact on privacy); control of reverberation; and the effect of noise within the space on the outside environment. It is worth noting that these items are strongly interlinked (control of reverberation helps to reduce occupational noise).

I was recently out and someone saw the hearing loop sign and had no idea what it was for, how it worked and why it was needed. This person was a teacher so I think there could be more education or just a panel underneath the hearing loop to explain its function.

– Kim

We operate in a society, and workplaces, designed for people who hear. Take fire alarms, for instance. If alarms are audio only and not accompanied by visual alerts, you may be dependent on other people to evacuate safely. During typical business hours, this loss of independence may be a compromise. However, this is raised as a work health and safety issue that limits one's ability to access flexible working hours in the absence of trained peers being on hand to relay the evacuation tones.

- Gillian

The wider acceptance and availability of FM systems would go a long way to ensuring communications were accessible in noisy places. One of the best examples is an FM system available at the ferry booking office at Circular Quay. With all of the background noises of trains and people having conversations and walking past etc. it's such a relief to be able to turn my hearing aid to FM and be able to converse with the person selling tickets. Why can't we have more of those kinds of well-placed FM systems to ensure accessible communications?

– Sarah

In addition to the 'passive' constraints, access to hearing augmentation systems, such as hearing loops and other technologies, should be a requirement for more public spaces, although it is certainly the case that poorly controlled acoustics can make hearing augmentation systems less effective even when they are installed. Finally, even when installed in an acoustically appropriate space, hearing loops are only effective if there is widespread understanding of their functionality and processes in place to test and maintain these systems.

There is also a safety case in larger public buildings, where audio warnings are used to manage the safe evacuation in an emergency situation (EWIS systems), for inclusive warning systems.

In some jurisdictions, the inclusion of acoustic controls in certain spaces is effectively mandated through the local building regulations. More common is the inclusion of acoustic controls in the Green Building rating tools (Green Star in Australia[28], WELL[29] globally). These are becoming popular with developers who see these as positive marketing tools. The rating tools usually cover acoustics under indoor air quality and points are available for spaces that have room acoustic treatments and adequate protection for noise intrusion and privacy. These features are not mandatory, but the additional points can make an important difference to the overall rating of the building. Such tools are largely written around large commercial developments (typically offices) but could easily be updated and extended to encourage designers to take note of acoustic issues in the design of public and social spaces.

Most often, as with the rating systems, design methodologies and regulation take as their starting point new developments, but our lives are not lived in new builds – our homes, workplaces, cafes and train stations are a palimpsest of decades of design decisions. Similarly, none of these approaches fully address the complex interplay of factors – the individual's hearing condition, their hearing device (if used), the accessibility technologies (such a hearing loop) in the space, the technology's age and the knowledge of how such technologies function as well as all the other interdependencies – that shape our interactions with the environment around us.

A carrot and stick approach through the inclusion of acoustic design requirements in a broadened green rating system and also standards that are referenced in the building regulations (and thus mandatory) would be one approach to embedding hearing accessibility as standard practice; another would be to recognise and reward best practice as well as empower businesses to be hearing friendly. However, this has to be done in parallel with education of the design community. Acoustics and hearing accessibility are not currently adequately covered in the training of designers and architects and here setting standards and education are paramount.

5. ADDRESSING THE SOCIAL FACTORS THAT SEED DISCRIMINATION

Audism is as deeply rooted in our society...and until we start dealing with audism at a social level, how can we possibly progress from the litany of negativity that is entrenched around hearing differently. Is it not a matter of using existing legislation to start calling our discriminatory practices, but it is a very effective way to attract attention to what discrimination is in the case of hearing (and indeed, can you actually define it?) and how to address it? If the environment is not acoustically accessible - it is discriminatory. If you don't use inclusive communicative strategies - it is discriminatory (and yes that means you need to use the microphone, the loop, live captioning etc). In short, unless a line is drawn in the sand and the fight is taken up to society, people won't change. It is the nature of 'unconscious bias' is that it is unconscious - people are not aware that they are discriminating against others.
– Anthony

Most of my schooling I was actually put in front of the class and the only problem with that was that all the kids all the other students in the class would be talking, creating background noise.
– Dale

Disability – much like 'ageing'[30], 'heterosexism'[31] or 'sexism'[32] – is difficult to research because its contested nature makes it difficult to define.[33] Moreover, the individual living with a hearing condition may or may not self-identify with having a disability, further complicating an already complex interplay of interrelated factors. That said, disability in general – and that associated with hearing conditions in particular – can be viewed as a social fact that is simultaneously constructed as an objective and subjective experience.[34]

Disability activism has focused on removing individualising and stigmatising representations and instead representing people with disabilities as a minority group who are making a claim to equal rights under the law, with the aim of humanising and including those who were previously othered and excluded.[35, 36] As we get closer to 2050 and the demographics of our society mean that more of us will be experiencing both ageing and hearing conditions, the applicability of this minority status comes into question for people with hearing conditions; however, it is unclear whether this demographic reality will lead to any shift towards hearing equality without advocacy for social change.

Our society is permeated with able-bodied norms – otherwise called ableism – for example, the expectation and assumption that everyone can hear. Starting from this expectation of hearing means that anyone with a hearing condition, once it is known about, is at risk of being regarded as 'different' or 'other'. This perception then leads to 'othering', a process that identifies those that are thought to be different from oneself or the mainstream, and it can both reinforce and reproduce discriminatory practices. Sadly, this othering starts early – sometimes within the family and often within school – being singled out for special treatment can, paradoxically, create a cycle of bullying and/or discrimination that has lifelong impacts on the person with a hearing condition.

There is, for many, also the double bind of having a hearing condition that is not known about (ie invisible – because devices are now designed to be unobtrusive, because devices are not used, or because devices are not appropriate for the condition) and therefore daily interactions are shaped by the ableist expectation of hearing.

While some work has been done on issues associated with employment[37] and access to healthcare[38, 39] for Deaf people, there is a paucity of academic research on the discrimination that people living with the full range of hearing conditions experience in their daily lives. As outlined in

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I had a boss when I was working in local government that would come to me twice a day, whispering in an open-plan office. For ages I just nodded and said yes. At some point I told her I couldn't hear her and asked if we could go to another room to talk. When we did, she still mumbled and covered her mouth when she talked. She just couldn't change her habits.
– Jack

Hearing aids are becoming increasingly 'invisible' and in my experience this comes with its own pros and cons. As much as younger me (and sometimes still me now) likes the fact that they are difficult to see, it requires a great deal more self-advocacy when communicating with others. With the common misconception that hearing loss occurs in the elderly, strangers naturally assume I can hear them…self-advocacy for me is difficult, I don't want to draw attention to myself and I most definitely don't want to draw attention to a part of me that I'm still coming to terms with.

However, the major point of frustration comes from when people are rude about it and make me feel like it's my fault for not hearing them. While I can now tell myself it's their problem and not mine, it is incredibly disheartening to open up about my hearing loss and have someone essentially tell me they don't care.
– Hannah

the introduction to this report, even while disability scholarship has been successful in promoting the social model of disability, hearing conditions are still frequently conceptualised within the medical model of disability. That is, hearing conditions are perceived as a medical issue that is the property of individual bodies and therefore only the responsibility of the person with the hearing condition.

In locating the source of difficulties within the person there is a straightforward narrative of who the hearing condition affects, whose responsibility it is, and what is required to treat and rehabilitate it (not to mention the expectation that it will be treated and thus the person rehabilitated). Likewise, considering disability as a medical pathology creates the foundation for prejudice and discrimination towards people with hearing conditions because the disability is then difficult to disentangle from the individuals who live with them.[40]

Media representations of hearing conditions are also subject to being presented through a medical model lens. For example, videos of babies and children having a cochlear implant device activated as a cure are frequently shared in the news and on social media platforms with the simple message of 'hearing for the first time' with no understanding of the complexity of living with such devices.[41] In the same vein, popular depictions of research and technological innovation focus on correcting the limitations of an individual's body as opposed to accommodating it through environmental changes.

It is unsurprising then that in schools and the workplace the medical model of disability is applied in such a way that people with hearing conditions are singled out – and it is incumbent on the individual to use technology to mitigate their hearing condition – rather than a general acceptance that good communication is everyone's responsibility. This singling out or differentiation then becomes an additional burden for the person with the hearing condition to carry, over and above the requirements for them to navigate a world that is full of barriers.

Although Shore's framework[42] (Figure 4) of belonging and inclusion is most often applied to diversity and inclusion measures, specifically in the workplace and generally for gender and race, it is clearly also applicable for all aspects of disability, including the full range of hearing conditions, and across society more broadly than just the workplace.

Soundfair believes that it is incumbent on employers – and society as a whole – to move beyond notions of accessibility and assimilation towards conceptualising and designing in supports for inclusion so that everyone can feel the sense of belongingness that is necessary to thrive and reach their full potential. To achieve this, we must centre lived experience and listen to the full diversity of stories from people living with hearing conditions. As a society, we need to reduce the expectation of assimilation, and make more room for difference.

I was a very tall kid, so I always sat in the back row at school. When I was diagnosed with a hearing loss in year 2, I remember that I wore hearing aids to school and the teacher decided that I needed to sit in the front row. This was the worst thing the teacher could've done because the other kids gave me grief because they couldn't see around me or over me. As a result of the abuse and bullying, I took out my hearing aids and didn't wear them again until I turned 30 and had a particular incident at work that made me realise the hearing aids and access to accurate communication was critical for other people's sake not just my own.
– Sarah

Belonging and inclusion are multidimensional: they encompass the social, political, cultural and economic. The most relevant aspects can be clustered under three interrelated domains: markets, services and spaces, with each representing both barriers to and opportunities for inclusion. Finally, inclusion (or lack thereof) is dynamic, it impacts people in various ways and to differing degrees over time and critically depends on as well as influences people's abilities, opportunities and their sense of dignity within our society. This helps explain why hearing conditions, which are heavily stigmatised and viewed through the medical lens, have such profound social and emotional impacts on people.

It is important to note that while adopting policies and investing in initiatives to foster society-wide inclusion and belonging for people with hearing conditions will certainly benefit individuals, it will also unquestionably benefit society. In 2019–20, the value of the wellbeing loss associated with hearing conditions was estimated to be $21.2 billion, which represents 52% of total costs attributed to hearing conditions. The productivity losses were estimated to be $16.2 billion, or $4,109 per person with a hearing condition, most of which was due to reduced employment of people with hearing conditions ($12.6 billion).[44] It is likely that these figures, as large as they are, are an underestimation of the true costs of the barriers people with hearing conditions face to social inclusion and belonging.

Figure 4. Inclusion framework: the value assigned to uniqueness and the fostering of belongingness work together to create inclusion.[42]

	Low belongingness	High belongingness
Uniqueness is valued	**DIFFERENTIATION** I am different I am uncomfortable	**INCLUSION** I belong I can be myself
Sameness is valued	**DIFFERENTIATION** I am different I am uncomfortable	**ASSIMILATION** I can fit in I have to be guarded

"Diversity is a strategy; Inclusion is a goal; Belonging is a feeling. And a feeling of belonging is the most important goal of all. Belonging is the most powerful diversity and inclusion measure of all: people who feel they belong are six-times more likely to be highly engaged."[43]

6. ASSISTIVE AND LIFESTYLE TECHNOLOGY

Consultation partners Intopia, PC2TP

Looking back at these devices [hearing aids] it is strange to believe that I spent over 15 years feeling too ashamed to wear them, but I can also understand why. I've come to realise that design is a crucial part of this discussion. How could I possibly have been proud to wear something that's very design is centred around the idea that it should be hidden? Beige to match the colour of my skin and then brown to match the colour of my hair.

I remember the first day I saw a man on a train with black airpods in his ears. I knew in that moment it would be a turning point for the hearing aid industry. So simple. Black, not beige. A device that is desirable. It was a bittersweet moment. Sad that I hadn't seen it earlier, but relief for all the generations to come.
– Kate

In many ways, people with hearing conditions have access to better and less stigmatising technology[45] now than ever before. The convergence of contemporary mobile phone features[46] and services that were only recently developed and previously available from specialist providers[47] has been a boon for many.

There is a great deal to be impressed about when it comes to technology and hearing equality. Hearing aids and their associated accessories have come a long way in their processing of sound and now win industrial design awards around the globe; cochlear implants provide a life-changing option for hearing to people who previously would not have such a choice; and hearables are conflating consumer-tech with health tech with mass appeal and scope for wide adoption.

On mobile and tablet platforms, accessibility settings are presented as just another part of the device setup, rather than being a separate section or extra download. This encourages people to customise/improve their experience, even if they do not identify as having a hearing condition or disability.

As seen in some of the most recent technology advances, by integrating accessibility features into contemporary devices, the design factor inherently reduces the stigma. The less medical a technology looks and behaves, the more it becomes just another accessory.

Hearing equality requires the pace of change and destigmatisation of technology to continue; however, we must recognise that technology is ultimately assistive and rarely is it a complete solution. That is, additional factors need to be addressed to ensure that people get optimal use out of technology because it is affordable, accessible, appropriate and addresses their needs. For example, as all aspects of life are moving more and more online and the expectation is for people with hearing conditions to be technologically literate, older Australians are at particular risk of exclusion. There is also a risk that instead of accessibility services being something that are provided, particularly for vulnerable Australians, accessing assistive technology is cast as a personal choice and responsibility.

The best approach is to provide choice. Multiple options to suit different hearing conditions, budget, familiarity/comfort with technology, prior experience, personal preference. When designing and developing assistive technology, input must be sought from as many people with hearing conditions as possible. Age, technology, digital literacy, long- and short-term hearing condition, socio-economic group – all these factors and more influence what people can and will use.

This means that information gathering must be performed via multiple methodologies too – not everyone can access an online survey. Consultation must be multimodal: online forms, paper forms; phone calls, in-person interviews; focus group discussions as well as individual feedback. Moreover, because inclusion requires a diversity of approaches, small groups of technology users should not be ignored in favour of 'maximising numbers' across more popular technologies.

Nowhere is this dichotomy of access/inaccess more stark than in the case of the removal of CapTel from the National Relay Service (NRS). Before 2020, the CapTel phone (a proprietary handset phone, with captions provided on screen by relay officers) proved to be a suitable tool to overcome this barrier when it comes to telephone communication: by simply pushing a button when using the phone, people with hearing loss could read accurate captions while listening to the person on call and voice their responses effectively without having to disclose their condition to anyone.

None of the NRS current services have been demonstrated to provide provide a comparable telephone service for people with hearing conditions that other Australians, without hearing conditions, can access from a landline.

The CapTel handset offered several unique benefits in comparison to the TTY Uniphone. Firstly, Uniphone uses 1970s TTY technology. It has a twin 6mm line scrolling display and requires users to interface either by typing or using walkie talkie type instructions. It also requires the use of two devices: PC/tablet for captions and mobile/phone for voice, the result is both impractical and requires users to be technologically savvy. In comparison, the CapTel handset is a full size, integrated phone with large multiline, variable text height display. Secondly, Uniphone has no voice mail, or text-and-listen SMS relay capability, while CapTel does. Lastly, and most importantly, Uniphone requires in and outbound calls to be placed through the NRS to offer captions, thus obligating users to notify callers of this additional, stigmatising requirement. CapTel, on the other hand, allows users to connect to the captioning service provider directly through the internet, needing only to press a button to request captioning of a conversation. They

can make and take calls directly from their device without the need to disclose their disability before every phone call.

The low uptake of NRS services post 2019 is evidence of the unsuitability of the new options provided. Before 2019, 50% of all call minutes were made through CapTel. After 2019, these calls did not migrate to other NRS services, but disappeared altogether – negatively impacting between 2000 and 4000 users, most of them seniors.

The phasing out of CapTel is instructive. Government failed to engage with user groups when deciding what NRS service-provider to choose, thus imposing a pre-determined outcome instead of seeking to understand the needs of people with hearing conditions. Evidence provided in Senate Estimates showed that CapTel users were not part of the consultation undertaken to issue a Request for Tender for the NRS service in 2018[48], which could explain why the service-provider failed to address the specific needs of these users.

When government-supplied/supported technologies, such as CapTel, are retired or sidelined, the onus must be on government to provide an equivalent or superior replacement technology, along with training or transition services for all affected users. There should also be a sufficient transition period to give users time to adapt to the alternative technologies.

While this is just one substantive example, optimisation can be provided in terms of access and support. It should also be acknowledged that the newest technology is not always the best solution. It is valid to want to continue using older, familiar products even after they have been superseded. Adopting a new technology can represent significant effort, anxiety, cost, interruption and inconvenience, particularly for senior Australians. Some people will want to avoid these negative experiences, even if the long-term gain is intended to be positive.

As highlighted in every chapter of this report, the importance of centring lived experience while, at the same time, understanding the diversity and complexity of people's lives is vital to ensuring equity and inclusion for all Australians. Technology, science and their interface with hearing conditions have changed the lives of many; however, technology, as with all aspects of our lives, is assistive and rarely a complete solution. It is therefore timely to recognise that technology will never overcome all barriers to social inclusion and participation, nor suit all people and thus supports that bridge this gap need greater attention and investment.

7. ENSURING UNIVERSAL CAPTIONING PROVISION

Consultation partner Intopia

You would never build a building and not include ramps. Ramps allow wheelchair users to navigate the world successfully and independently. Ramps also create easier access for parents pushing strollers and travellers rolling heavy luggage. Universal design benefits everyone.

For people with hearing loss, captions are our ramps. We require them for equal access to communications. This is true in public spaces, on television, and online – everywhere that information or entertainment is presented.

Like ramps, captions benefit everyone. They enhance viewer attention and the retention of information. Captions also help non-native English speakers and people with sensory processing disorders. Given all their benefits, captions should be a required and normal part of all communications.

Accessibility costs money. However, the cost cannot be born by the person with hearing loss. We should not have to pay to use the feature we require for equal access.
– Shari

Hearing conditions are heterogeneous and, as such, are experienced and conceptualised within a person's narrative in many markedly different ways. There is no one-size-fits-all accessibility solution for people living with hearing conditions. However, of all the possible interventions to mitigate hearing inequality, the universal provision of closed captioning (including dialogue, sound effects, relevant musical cues and other relevant information when sound is unavailable or not clearly audible) is the closest thing we have to a panacea.

A report by the Australian Communications Consumer Action Network (ACCAN) and Media Access Australia (MAA) in 2011 found that in the previous year, 6.5 million Australians were using closed captions some of the time while watching television.[49] However, the same survey found that few programs offered captions, despite the huge appetite for them. In 2015, MAA also found that Australia's leading commercial video-on-demand and catch-up TV content providers were still failing to provide captions.[50] According to the research, even when content has been broadcast on TV with the appropriate captioning, Australia's online video players (including Foxtel On Demand, Telstra BigPond, Quickflix and Fetch TV, along with the free-to-air TV networks) failed to provide the same captions for online viewers. The increased provision of captions, by default rather than by request, and emphasising the benefits of captioning and transcripts to the broader community, particularly in post-event consumption, should help "sell" captioning to reluctant content creators. There needs to be more emphasis on caption benefits for the entire community. Greater engagement, particularly in noisy and silent spaces, should surely appeal to creators.

Media access is more than simply television. For example, computer games accounted for approximately 10% of all media consumption in 2019.[51] Massively multiplayer online games and streaming platforms, such as Twitch, have become an increasingly important part of young Australians' social lives[52], but without live captioning, they are inaccessible to many. Equally, use of captions across cinemas, stage performances and live performances generally are critical to ensuring inclusion and accessibility not only for Australians with hearing conditions, but also those with sensory processing issues and other accessibility requirements.

In some sectors, such as technology, it is common at in-person conferences to have a large captions screen located on stage beside the

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There needs to be captions in videoconferences and in any audiovisual material and written announcements in public places.
– Courtney

Many people are skipping Insta stories or live because they have been posted without captions. Can you imagine how you miss out on lot of important information that may help you to succeed?

I really appreciate that some thoughtful users who add captions on their stories. Hopefully, there will be more such users! We are not disabled, rather the world is often inaccessible. Captioning is beneficial for everyone:
1. It increases potential viewing figures
2. It's educational, accessible and improves brand image
3. Videos appear higher in search algorithms
4. The Deaf community can access them and feel included!

- Ashton

presenter screen. Attendees can also have the option to view captions on their own devices via a web link. It is past time for such facilities to be normalised. The more we treat captioning as part of the baseline, the question will flip from "why do you have captions?" to "why don't you have captions?"

Most recently, as more people are working from home in response to the COVID-19 pandemic, the challenges people with hearing conditions have faced in participating in online meetings, both socially and for work, have been astounding. Online meeting services can support integrated captioning. Live captioning companies, such as Ai-Media, know how to integrate with these platforms and can support event hosts. We have seen huge growth in the accessibility of auto-captions in video-conferencing software and yet many organisations still do not use this as standard. Here, it is important to recognise the advocacy and international leadership of Shari Eberts, who has helped raise awareness of this issue.

Since 2011, there have been various reports, agreements and parliamentary inquiries (including the Parliamentary Inquiry into Emergency Communications [2010-2013]) which have all indicated the need to increase the frequency and quality of captioning. There have been several wins. For example, there is now a requirement of all free-to-air television to provide captions between 6 and 10.30pm, albeit only on their core channels. However, gaps remain. For instance, there are currently no standards for content shared on social media to meet accessibility requirements.

One of the main problems is that in many cases, the organisation responsible for broadcasting official messages is the one responsible for financing captioning rather than the organisation distributing the message. We have seen across recent government broadcasts where the same media conference broadcast on Facebook via one organisation is captioned, and not via another. Time and time again the same argument is offered by broadcasters and distributors – the cost of captioning is prohibitive. This argument should no longer stand. In an age of equality, accessibility and disability advocacy, it is not acceptable to say 'it's too hard' when there are multiple innovative ways forward and the solutions are beneficial to the entire audience. For instance, while the highest quality captioning available is live captioning (where a highly qualified person creates the content), there is an increasing availability of automatic speech recognition (ASR) technologies that convert speech to text quickly and accurately (which with greater use will increase in quality) and come at a more accessible cost.

Soundfair believes captions should be mandatory on all free-to-air television broadcasting, especially all emergency announcements. Moreover, that all media should be made more inclusive by providing effective captioning. To this end, minimum standards and guidelines are needed that recognise the requirement to ensure the face of the speaker is visible and that the delay between spoken word and caption is minimised.

8. AUSLAN AS A NATIONAL LANGUAGE

Consultation partner Deaf Victoria

My first language is British Sign Language (BSL), but I am also fluent in Auslan and American Sign Language. I started to use BSL when I was about two years old. Mum and I only communicate in BSL and when she asked if I wanted to speak when I was seven, I refused. So she decided that BSL should be my primary language and that is how I developed my Deaf identity. Best present ever. I am so grateful for being Deaf. I have gained insight into sign languages, cultures and communities which guide me through life. Having a strong Deaf identity and positive experience makes my relationship with the rest of the world easier.

– Ashton

When we have to deal with people that have never dealt with someone with a hearing loss or deafness in their life and don't know how to communicate with deaf people that makes it very hard. [...] I think it would be a good idea to for sign language to be more included in school education because it will help people that deal with people who do use sign language. It will make it easier for them. That'd be a good place to start.

– Dale

Auslan is the language of Australia's Deaf community – this simple statement of fact encompasses a complex and fraught history and carries with it a significant weight of interdependencies: ownership, autonomy, lived experience, belonging and pride as well as exclusion, oppression and lack of access, respect and understanding.

There are currently significant barriers to inclusion, both for those with Auslan as their primary language (who want to access the community life that Australia's hearing community takes for granted) and for those with English as their primary language (who are seeking to learn Auslan). Even within families, without significant support, there can be language barriers and inequities, most particularly for Deaf children in hearing families (studies assessing language acquisition in children of Deaf adults [CODA] have shown that bimodal bilingualism does not delay acquisition of the spoken language[53]).

For people with Auslan as their first language, the most effective long-term hearing equality intervention is teaching Auslan in mainstream F-10 schooling. However, at the present time, there are simply not enough qualified Auslan educationalists to make this a reality without encroaching on the already limited educational opportunities available to Deaf children and their families.

The most contemporary data[54] reported that 11,682 Australians use sign language as their primary mode of communication; noting that this number is likely an underestimation due to the intrinsic inaccessibility of the Census survey for people whose primary language is Auslan. To put this into perspective, consider that most languages in the world are spoken by fewer than 10,000 people.[55]

Strikingly, Australia has no official language, making English the de facto standard by default, despite there being a steady decline in the percentage of Australians who speak only English at home since at least 2001.[56] In contrast, our nearest neighbour, New Zealand, recognised Te reo Māori in 1987 and New Zealand Sign Language in 2006. The push for official recognition of First Peoples' languages and a country's sign language have many parallels – there are shared

The idea of Auslan being more prevalent and being taught from a younger age I think is really critical in terms of forming a foundation of understanding, awareness and assistance. The Australian curriculum supports students to develop personal and social capability so that they can learn to understand themselves and others. It talks about developing empathy for others and establishing positive relationships and if you don't have an understanding of a person and their needs it's very difficult to even begin to establish those positive relationships.
– Maxine P

sensitivities around ownership, identity and colonisation by the dominant population group – and, in both, Australia continues to be slow and complacent.

Despite its prevalence and its centrality to Australia's Deaf community, there is consensus that powerful forces are pressuring Auslan use in Australia. The introduction of cochlear implants, mainstreaming in education, and genetic screening may negatively impact the use of Auslan. Johnston[57] projects the possibility that numbers may decrease to the point that a viable language community cannot be maintained.

Auslan as a language of formal study in primary and secondary schools has, historically, not been widely supported in Australia.[58] Inconsistency in the provision of formal Auslan teaching has led to the creation of a dual-pathway national curriculum for Auslan, offering it to learners as both a primary and a secondary language. However, second language teaching in Australia is in decline. The percentage of students studying a foreign language in Year 12 has decreased from 40 per cent in 1960 to around 10 per cent in 2016.[59] Furthermore, those schools that have provided some form of teaching and learning in Auslan have often offered it as informal lunchtime or hobby/interest classes, rather than formal courses of study included in a school timetable. This is indicative of a society-wide attitude that Auslan is akin to a hobby or a trend, devaluing the complexity, sophistication and intellectual capital that the Deaf community own, create and express with Auslan.[60]

There are also difficult issues around appropriation of Auslan by non-fluent, hearing users, particularly in packaging and promoting learning resources for profit. Therefore, recognition as an official language, capacity building of the educational workforce and inclusion of, and respect for, the Deaf community as the owners and guardians of Auslan are vital first steps towards building a society that moves beyond the minimum standard of accessibility towards a culture of inclusion and belonging for all Australians, regardless of their hearing status.

In the last 30 years, many neurocognitive studies have revealed specific functional brain patterns in the learning of a second language.[61, 62, 63] These studies indicate that learning a second language, even if it occurs late in adulthood, leads to both behavioural and neural changes that can approximate the patterns of the first language. These second language experience-induced brain changes, including increased grey matter density and white matter integrity, have been studied in children, young adults and the elderly. They can occur rapidly with short-term language learning or training; and are sensitive to age as well as age of acquisition, proficiency or performance level, language-specific characteristics, and individual differences.[64]

There are ways even I feel limited in English where in Auslan I don't feel limited, and other times the opposite is true.

– Matt

Studies of bilingual CODA have shown 'greater left-hemisphere language lateralisation' compared to hearing monolingual speakers.[65] It has been suggested that this possibly reflects 'the additional recruitment of left-parietal regions in articulating signs in space.'[66] It is, therefore, reasonable to posit that learning Auslan, at any stage in life, will result in beneficial changes to the brain and that these changes can provide a protective mechanism against age-related cognitive decline.[67] Uniquely, in addition to the standard benefits of second language learning, learning Auslan may also aid spatial processing.[68]

Embedding Auslan in schooling for all children will result in lifelong benefits for them, as well as Australia's society as a whole. Although a significant long-term investment, both in capacity building (first) and deployment (second), with consistent, universal and dedicated Auslan teaching throughout F-10, Auslan would be embedded within Australian society within a few generations – increasing opportunities for, and society-wide inclusion of, Australia's Deaf community as well as those with adult-onset hearing conditions.

'Having multiple ways of being, speaking, knowing and doing make for an abundant world. A soup of possibility to share. A network that is stronger because of its multiple parts [...] where there is a slight crack, movement enough to change the shape of the structure, to bring in multiple knowledges, to widen the frame, there is the possibility of life.'[69]

9. TINNITUS: A SIGNIFICANT AND UNADDRESSED HEALTH BURDEN
Consultation partner Tinnitus Australia

As an extrovert, my tinnitus has deeply affected my social life. People that have lived in lockdown will now understand; you want to go out, but you can't. I started being really angry. I broke up with old friends and haven't seen them again for 15 years.

– Jane

Tinnitus is a widespread condition in our society. One in three people in Australia live with tinnitus and one in six experience it constantly.[70] In addition, a study by Hearing Australia, an Australian Government statutory authority, showed that up to 70% of people aged 18–35 years old have experienced tinnitus and 16% experience it more than once a week.[71] And between 70 and 85% of people with hearing loss also experience tinnitus.[72]

Although the leading cause of tinnitus is ageing, other causes include acoustic shock, noise-induced hearing loss, head or neck trauma, ototoxicity, viral and vascular diseases, and a host of other medical and psychiatric conditions. There is mounting evidence that young people are increasingly vulnerable to hearing loss owing to frequent use of earphones and loud music.[73] These possible causes indicate that tinnitus cannot be thought of as a single disease specific to the auditory system, but 'a complex problem that may involve both psychological and neurophysiological mechanisms'.[74]

The impact of tinnitus on a person's life can be devastating, increasing risk of depression, anxiety and even suicidal ideation. The International Tinnitus Journal reported in 2017 that 45% of tinnitus sufferers experience anxiety and 33% have major depression.[75]

People with tinnitus often also experience insomnia, difficulty falling asleep, waking in the middle of the night and early morning, morning fatigue and chronic fatigue.[76] The combination of tinnitus and insomnia has been assessed to give whole-person impairment ratings of up to 50%, depending on the individual's ability to perform regular daily activities, daytime alertness and level of self-care.[77]

Because of the above, the direct and indirect costs of tinnitus to Australian society are difficult to quantify. However, as an indicative figure, a study from the Netherlands estimated an annual productivity cost of €3702 per person with tinnitus and mean societal cost of illness of €6.8bn in 2009.[78] By way of comparison, a top-down study of low-back pain in the Netherlands reported total societal costs of €3.5bn in 2007.[79]

Seven years ago, a roaring sound arrived in my head. It was as if white noise static had meshed with an ear-piercing ringing and it was here to stay. I was filled with the greatest anxiety and fear.

I visited my GP. I visited my ENT. I visited my dentist. I had MRIs, scans, audiology tests and x-rays. In the end, I was diagnosed with mild upper frequency hearing loss as well as 'garden variety' tinnitus. These were the exact words used by my ENT. I was told 'not to stress' (no-one told me HOW to do this) and that it would go away in time and I would stop noticing it (I continue to notice it and it HASN'T gone away). I was prescribed anti-depressants and sleeping tablets, which I didn't take.

I walked away from this process feeling depressed and let down by the medical community. I started to think: "I've had a good life. If I die now, then I will be at peace. If the ringing won't go away from me, then I will go away from the ringing." These were the darkest moments of my life. My thoughts frightened me, but at the same time offered a bizarre type of comfort. I had an answer to the ringing. I had an 'out'. I had control.

– Victoria

The authors concluded: the economic burden of tinnitus to society is substantial and the severity of tinnitus is an important predictor of the costs that patients make to the healthcare system.

With an ageing population, increasing prevalence and no accepted cure, tinnitus is set to cost Australians dear – individually and collectively. Despite this, tinnitus research is currently largely under-recognised and underfunded.

While an encouraging upturn in the volume of tinnitus research being performed is evident – with, of particular note, an increase in funding from the European Commission – it is also apparent that a significant change is needed to deliver progress toward truly effective treatments. To do this, research foundations must be built, including biomarkers, robust outcome measures, and meaningful subtyping of clinical phenotypes. While good progress is being made at the Bionics Institute[80], it will need to be bolstered by interdisciplinary and international work to engage researchers and clinicians along the whole of the translational research pathway.

In addition, the role of the pharmaceutical industry in this endeavour is likely to be fundamental, using experience in clinical trial design, and attracting resources for large scale trials that intentionally address the clinical need.[81]

Finally, as mentioned in Chapter 1, it is vital that the lived experience of people with tinnitus is centred throughout this journey in order to ensure solutions respond to the core needs of people living with tinnitus and that the diversity of those experiences are recognised.

The opportunities for societal financial benefit and the alleviation of tinnitus-related burden and distress are substantial. Long-term investment in research needs to be supported by significant short-term funding to support people who are suffering daily. In particular, there is an urgent need for accessible, reliable and impartial information for consumers on treatment options and a network of trusted multidisciplinary professionals. There are few such high-prevalence conditions that are so poorly resourced in terms of health literacy, professional training, and development and individualised support services.

10. POPULATIONS OF SPECIAL CONSIDERATION

People with hearing loss from CALD and minority backgrounds. People who face more challenges than others, including women – most research does not focus on their voices and experiences directly. We do need more research about voices and experiences of people with hearing loss from diverse backgrounds. But also more social and community inclusion, and more media awareness of people with hearing loss from different cultural or religious backgrounds.

– Ayah

In 2011, I got a call from a judge who was worried an Indigenous woman on trial was not understanding what was happening in court and wanted me to check her hearing. I found that she was profoundly deaf, but knew Auslan. We got an interpreter for her and she was so thrilled that she was able to communicate. After a successful process, she was allowed to leave corrections early and return to community. It's something I'll never forget. After that, I wanted to make sure all people who are hard-of-hearing have the same opportunity that any hearing person has to defend their case.

– Rebecca

The 2016 Inquiry into Hearing Health and Wellbeing of Australia[82] identified several groups with a high prevalence of untreated hearing loss, many of whom struggle with lack of access to the services they need. These include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse communities, the elderly (especially those in the aged care system), veterans, prisoners and people in rural areas.[82]

These populations often intersect in ways that significantly increase their disadvantage. Intersectionality here refers to the ways in which different aspects of a person's identity can expose them to overlapping forms of discrimination and marginalisation. For people living with hearing conditions, and thus already subject to disadvantage, this can mean:

- they find it harder to get the help they need, owing to systemic barriers
- there is an even greater increased risk of social isolation

By overlaying an intersectional analysis, we can see that services should take into consideration the additional barriers inherent in aspects of identity, including: gender; sex; sexual orientation; gender identity; ethnicity; refugee or asylum seeker background; migration or visa status; language; religion; age; mental health; socioeconomic status; housing status; geographic location; medical record; and criminal record.

For instance, the most recent Inclusive Australia Social Inclusion Index report[83] revealed that experiences of everyday discrimination were most common among Aboriginal and Torres Strait Islanders with a disability and that experiences of major discrimination were most common among Aboriginal and Torres Strait Islanders who identify as LGBTI and young people with a disability.

Another clear example of this is that one third of our war veterans, almost 70% of Aboriginal and Torres Strait Islander people, and proportionally more older people, live in rural areas[84], where communities often have insufficient access to hearing health professionals of any kind, and the importance of telehealth and video diagnostic services, which in and of themselves also have accessibility barriers that need to be overcome, are paramount.

Cultural competence is needed across all aspects of society, as family heritage, culture, religious backgrounds should be taken into account as they could influence choices and decisions that affects the person with hearing condition.

Also, we need to include the people with hearing loss themselves in the conversations. Their experiences, their voices. Everyone else is working to support them, but are they really listening to their needs?
– Ayah

I moved to Melbourne by myself at 14 from a rural area where I was living entirely in the hearing world. When I had dinner with my host family, who were also Deaf, it was beautiful to see, for the first time, the same mannerisms that I had, the same way of being. I discovered I had Deaf culture inherently within me.
– Catherine

Equally, certain occupations, such as musicians and industrial workers (before occupational health regulations reduced noise exposure), are at risk of hearing conditions, including tinnitus. Of these at-risk occupations, the professions most underserved is notably farmers and agricultural workers, as the National Rural Health Alliance has reported that over half the farmers in Australia are likely to suffer from hearing loss due to noise exposure, and of course they are likely to be further disadvantaged by the intersection of their rural location and the very nature of their work precluding time away to access metropolitan services.

As we understand from the social model of disability, factors beyond the individual can be actively and passively disabling. The additional labour required on the part of people with hearing conditions to participate in education and all aspects of community life is considerable and is an additional heavy burden to be carried. In rural areas where 'strength in numbers' does not apply, this can result in substantial isolation and social exclusion. For individuals, and most especially children, who have hearing conditions and live in rural areas, beyond issues of access to services, this inaccessibility of community is felt keenly. Exclusion can manifest in many ways, but perhaps most striking – and underpinning all other aspects of inaccessibility – is language deprivation and with it a lack of cultural belongingness.

Soundfair's community enablement programs – including the Hearing Bank, which provides low- or no-cost hearing health care and devices to people in Victoria – have been developed in response to the requirements of, and in partnership with, underserved communities of need, but many other such initiatives are needed across Australia.

Institutional and government responses for high-need groups have traditionally led to a proliferation of specialised and 'targeted' programs and services. We question, though, whether this approach has squarely addressed the structural and systemic barriers experienced by people with hearing conditions in our richly diverse society.

Only by centring lived experience and developing services through programs of co-creation within communities, in parallel with driving far-reaching programs of social change, can these well-recognised intersectional disadvantages truly be overcome to the benefit of all.

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CONCLUSION

Creating a fair world for people with hearing conditions requires interconnected sweeping changes across our society and our systems. To achieve a future where hearing conditions are no longer a limitation, collective action is needed to understand the lived experience of people with hearing conditions and embed this knowledge into society, from policy design through to industrial design.

'By failing to create inclusive opportunities for people with lived experience, we are missing out on the expertise and insight they can bring into the change-making process. Lasting and transformational change is not possible without them.'[85]

- Listen to and understand people who live with hearing loss and hearing conditions to ensure effective and human-centred design and decision-making at every level. This responsibility belongs to all of us.
- Embrace and support Auslan as a national language with the same openness and energy as we do for any first language.
- Apply the same level of consideration to acoustic needs in workplaces, institutions and public buildings as physical accessibility needs.
- Take a social determinants of health approach to public health initiatives, informed by contemporary research, lived experience and human-centred design principles. Specific and targeted co-created programs must be developed for minority and disadvantaged populations.
- Engage with consumer experience during the development of new hearing technology and support consumers' right to service and device choice and control.
- Recognise that investment in inclusion and hearing diversity is an investment in our social capital and economy.
- Make free-to-air television freely accessible for people with hearing loss through minimum accessibility standards and mandatory captioning for emergency announcements.
- Prioritise funding for tinnitus services and research.

We acknowledge that these changes are extensive, but our recent shared experience of rapid and agile society-wide change in response to the COVID-19 pandemic has shown that this type of evolution is possible. We can pivot towards inclusion as organisations and governments. Individually, we can be change-makers and innovators.

Soundfair would like to acknowledge the daily commitment to inclusiveness and achieving hearing equality by everyone within the hearing sector from its leaders, to its researchers, service providers and policy makers. Soundfair is grateful to all those who contributed to this report, particularly those who shared their stories.

Soundfair believes in a fair world for people with hearing conditions.

Will you join us?

REFERENCES

1. Smart, JF. The power of models of disability. Journal of Rehabilitation. 2009. 75(2), 3–11.

2. Dembo, T. Some problems in rehabilitation as seen by a Lewinian. Journal of Social Issues. 1982. 38, 131–139.

3. Hahn, H. The political implications of disability definitions and data. Journal of Disability Policy Studies. 1993. 4, 41–52.

4. Zola, IK. Disability statistics, what we count and what it tells us. Journal of Disability Policy Studies. 1993. 4, 9–39.

5. Shakespeare, T. The social model of disability. In L. J. Davis (Ed.), The disability studies reader (2nd ed., pp. 197–204). 2006. New York: Routledge.

6. Smart, JF. The power of models of disability. Journal of Rehabilitation. 2009. 75(2), 3–11.

7. Smart, JF, & Smart, DW. Models of disability: Implications for the counselling profession. Journal of Counselling and Development. 2006. 84, 29–40.

8. Geels, F et al. The Socio-Technical Dynamics of Low-Carbon Transitions,Joule, Volume 1, Issue 3, 2017, https://doi.org/10.1016/j.joule.2017.09.018. Accessed 28 November 2020.

9. Fraser F, Glass J. Bridging the fields of feminist and systems practice: Building ecosystems for gender equity. The Systems Sanctuary September 2020. Downloaded from http://systemsanctuary.com/researchsystemspractice. Accessed 28 November 2020.

10. Burke, K. 1931. Counter-statement, Berkeley, CA: University of California Press.

11. Young A et al The Lived Experience and Legacy of Pragmatics for Deaf and Hard of Hearing Children Pediatrics Nov 2020, 146 (Supplement 3) S304-S309.

12. Charon, R. 2006. Narrative medicine: Honoring the stories of illness, New York and Oxford: Oxford University Press.

13. Frawley, P. Lived experience of people with disabilities: Shaping policy and practice. Australian Institute of Family Studies. 13 October 2020. Available at: https://aifs.gov.au/cfca/2020/10/13/lived-experience-people-disabilities-shaping-policy-and-practice. Accessed 6 February 2021.

14. Australian Institute of Health and Welfare. Social determinants of health. Australian Institute of Health and Welfare, 2020. Available from: https://www.aihw.gov.au/reports/australias-health/social-determinants-of-health. Accessed 6 February 2021.

15. Barr C, Hogan A, Westhaven L. Hearing loss in the over 50s: is there a case for a public health approach? (Part I – A social epidemiology of hearing loss). Public Health Res Prac. 2021; In press.

16. Barr C, Hogan A, Westhaven L. Hearing loss in the over 50s: is there a case for a public health approach? (Part II - Equity in access to, and benefit from, hearing services). Public Health Res Prac. 2021; In press.

17. Solar O, Irwin A. A conceptual framework for action on the social determinants of health – social determinants of health discussion paper 2. Policy and Practice 2010. WHO. Geneva.

18. Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. The public health approach to violence prevention. Available at: https://www.cdc.gov/violenceprevention/publichealthissue/publichealthapproach.html. Accessed 29 November 2020

19. Satcher D, Higginbotham EJ. The public health approach to eliminating disparities in health. Am J Public Health. 2008;98(3):400-403. doi:10.2105/AJPH.2007.123919

20. Australian Commonwealth Government. Roadmap for Hearing Health. https://www1.health.gov.au/internet/main/publishing.nsf/Content/roadmap-for-hearing-health Accessed 28 November 2020.

21. Bauman, Hansel. "DeafSpace: An Architecture toward a More Livable and Sustainable World." Deaf Gain: Raising the Stakes for Human Diversity. University of Minnesota. 2014.

22. See https://www.washingtonpost.com/news/magazine/wp/2019/09/12/feature/the-rise-of-deaf-architecture/ Accessed 29 November 2020.

23. Edwards, C; Harold, G . DeafSpace and the principles of universal design. Disability and Rehabilitation, 2014 36(16), 1350–1359. doi:10.3109/09638288.2014.913710

24. Mace R. Universal design: housing for the lifespan of all people. Rockville (MD): Department of Housing and Urban Development; 1988.

25. Ostroff E. Universal design: the new paradigm. In: Preiser W, Ostroff E, eds. Universal design handbook. New York (NY): McGraw-Hill; 2001:1.3–1.12.

26. Heylighen, A. Sustainable and inclusive design: a matter of knowledge? Local Environ 2008;13:531–40.

27. Heylighen A, Rychtáriková M, Vermeir G. Designing spaces for every listener. Univ Access Inf Soc 2010; 9:283–92.

28. Green Building Council Australia. What is Green Star? Accessed 1 February 2021. https://new.gbca.org.au/rate/green-star/.

29. International WELL Building Institute. WELL v2™ pilot. Q1 2021. Accessed 1 February 2021. https://v2.wellcertified.com/v/en/concepts

30. Trethewey A Reproducing and resisting the master narrative of decline: Midlife professional women's experiences of aging. Management Communication Quarterly 2001 15(2): 183–226

31. Speer S and Potter J The management of heterosexist talk: Conversational resources and prejudiced claims. Discourse & Society 2000 11(4): 543–572.

32. Dick P The politics of experience: A discursive psychology approach to understanding different accounts of sexism in the workplace. 2013 Human Relations 66(5): 645–669.

33. Albrecht GL American pragmatism, sociology and the development of disability studies. In: Barnes C, Oliver M and Barton L (eds) Disability Studies Today. 2002 Cambridge: Polity, 18–37.

34. Mik-Meyer, N. Othering, ableism and disability: A discursive analysis of co-workers construction of colleagues with visible impairments. Human Relations. 2016. 69(6), 1341–1363.

35. Shakespeare, T. Disability rights and wrongs. 2007 New York, NY: Routledge. Shakespeare, T. Disability rights and wrongs. 2007 New York, NY: Routledge.

36. Shapiro, JP. No pity. 1993 New York, NY: Times Books. Shapiro, JP. No pity. 1993 New York, NY: Times Books.

37. Winn, S. "Employment Outcomes for People in Australia Who Are Congenitally Deaf: Has Anything Changed?" American Annals of the Deaf 152, no. 4 (2007): 382-90. http://www.jstor.org/stable/26234465. Accessed 28 November 2020.

38. Kuenburg A, Fellinger P, Fellinger J, Health Care Access Among Deaf People, The Journal of Deaf Studies and Deaf Education, Volume 21, Issue 1, January 2016, 1–10, https://doi.org/10.1093/deafed/env042

39. Ubido J, Huntington J & Warburton D. Inequalities in access to healthcare faced by women who are deaf. Health & Social Care in the Community, 2002, 10: 247-253. https://doi.org/10.1046/j.1365-2524.2002.00365.x Accessed 29 November 2020.

40. Dirth, TP; Branscombe, NR. Disability Models Affect Disability Policy Support through Awareness of Structural Discrimination. Journal of Social Issues. 2017. 73(2), 413–442.

41. See, for example https://edition.cnn.com/videos/us/2020/09/18/baby-hearing-aids-hears-mom-first-time-moos-pkg-vpx.cnn. Accessed 29 November 2020.

42. Shore, L. et al. Inclusion and Diversity in Work Groups: A Review and Model for Future Research. Journal of Management 37 (2011): 1262-1289.

43. Bersin, J. Why belonging is such a big issue in business today. https://joshbersin.com/2020/08/why-belonging-is-a-big-issue-in-business-today. Accessed 2 February 2021.

44. HCIA Hearing For Life The Value Of Hearing Services For Vulnerable Australians March 2020. https://www.hcia.com.au/hcia-wp/wp-content/uploads/2020/02/Hearing_for_Life.pdf Accessed 2 February 2021.

45. See, for example, https://abilitynet.org.uk/news-blogs/9-useful-apps-people-who-are-deaf-or-have-hearing-loss Accessed 29 November 2020

46. See, for example, https://support.apple.com/en-au/HT210070 Accessed 29 November 2020.

47. See, for example, https://techcrunch.com/2016/07/12/furenexos-soundsense-is-a-simple-open-source-gadget-that-helps-deaf-people-stay-aware-of-their-surroundings/ Accessed 29 November 2020.

48. Official Committee Hansard – Senate Environment and Communications Legislation Committee Estimates 22 Oct 2019, page 100.

49. Analysis of ACCAN captioning survey, conducted in October 2010 available from https://accan.org.au/files/Reports/ACCAN%20captioning%20results%20analysis%20FINAL.pdf Accessed 29 November 2020.

50. Available from https://mediaaccess.org.au/sites/default/files/files/MAA%20Video%20on%20Demand%20report.pdf. Accessed 29 November 2020.

51. Comparing Consumption Patterns In Gaming, Movies/TV, And Music. Parsec July 2019. Available from: https://blog.parsec.app/comparing-consumption-patterns-in-gaming-movies-tv-and-music-26f50088da1d/ Accessed 29 November 2020.

52. See, for example, https://www.smh.com.au/technology/aussie-twitch-streamers-become-refuge-for-young-and-lonely-during-lockdown-20200821-p55o5l.html Accessed 2 December 2020.

53. Toohey, Erin N., "Phonological Development in Hearing Children of Deaf Parents" (2010). Honors Scholar Theses. 153. https://opencommons.uconn.edu/srhonors_theses/153 Accessed 2 December 2020.

54. Australian Bureau of Statistics 2016 Census accessed via https://identitycomms.com.au/2017/07/key-statistics-2016-australian-census/ Accessed 29 November 2020.

55. Austin, PK; Sallabank, J . "Introduction". In Austin, PK; Sallabank, J (eds.). Cambridge Handbook of Endangered Languages. 2011. Cambridge University Press. ISBN 978-0-521-88215-6.

56. Australian Bureau of Statistics 2001 Census QuickStats https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2001/quickstat/0#:~:text=In%20the%202001%20Census%20for,decrease%20from%2082.0%25%20in%201996, Accessed 26 January 2021.

57. Johnston TA. "W(h)ither the Deaf Community? Population, Genetics, and the Future of Australian Sign Language." Sign Language Studies 2006. 6 (2): 137–173.

58. Australian Curriculum: Auslan; Introduction. Available from https://www.australiancurriculum.edu.au/f-10-curriculum/languages/auslan/introduction/. Accessed 3 December 2020.

59. Mayfield, T. 'Australia's 'Spectacular' Failure in Languages' https://pursuit.unimelb.edu.au/articles/australia-s-spectacular-failure-in-languages First published on 6 July 2017. Accessed 3 December 2020.

60. See, for example, Kirkness J. COVID has brought Auslan into the spotlight, but it would be wrong to treat the language as a hobby or fad. https://theconversation.com/covid-has-brought-auslan-into-the-spotlight-but-it-would-be-wrong-to-treat-the-language-as-a-hobby-or-fad-151667 First published 25 January 2021, accessed 26 January 2021.

61. Abutalebi J, Cappa SF & Perani D. (2005). What can functional neuroimaging tell us about the bilingual brain? In J. F. Kroll, & A. M. B. De Groot (Eds.), Handbook of bilingualism: Psycholinguistic approaches (pp. 497e515) New York: Oxford University Press.

62. Costa, A., & Sebastian-Galles, N. (2014). How does the bilingual experience sculpt the brain? Nature Reviews Neuroscience, 15, 336e345.

63. Hernandez, A. E. (2013). The bilingual brain. Oxford, UK: Oxford University Press.

64. Li, P., et al., Neuroplasticity as a function of second language learning: Anatomical changes in the human brain, Cortex (2014), http://dx.doi.org/10.1016/j.cortex.2014.05.001

65. Gutierrez-Sigut, E. et al. Language lateralization of hearing native signers: A functional transcranial Doppler sonography (fTCD) study of speech and sign production. BRAIN AND LANGUAGE (2015), 151 23-34.

66. Campbell, C. 'Past, Present, Future' in Morgan G (Ed) Understanding Deafness, Language and Cognitive Development: Essays in Honour of Bencie Woll. John Benjamins Publishing Company 2020.

67. Antoniou M, Wright SM. Uncovering the Mechanisms Responsible for Why Language Learning May Promote Healthy Cognitive Aging. Front Psychol. 2017 Dec 15;8:2217. doi: 10.3389/fpsyg.2017.02217. PMID: 29326636; PMCID: PMC5736569.

68. Keehner M, Gathercole SE. Cognitive adaptations arising from nonnative experience of sign language in hearing adults. Memory & Cognition 35, 752–761 (2007).

69. Lana Nguyen, writing about the decision to cut the Vietnamese bilingual program at Footscray primary school, https://hyphenatedbiennial.art/MONOCULTURE Accessed 6 December 2020.

70. https://www.healthdirect.gov.au/tinnitus#:. Accessed 20 August 2020

71. Williams W & Carter L. Tinnitus and leisure noise. International Journal of Audiology. 2017 56:4, 219-225.

72. Characterization of Tinnitus in Different Age Groups: A Retrospective Review, Jamil Al-Swiahb, Shi Nae Park, Noise Health. 2016 Jul-Aug; 18(83): 214-219. Accessed 6 October 2020

73. Hearing Health Sector Committee (2019) Roadmap for Hearing Health,

Soundfair is grateful for the support of a sponsor at the HearMe Report launch event:

AGPS, Canberra p.12.

74. Colucci, DA. Insomnia and Tinnitus: A Worrisome Cycle, The Hearing Journal: June 2017 - Volume 70 - Issue 6 - p 43,45.

75. Ziai K, Moshtaghi O, Mahboubi H, Djalilian HR. Tinnitus Patients Suffering from Anxiety and Depression: A Review. Int Tinnitus J. 2017; 21(1): 68-73 Viewed Oct 12, 2020.

76. Minen MT, Camprodon J, Nehme R, Chemali Z. The neuropsychiatry of tinnitus: a circuit-based approach to the causes and treatments available. J Neurol Neurosurg Psychiatry. 2014 Oct;85(10):1138-44. .

77. Rondinelli, RD, Eskay-Auerbach, M. AMA guides sixth: guides to the evaluation of permanent impairment, sixth edition. 2009. [Chicago], American Medical Association.

78. Maes IHL et al. Tinnitus: a cost study. Ear and Hearing. 2013. 34(4), 508-514.

79. Lambeek, LC et al. The trend in total cost of back pain in The Netherlands in the period 2002 to 2007. Spine. 2011. 36, 1050–1058.

80. See https://www.bionicsinstitute.org/tinnitus Accessed 29 November 2020.

81. McFerran, DJ et al. Why Is There No Cure for Tinnitus?. Frontiers in Neuroscience. 2019 13(), 802.

82. House of Representatives Standing Committee on Health, Aged Care and Sport, 2016 Still Waiting to be heard, Report on the Inquiry into the Hearing Health and Wellbeing of Australia, AGPS, Canberra p.59. Accessed 3 December 2020.

83. https://www.monash.edu/msdi/news-events/news/social-inclusion-index-2019-20-report

84. National Rural Health Alliance (2014) Hearing loss in Rural Australia fact sheet, NRHA, Canberra Accessed 3 December, 2020.

85. Sanju B. 'Lived Experience Leadership: Rebooting the DNA of Leadership' Clore Social Leadership 2019. http://www.lexmovement.org/wp-content/uploads/2019/07/LEx-Report-Final-1.pdf. Accessed 6 December 2020.

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