DEAFNESS FORUM AUSTRALIA

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2 MAY 2023

Future trends in hearing healthcare.

Are classroom holograms: a sign language future?

Essential hearing access: Telecoils and hearing loops.

A new story of self and society.

Elephant in the room — a cure for hearing loss.

Prof David McAlpine revisits his outstanding 2022 Libby Harricks Memorial Oration address. He asks, do we need a cure or is what we have enough to solve the problem?

“I'm going to say that the answer is — we need a cure, and the reason is because there is much of hearing loss we can't prevent — even so-called preventable hearing loss.”

If we look, or perhaps listen, to the future—is the future for hearing health 'bright'—I hesitate to say 'loud'? Will hearing health improve over time? Will hearing healthcare become 'mainstream'? Can we deliver a national agenda for preventing hearing loss. Could we scale that up globally? Or are we on the path to declining hearing health? Is preventing hearing loss beyond us and do we simply have to accept the inevitable? What does our future sound like?

To help us on that one, we can look to the World Health Organisation’s 2021 World Report on Hearing. It confirms what we knew — hearing loss is a chronic health condition that manifests right across the life course *in utero* to late age. And it's increasing globally at a time when vision loss is declining. It affects 1 in 6 of us, and will rise to 1 in 4 by 2050, a product of our ageing societies, yes, but also our life-style choices. The WHO also estimates the annual cost of untreated hearing loss is close to 1 trillion dollars in lost productivity and the like. And despite it being the most common sensory deficit — comorbid with other health issues in later life — hearing loss still has the status of an orphan disease in terms of ring-fenced research funding, public-health profile, and other initiatives. To date, its known consequences on speech and language, life-chances, cognition, mental health—have failed to shake the nation, and indeed the globe, out of its torpor when it comes to preventing hearing loss and protecting our listening abilities over the life course. Why is this the case? Are we not cutting through when it comes to messaging the dangers of hearing loss? Is anyone listening — communities, governments, healthcare systems, businesses, regulators? And what is our message on prevention? Are we trying to prevent hearing loss itself, or should we focus simply on preventing the consequences of hearing loss? More radically, might we better seek a cure for hearing loss — should we be trying to reverse it, say, through biological means? Are those lifestyle choices contributing to hearing loss 'hardwired', and therefore the only way forward is for us to develop 'a pill for deafness'? And how does the concept of prevention work in the charge towards over the-counter, or OTC, hearing aids? Hearing loss is increasingly part of the business model for major tech companies. Will cheaper hearing aids — if they even are cheaper — get them off the hook for their negative behaviours when it comes to our hearing health?

We need a cure

Do we need a cure or is what we have enough to solve the problem? I'm going to say that the answer is — we need a cure, and the reason is because there is much of hearing loss we can't

prevent — even so-called preventable hearing loss. But finding, and funding, a cure won't be easy. Therapies for hearing loss are a hard problem. We don't have the diagnostic toolbox, or an effective delivery system for bringing drugs to the inner ear, though cochlear implants are an idea choice in my view. Importantly, we don't understand the patient populations — their genetics or their phenotype — required to make effective therapies and make therapies effective. We also know that the money invested into the science of hearing and deafness is much less than is invested into other health conditions including vision loss.

We know that Libby Harricks — whom this oration honours — was a pioneering advocate for people with hearing loss, but we also know she died of breast cancer at the terribly young age of 52 in the late 1990s. At that time survival rates for breast cancer were not as good as they are today. What changed? First, prevention. You can't easily prevent the **onset** of breast cancer, but you can prevent its progression through timely diagnosis — a combination of personal knowledge and behaviour and better diagnostic tools. Sound familiar? Second, the possibility of a cure. You can't manage breast cancer, you must get rid of it — new drug therapies, new combination therapies, augmented by radio- and surgical interventions. People survive breast cancer today because their breast cancer—diagnosed in a timely manner — is eradicated, not because it is managed. The broader point I want to make is that once you have evidence of an effective therapy, money pours into that disease model. This kickstarts new diagnostics, changes behaviours, engages public health agendas, gets commercial, government, and clinical partners talking. And it doesn't matter what the therapeutic intervention is going to be: it could still be hearing aids, it could still be a cochlear implant, it could be a combination of all these things—therapies, hearing aids, implants.

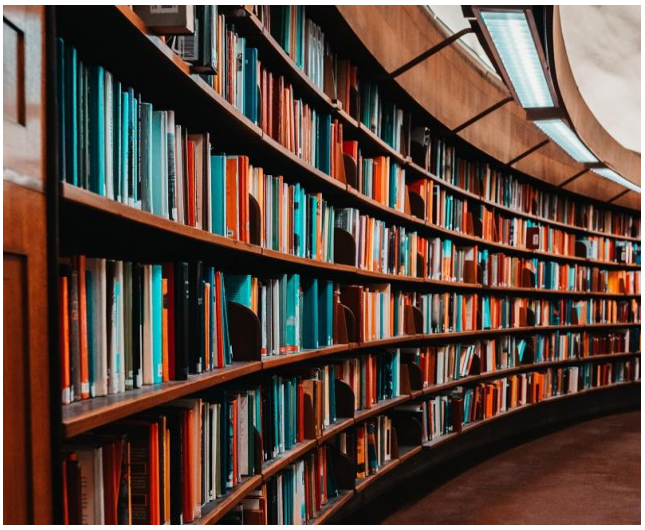
Success in finding a potential cure for hearing loss raises all boats. People take effective drugs for breast cancer **and** have radiotherapy **and** have surgery.

Australia is one of a handful of countries that could achieve the unity of purpose required to deliver a cure for hearing loss. So, I believe we should be working together to deliver the next generation of hearing therapies—genetic, biological, pharmaceutical. These will become effective tools in our armoury not just for curing hearing loss but informing the public, empowering them to take charge of their hearing health, driving prevention campaigns, and showing that prevention and cure, together, will transform the hearing health and the wealth of our nation and the globe.

The author of this article, David McAlpine is Distinguished Professor of Hearing, Language & The Brain, Dept of Linguistics, and Academic Director of Macquarie University Hearing.

Read his complete Libby Harricks Memorial Oration here.

ChatGPT and related techs will change hearing care.



ChatGPT is a computer program that can understand and generate text like a human. It has been trained on a huge amount of text – think of vast libraries - so it can respond to questions and have conversations in a way that seems natural.

Hearing care, like many other fields, is being revolutionised by advancements in technology, and one of the most impactful innovations in recent years is Chatbot-based technologies, such as ChatGPT. These cutting-edge technologies have the potential to transform how hearing care is delivered, making it more accessible, efficient, and personalised.

Improved Accessibility

One of the major challenges in hearing care, particularly in developing countries is accessibility. Many people with hearing loss face barriers in accessing hearing care services due to factors such as geographical location, financial limitations, or limited availability of qualified hearing care professionals. ChatGPT and related technologies can bridge these gaps by providing remote and virtual hearing care services. Chatbots can offer online consultations, assessments, and screenings, eliminating the need for physical visits to hearing care clinics. This can greatly benefit individuals who live in rural or remote areas, or those who have mobility issues, enabling them to access hearing care services from the comfort of their own homes.

Personalised Care

ChatGPT and related technologies can provide personalised care for individuals with hearing loss. By leveraging artificial intelligence (AI) and natural language processing (NLP), Chatbots can analyse data about a person's hearing health, including their hearing history, lifestyle, and communication needs, to generate customised recommendations and solutions. Chatbots can also provide real-time feedback on hearing aid usage, helping users optimise their device settings for their specific needs. This personalised approach can greatly enhance the effectiveness of hearing care interventions, leading to improved outcomes for individuals with hearing loss.

Education and Empowerment

Chatbots can deliver educational content about hearing health, prevention of hearing loss, and proper use and maintenance of hearing aids. They can provide guidance on communication strategies, hearing protection, and coping strategies for managing hearing loss in various social settings. This knowledge empowers individuals to take control of their hearing health and make informed decisions about their hearing care.

Efficient Workflow

ChatGPT and related technologies can streamline the workflow of hearing care professionals. Chatbots can handle routine tasks such as scheduling appointments, managing patient records, and providing basic information, freeing up hearing care

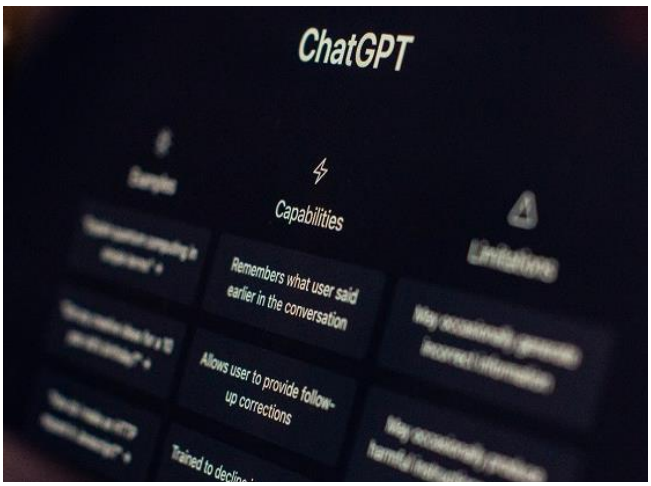
professionals to focus on more complex and specialised care. Chatbots can also facilitate remote monitoring of hearing aids, allowing hearing care professionals to remotely adjust hearing aid settings and troubleshoot issues, reducing the need for frequent in-person visits.

Continuous Monitoring and Predictive Analytics

ChatGPT and related technologies can enable continuous monitoring of hearing health, leading to early detection of changes in hearing status. Chatbots can collect data from connected hearing aids, such as usage patterns, listening environments, and feedback from users, which can be analysed using AI and predictive analytics (Privacy alert!). This data can provide valuable insights into a person's hearing health and help detect changes in hearing status over time. Early detection of changes in hearing can trigger interventions, such as adjustments to hearing aid settings or referrals for further evaluation, leading to better hearing outcomes.

Transformative

ChatGPT and related technologies are poised to revolutionise hearing care by improving accessibility, providing personalised care, empowering individuals with hearing loss, and enabling continuous monitoring and predictive analytics. As technology continues to evolve, we can expect ChatGPT and related technologies to play a pivotal role in shaping the future of hearing care delivery.



A new way to regulate aged care.

The Department of Health and Aged Care is developing a new model for regulating aged care. It proposes a number of changes, including how providers enter the sector, their obligations, and strengthened monitoring and enforcement powers for the sector regulator.

This new model is in response to the findings of the Royal Commission into Aged Care, including cases of neglect, abuse, and mistreatment of elderly residents.

The Department of Health and Aged Care is seeking feedback on its latest consultation paper: Full consultation paper or a summary.

Your feedback will be used to refine the proposed regulation model and the new aged care law. You can read more here.

Deafness Forum Australia members want to change how hearing health is treated in Aged Care settings.

People in aged care have a much higher prevalence of hearing and communication impairment than those living in the community, contributing to further barriers to their psychosocial wellbeing. They are more likely to have complex health conditions combined with their hearing loss, such as dementia, vision loss and physical impairments, requiring a program that can provide specialist care and support.

Addressing the hearing needs of people in aged care is a complex and challenging problem. It is poorly done at the moment and needs a new approach. The free market has been unable to respond - servicing this group is financially unattractive to commercial audiology service providers.

The solution is obvious, but difficult to implement - the Government should manage aged care hearing through its Hearing Services **Community Service Obligation** program.

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Outlook to future trends in hearing healthcare.

Interview with Brent Edwards, director of National Acoustic Laboratories.

The National Acoustic Laboratories, aka NAL, provides world-leading hearing research and evidence-based innovation to improve hearing health and transform the lives of people with hearing difficulties. It is a part of Australian Hearing.

NAL collaborates with organisations around the world to innovate on novel solutions to hearing health services and technology, conducts sophisticated validation trials on treatment benefit, and provides insight into the needs of people with hearing loss and clinicians who treat them. NAL's research findings are published in leading peer-reviewed journals and its solutions are used worldwide.

Question: What technological advances will change hearing healthcare in the future?

Brent Edwards: As we've seen with the explosion of interest in ChatGPT, artificial intelligence (AI) is going to transform every industry, including the field of hearing healthcare. How, exactly, remains for the innovators to figure out and will depend on what unmet needs AI can fill.

We are looking at AI and machine learning in a number of ways, including its use in identifying that someone has hearing loss from their speech pattern and its use in identifying whether someone is at risk of progressive hearing loss.

What big changes are coming for Audiology hearing service delivery?

The introduction of over-the-counter hearing aids in the US is forcing a conversation on the value of services delivered by traditional models. There is strong evidence, including data from NAL, that people are more successful with their hearing devices with assistance from a hearing care professional, but different people have different needs - needs for different technology solutions, services and delivery channels.

What will this change look like for the profession of audiology?

The most important improvement to hearing healthcare in the next few years will be diversity in channels, services, and technology solutions available to people who need hearing help.

Our traditional approach will continue to thrive, but audiology will need to adapt to a more personalised approach to hearing service delivery rather than a one-type-fits-all approach that has been the norm in our field for decades.

What would be your recommendation to decision makers in preparation for these changes?

As new approaches develop to meet the unique needs of different populations, the number of people accessing hearing health help will also

increase in the future. Decision makers will need to consider carefully when and how to transform their modes of engagement and service depending on the needs of their clients and the business. It is equally important to meet the needs of hearing healthcare professionals to be able to address different hearing challenges in more diverse ways.

What are the important priorities that NAL is focused on in the coming year?

NAL is focused on exploring the emerging approaches to hearing healthcare, including the upcoming changes mentioned in the previous questions. Our goal is to provide insights and develop solutions with and for hearing healthcare partners. We have a history of co-developing and validating innovative technology for partners, and we foresee an urgent need for this given the emerging novel approaches to hearing technology, hearing services that includes teleaudiology and self-treatment, and channels for hearing healthcare delivery. We are also focused on engaging with thought leaders on the ways that people are changing in their listening behaviour, such as whether hearing loss (and hearing technology) affects people's ability to communicate when videoconferencing on platforms such as Zoom.

If NAL had unlimited resources, what would it do first?

NAL would expand into an international virtual research conglomerate that allows the many amazing researchers from a variety of disciplines around the world to collaborate on the top research challenges facing hearing healthcare. We would also fund Grand Challenge competitions to get other researchers focused on the same hearing healthcare challenges that we are focused on at NAL. Combining NAL's team of hearing healthcare experts and its ability to direct research towards high-impact solutions with the deep research and innovation talent that exists around the world would be amazing.

Read the NAL Annual Impact Report 2022.

NDIS future reset.

The Minister for the NDIS Bill Shorten announced a reset to the National Disability Insurance Scheme. He said there would be:

- More staff employed to crack down on fraud
- Longer NDIS plans so people won't have to keep proving they still have a disability
- Improvements to Supported Independent Living, support for people who need assistance to live at home
- Try to make sure mainstream services like health, education, and transport work together with the NDIS.

Comment by Deafness Forum

The strategic issue is attaining universal inclusion of all people who need the support of the NDIS – only 5 percent of people with hearing difficulty are currently eligible. It means ongoing advocacy, policy changes, and the support of the taxpayer.

Jane from Tasmania (name changed to "protect against victimisation because it happens") said, "When it comes to hearing loss the bar for access appears far too high. People with a "moderate" hearing loss are extremely impacted by their hearing loss and unable to participate in the community without hearing assistance yet the severity of their disability goes without support as it is described as only a moderate disability. I'm wondering if the descriptors used are harming deaf people and preventing us from accessing the level of help that we need?"

Other concerns

NDIS supports cease when a person enters hospital, hospice or residential aged care.

If a participant becomes a prison inmate they lose NDIS supports at a time that they are probably most needed in their lives.

There is the gross unfairness of excluding people from the Scheme who acquire a disability after their 65th birthday.

Classroom holograms: a sign language future?

Holograms could become the next wave of communications.

Pupils from America's oldest higher learning institution for Deaf students are testing how holograms might pair with America Sign Language communication.

Communications company Proto developed two-metre-tall units. Proto's software captures a user's actual physical scale and nuances like shadows and reflections. On each end is a set of encoders and decoders that communicate only with each other through cloud software. The person projected as a hologram into the Proto box can see the people on the other side and hear anything they say.

"The feeling of presence, the feeling of physically being there, creates almost a chemical reaction within the body that allows the people sharing that experience to feel connected," founder and CEO David Nussbaum told Technical.ly.

Gallaudet University's Chief Bilingual Officer Laurene Simms said holograms are better for sign language because of the 3D nature of the language, whereas Zoom is more 2D. In the same way that vocal intonations can change a message in English, facial expressions are essential in ASL. Body language is also necessary to communicate fully; certain words build on other signs, which is easier to see in 3D.

Simms said that Gallaudet University had experimented with a GoPro-type technology for 3D interaction: ultimately it was less cost-effective than the hologram tech. How Gallaudet University would incorporate holograms into everyday teaching and campus life is yet to be seen.

"With the hologram, there are so many possibilities as far as being able to interact. You don't have to be physically present at that place, and you can be somewhere else and still have more people at different places watching and interacting with one another."

What about avatars?

Avatars or animated characters are computer-generated visual representations that can mimic sign language gestures.

Signing avatars are not (yet) regarded as replacements for human sign language interpreters because they lack the full range of expression and cultural nuances that human sign language interpreting provides.

Avatars are useful tools in straightforward communications, it's just that they may fall short in complicated situations.

Deafness Forum news.

If you are reading this One in Six on Tuesday 2 May, we are today representing our sector and presenting the views of members at the **Australian Government Community Roundtable on the Early Years Strategy**. The roundtable has been convened by both the ministers for Social Services and for Early Childhood Education. Ann Porter AM, the CEO/founder of Aussie Deaf Kids is at the meeting on our behalf. The Government's Early Years Strategy aims to create a whole-of-Commonwealth approach to help ensure children aged five and below and their families and communities have the tools and supports in place to thrive.

We are preparing a submission to the NDIS Review Taskforce that was formed in response to Minister Bill Shorten's promise of big improvements to the Scheme.

In the health sphere

We are helping the Department of Health and Aged Care obtain citizen feedback on its latest consultation paper for a new model for regulating aged care.

We were guests at the Health Minister's National Press Club address in Canberra.

Later this week, we are in Adelaide for a conference about the National Preventive Health Strategy, a whole-of- government approach to assist in making Australia a more equitable and healthy place to live; followed by a national Health Peaks Roundtable.

Coming to Perth

The Board of Deafness Forum has meetings in Perth at the end of this month. On Saturday 27 May there will be a lunch for our members and friends at Telethon Speech and Hearing, then some brilliant presentations that will get you thinking. We have invited WA's Disability Minister Don Punch, Paul Higginbotham from Earbus Foundation of WA, Prof Mel Ferguson at Curtin University, Prof David McAlpine from Macquarie University, the Department of Health to speak about the Hearing Services Program, and more. We will be sending invitations this week and next. If you don't hear from us but would like to attend as our guest, send an email to steve.williamson@deafnessforum.org.au

Hospital cochlear implants problems in SA and now Queensland.

There have been problems with Children's cochlear implants in hospitals in two states. You can read our reports here–

- Cochlear implant crisis at Adelaide Children's Hospital
- Two stood down as QLD health investigates cochlear crisis

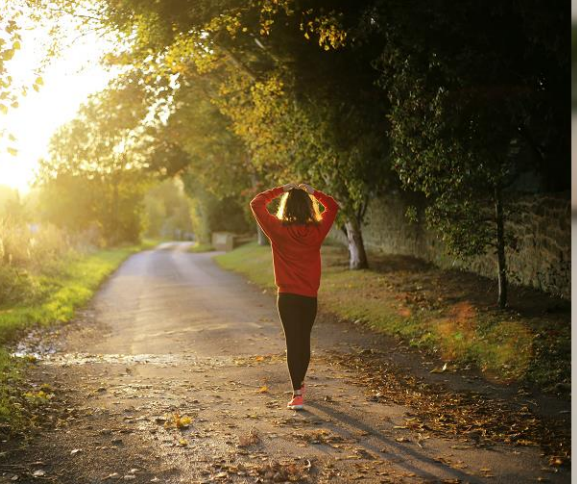
We are talking about it with our members including UsherKids Australia, Aussie Deaf Kids, Parents of Deaf Children.

We reached out to Australian College of Audiology, Independent Audiologists Australian, First Voice Australia, Audiology Australia, Australasian Newborn Hearing Screening Committee, Deafblind Australia and Deaf Australia. As we receive their statements, we will add them to this post on our website and on Facebook.

There are two separate state government investigations currently underway, but independent investigations may be necessary to earn community trust. Without wishing to prejudice the findings of these investigations, it raises concerns about a systems failure.

We will keep our community posted as we work through if & how we can constructively contribute to the investigation and systems improvements.

The immediate priority is supporting the families and children, and if you go to the web links at the beginning of this article you can read what we have recommended on their behalf.



How a ‘pathologically modest’ nation broke new ground on wellbeing.

In 2015, Wales became the first country in the world to legislate for the wellbeing of future generations. The Wellbeing of Future Generations Act followed an inclusive national discussion about the kind of country people want for generations to come.

By Sophie Howe, former Future Generations Commissioner of Wales U.K., for Pearls and Irritations.

People told us they wanted Wales to be more equal and healthier. They wanted more cohesive communities, a vibrant culture and language, and to act responsibly on the global stage. They wanted Wales to be resilient and prosperous. And they wanted prosperity to be about people and planet, not just economic growth.

Alongside these seven goals we legislated five ways of working for government. Leaders and decision-makers must take account of the long-term, prevent problems occurring or worsening. They must take an integrated and collaborative approach, and involve citizens of all ages and diversity – and “involve” is more than just “consult” or “inform”.

We also established a Future Generations Commissioner to act as guardian of the interests of the unborn.

Whatever point, issue or policy you start from, it is vital to make long-term connections and identify the sweet spots that promote long-term wellbeing. That means breaking down organisational silos to deliver wellbeing for everyone.

I could tell you about the good things; the champions using the act to change the way they procure, the doctors reforming city transport, the engineers greening our cities and the economic agencies focused on sustainable food chains.

Rather than listing achievements, I will emphasise this – a legislative framework alone does not drive change. Without strong oversight that produces supportive and challenging interventions, the system will not change.

Everyone needs to be involved, and wellbeing goals must underpin everything a country does to avoid being lost in the next political initiative. We had to build new ways from scratch and there are many barriers to overcome.

To those in the policymaking world advocating for long-term, connected, holistic solutions, never give up. Our actions add up, and our decisions will play out for decades – sometimes centuries – to come.

This article is an extract of the John Menadue Oration that Ms Howe delivered for the Centre for Policy Development on 18 April 2023. You can watch Sophie Howe’s full speech here.

Your ear can detect the start of Alzheimer's.

A new 'ear-EEG' device can potentially be used for the early detection of neurodegenerative disorders.

The project, called Progression Assessment in Neurodegenerative Disorders of Aging (PANDA), is a collaboration between Rigshospitalet University, Denmark's Aarhus University, and MedTech company T&W Engineering.

The aim of the project is to develop and test a small earbud-like experimental device that can detect early signs of Alzheimer's or Parkinson's disease.

So, how does it work? Unlike traditional sleep-monitoring systems, which require you to stay in a clinic with multiple electrodes attached to your body, the ear-EEG device is much more comfortable for use at home. It monitors electrical activity in the brain by measuring tiny voltage changes on the skin surface within the ear canal. It is also equipped with an oximeter for measuring blood oxygen levels, a microphone for monitoring respiration and heart rate, and a thermometer for measuring body temperature.

The ear-EEG technology provides a more accurate representation of your natural sleep patterns and is less intrusive than conventional monitoring systems. People who are at risk of Parkinson's or Alzheimer's could use the ear-EEG to track their sleeping patterns for several days or weeks. By doing so, early signs of the diseases can be detected years before the first problems begin to occur.

Aarhus University's Prof. Preben Kidmose said, "Alzheimer's and Parkinson's are diseases that creep up over many years.

"In the project, we're going to try to identify signs of the two diseases 10 to 15 years before the first problems begin to occur, and if we can, far better treatment options will be possible."

Currently, diagnosis of Alzheimer's or Parkinson's disease often comes too late for effective treatment options. But if the PANDA project is successful in detecting the disorders earlier, it could lead to more effective treatment options for people, allowing them to live better and longer lives.

The ear-EEG device can allow researchers to examine patients in their everyday lives and track changes in sleep patterns and treatment effects. This makes the technology a good screening tool that can be used at home like a blood pressure metre.

There are links between hearing loss and cognitive decline.

There is strong evidence to suggest that hearing loss is linked to an increased risk of developing Alzheimer's disease or other forms of dementia.

Studies have found that people with hearing loss are more likely to experience cognitive decline and have a higher risk of developing dementia compared to those with normal hearing. It is thought that hearing loss may lead to changes in the brain that contribute to cognitive decline, such as increased cognitive load and social isolation.

Telecoils and loops.

As hearing aids technology continues to develop, there has been debate about what is "the best" form of wireless connection in public venues for hearing augmentation.

On the one hand, there's hearing loops and on the other Bluetooth. Let's understand more about their differences and the pros and cons.

A hearing aid with a telecoil, also known as a T-coil or T-switch, is designed to work with hearing loop systems (Audio Frequency Induction Loops or just 'loops' for short), which are installed in theatres, auditoriums, railway and bus stations, places of worship, and other public spaces. The system uses a wire loop that generates a magnetic field, which is picked up by the telecoil in the hearing aid. This allows the wearer to receive audio signals wirelessly from the sound source that is connected to the hearing loop system, such as a microphone or sound system.

Not all hearing aids are equipped with Bluetooth capabilities, and not all Bluetooth-enabled devices are compatible with all hearing aids. Telecoils and hearing loops, on the other hand, are widely supported in many hearing aids, making them a reliable and consistent option for hearing assistance in various settings. Every major brand of hearing aids has models with the telecoil.

Hearing loops are generally preferred as they require no self-disclosure on the part of the hearing aid wearer; no request for a 'device' which must then be worn; and no ongoing management in terms of charging and cleaning by venue managers.

While there are always situations where Bluetooth and other solutions may be preferred it's not necessarily a preferred technology, more a best fit for a particular use case.

Bluetooth technology does not directly connect hearing aids with hearing loops. But some hearing aids have Bluetooth functionality that allows them to connect to accessories that are intermediary devices, which then be connected to a hearing loop system.

A new Bluetooth protocol has been released. Bluetooth LE will work with Auracast transmitters but there are no known hearing aids fitted with working Bluetooth LE. Also, there are no Auracast transmitters on the market. It will be many years before all hearing aids are fitted with Bluetooth LE, and many more years before all hearing aids currently in use are replaced with hearing aids with Bluetooth LE.

The **International Hearing Access Committee** – members include the International Federation of Hard of Hearing People, the Hearing Loss Association of America and the European Federation of Hard of Hearing - says "The rights of hearing aid and cochlear implant users to access (hearing loops) must be continued and maintained during this period of technological change and shall not be compromised by the promise and overly optimistic expectations of a future technology development."

The International Deafness Symbol shows that a hearing loop has been installed in a public place.

The Australian Government Hearing Services Program.

Under the Commonwealth Department of Health and Aged Care's Hearing Services Program, a hearing services provider is required to offer you a hearing device which has a telecoil in the first instance – a large number of the fully subsidised hearing devices have a telecoil fitted.

You can then choose a device without a telecoil if you wish. Your hearing clinic can talk to you about how to use the telecoil feature on your hearing device.

Citizen future: a new story of self and society.

Are you a 'subject', a 'consumer' or a 'citizen'? The authors Jon Alexander and Ariane Conrad argue that our societies need a new narrative, and it starts by ditching the stories sold by authoritarianism and consumerism.

The doom-laden headlines of our times would seem to indicate there are two futures on offer.

In one, an Orwellian authoritarianism prevails. Fearful in the face of compounding crises – climate, plagues, poverty, hunger – people accept the bargain of the "Strong Man": their leader's protection in return for unquestioning allegiance as "subjects". What follows is the abdication of personal power, choice, or responsibility.

In the other, everyone is a "consumer" and self-reliance becomes an extreme sport. The richest have their boltholes in New Zealand and a ticket for Mars in hand. The rest of us strive to be like them, fending for ourselves as robots take jobs and as the competition for ever-scarcer resources intensifies. The benefits of technology, whether artificial intelligence, bio-, neuro- or agrotechnology, accrue to the wealthiest – as does all the power in society. This is a future shaped by the whims of Silicon Valley billionaires. While it sells itself on personal freedoms, the experience for most is exclusion: a top-heavy world of haves and haves-nots.

Yet despite the bandwidth and airwaves devoted to these twin dystopias, there's another trajectory: we call it the "citizen future".

Over the past few years we have been researching a book called Citizens, in which we propose a more hopeful narrative for the 21st Century. In this future, people are citizens, rather than subjects or consumers. With this identity, it becomes easier to see that *all of us are smarter than any of us*. And that the strategy for navigating difficult times is to tap into the diverse ideas, energy and resources of everyone. This form of citizenship is not about the passport we hold, and it goes far beyond the

duty to vote in elections. It represents the deeper meaning of the word, the etymological roots of which translate literally as "together people": humans defined by our fundamental interdependence, lives meaningless without community. It's a practice rather than a status or possession, almost more verb than noun. As citizens, we look around, identify the domains where we have some influence, find our collaborators, and engage. And, critically, our institutions encourage us to do so.

Seizing this future, however, will depend on seeing and embracing a bigger story of who we are as humans. So, how do we do that?

While writing our book, we have encountered myriad examples of the citizen perspective. Look beyond the headlines, and you soon discover a global, cross-sector phenomenon – and what may look like isolated examples are connected by common themes.

Consider governance. The city of Paris has just approved the creation of a standing Citizens' Assembly that guides policy, and has committed to distributing more than €100m (£84m/$101m) a year through participatory budgeting. Mexico City has crowdsourced a constitution for its nine million people. In Reykjavik, game designers have built a participatory democracy platform that has brought hundreds of people into the operation of the city.

The citizen future is gaining a foothold in the world of business, too. Many businesses now aim to create "stakeholder value" not just "shareholder value". The former CEO of Unilever, for example, set the company a goal to be "net positive" contributors to society. And some of the biggest and some of the fastest growing companies in the world are experimenting with crowdsourcing and crowdfunding. General Electric, for example, routinely crowd-sources solutions to some of its key challenges. And the Body Shop cosmetics brand has instituted a pioneering Youth Collective as part of its governance structure.

Much more is going on below the conventional radar, rooted in business models that are built to spread rather than scale. Platform co-operativism (where Airbnb and Uber face competition from companies like Ride Austin and Peepl Eat, whose customers are also their owners) and equity crowdfunding (blurring the line between shareholder and customer and powering established businesses like Brewdog and new kids on the block like Yuup) are examples of such underlying models.

Not for profits, Deafness Forum included, take note.

The citizen future is also taking shape in the nonprofit sector, as organisations reimagine themselves as enablers of citizen-led movements. In the UK, organisations like the Royal Society for the Protection of Birds (RSPB) the World Wide Fund for Nature (WWF), and Friends of the Earth **are re-orienting their strategies towards participation, coming in behind campaigns rather than starting their own**. Greenpeace USA is embracing **a more collective approach**, seeking to be, in the words of chief executive Annie Leonard, "a hero among heroes".

At the same time, community groups are rejecting the old models of aid and charity, and finding local solutions instead. Community share offers, for example, are a UK innovation that makes it simple for local people to invest in their own communities. In Grimsby in northern England, a group called East Marsh United have just successfully completed a £500,000 community share offer that will enable them to buy 10 houses, create local jobs to refurbish them, and then let them out as a social landlord, creating a sustainable revenue stream for the rest of their operations.

And if there is one citizen who stands out above all in this whole story, it is Kennedy Odede: a man who started with a football and street theatre in one of the slums of Nairobi and has grown his organisation Shining Hope for Communities to a scale where it enabled over two million slum dwellers to support one another.

The challenge is not that the citizen future is difficult to find or complicated to articulate. It is simple, rooted in deep truth, and emerging everywhere. But it is hidden because every day people are telling themselves other stories of society, and their role within it. Critically, institutions reinforce these other narratives, taking up the oxygen of imagination, making them seem like the only possibilities.

We propose that one of the most pervasive deep stories is the "consumer story". It goes like this: our role as individuals is to pursue our own self-interest, on the basis that will aggregate to the best outcomes for society. We define ourselves through competition. Along the way, our choices represent our power, our creativity, our identity – they make us who we are. Every organisation and institution, from businesses to charities to government, exists to offer these choices. All are reduced to providers of products and services. This consumer story is how we get to Future B and its escapes to Mars, billionaires with disproportionate power, and extreme inequality.

As for Future A, this Orwellian future corresponds to the return of the "subject story", as in "subjects of the King". In this story, the leader knows best, charting the way forward. The rest of us are innocents, ignorant of important matters. This deal becomes more attractive the greater the danger, which is why this story is making a comeback today. Governments and organisations that arise from the subject story are paternalistic and hierarchical, with a supposedly superior few at the top of the pyramid.

The subject story preceded the consumer story. It was the dominant story for centuries, shaping the interactions of the majority of humanity, from at least the 1600s, up until it crumbled over the course of the two world wars of the 20th Century. The consumer story, as inevitable as it often seems, only arose from the ashes of the subject, and has only been humanity's dominant story for the past 70 years.

By contrast with the subject, the consumer story seemed to promise a golden dream, with its broader distribution of resources and wealth, its replacement of aristocracy with meritocracy. But now the consumer story is collapsing under the weight of its own contradictions, and threatens to take us down with it.

We have such pervasive inequality that it threatens the safety of everyone (even the wealthiest), while the story says that our primary responsibility is to compete to hoard more. We have ecological breakdown, while the story insists that our identity and status rely upon ever-increasing consumption. We have an epidemic of loneliness and mental health challenges, yet the story tells us we stand alone.

Citizens of tomorrow

It is the old stories that are broken, not humanity.

The fall of the subject story and the rise of the consumer are proof that change at the level of a deep story is possible. The citizen story can replace the consumer, as the consumer replaced the subject.

In order to realise the citizen future, we must neither accept what we are given as the only possibility, as subjects do; nor throw our toys from the pram when we do not like what is on offer, as consumers do. As citizens, we must

propose, not just reject. We must establish a foundation of belief in one another. We must start from where we are, accept responsibility, and create meaningful opportunities for each other to contribute as we do so. We must step up, and step in. As the pioneering architect and designer Buckminster Fuller wrote: "You never change things by fighting the existing reality. To change something, create a new model that makes the existing models obsolete."

The process of rewriting the story is demanding for all of us. When the cracks appear in a long-held belief, it causes anxiety and pain. As the certain world is replaced by great uncertainty, the risk is that we cling to what we know more than ever. The gravitational pull of the familiar exerts itself, no matter how dysfunctional we know the familiar to be. When we recognise this, we can hold the space for this collapse and this transition more gently, more respectfully, with greater care. Otherwise, anxiety flips into anger, and people lose trust and faith in one another and their institutions. The result risks becoming a vicious cycle: as the challenges of our time intensify, we trust our leaders less, the outlets we seek in our dissatisfaction – such as anti-scientific beliefs, or conspiracy theories – become more extreme, and our leaders in turn trust us less. They become more inclined to stick to what they know – the old stories – denying us agency as they engage in futile attempts to solve the challenges for us, without us.

This is why the most essential work in this time should be a reimagination of what leadership is. If those in positions of power act as if there is nothing wrong, our mistrust in them deepens still further. Leaders who build the citizen future start by acknowledging uncertainty, sharing questions and challenges *with* us rather than providing (or failing to provide) answers *for* us. They create opportunities for us to participate and contribute. They cultivate so-called "safe uncertainty": acknowledging unknowns, not denying them. They don't pretend to know exactly what the future looks like. They do reassure us that we will best build it by working together.

In order to survive and thrive, we must step into the citizen future. We must see ourselves as citizens – people who actively shape the world around us, who cultivate meaningful connections to their community and institutions, who can imagine a different and better life, who care and take responsibility, and who create opportunities for others to do the same. Crucially, the leaders of our institutions must also see people as citizens, and treat us as such.

If we can step into the citizen future, we will be able to face our myriad challenges: economic insecurity, ecological emergency, public health threats, political polarisation, and more. We will be able to build a future. We will be able to *have* a future – together.

The authors

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