Can:Do 4Kids Bright Start group, making loud pig cookies for Loud Shirt Day

Our voices

firstvoice
THE FUTURE IS HEAR

April 2022

From the Chair

"The time has come", the Walrus said, "to talk of many things . . ."

It is over 2 ½ years since I became Chair of First Voice and at the end of March, I passed the baton on to my colleague Dr Jim Hungerford, CEO of The Shepherd Centre, (I will remain on the Board).

The challenges

It has been a challenging, but rewarding, time. COVID turned the world upside down – with social distancing; masks; lockdowns; restrictions on gatherings and face-to-face therapy; vaccination requirements; contact tracing; and multiple pressures on staff working from home, home-schooling their children and supporting parents and grandparents. COVID has impacted our service delivery models, fundraising, finances, human resources and advocacy, research and innovation activities.

The upside

As reported in previous editions of **Our Voices,** and in the newsletters and other publications of First Voice member centres, has been stronger parent/family engagement and a raft of new initiatives in tele-practice including tele-(AVT) therapy, tele-audiology and webinars and online education and training programs for families and staff. In countries where access to specialist early intervention therapy is limited or non-existent, these developments in tele-practice hold huge potential to bring Auditory Verbal Therapy/Listening & Spoken Language therapy to thousands of children with hearing loss who might otherwise never have accessed it.

Global action – at last

Chief among the other "many things" to be mentioned is the fantastic new global effort to increase awareness of, find solutions to, and marshal resources for preventing, treating and managing hearing loss/deafness in children and adults in every country of the world. Key to this has been the **WHO World Hearing Report** (2021) packed full of data, bold recommendations and a clarion call to action and the subsequent establishment of the **WHO World Hearing Forum**; Cochlear Limited's leadership to support the establishment of the **Cochlear Implant International Community of Action (CIICA)** with an impressive membership of 78 organisations and 368 individuals from 47 countries; the **Alexander Graham Bell Academy's Global Matters Committee** (2017) and other initiatives including our own revision of First Voice strategic goals and objectives and expansion of our overseas membership.

Sustainability

This edition's theme is Sustainability – could anything be more appropriate? Mostly this is seen in financial terms but there are other important aspects such as *client caseload size; specialist clinical staffing* (noting widespread scarcity of AVT/LSL © professionals); *service adaptability and continuity* (as demonstrated during Covid); and increasing public, political and professional awareness of the extraordinary communication, education, social and economic benefits of evidence-based early childhood speech and language therapy. In regard to the latter there is a very long way to go!

Mark Fitzpatrick
Chair First Voice

OUR STRATEGIC PILLARS:

Advocacy; Research; Clinical Outcomes; Sustainability; Mutual Support

In This Issue

From the Chair

Key Aspects of Sustainability

Centre Theme Stories

- Support Beyond the Screen
- Online Telehealth
- Music Matters
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- Going Virtual Amid Lockdowns
- Childhood Hearing Gets a Boost in Africa
- Telepractice Study

Centre Highlights

30 Years of Hear and Say

Hearing Awareness Week 2022

Carel du Toit Centre, South Africa

Key Aspects of Sustainability:
Caseloads; Staffing and Stakeholder Awareness

Strong financials, including reliable income, managed costs, liquid assets and a strong balance sheet, are clearly fundamental to the long-term sustainability of any business including specialist disability service providers. However, there are other significant aspects to the sustainability of specialist speech and language early intervention services.

CASELOAD: Most Listening and Spoken Language (LSL) centres start small and are built around a few very committed families determined to assist their deaf child in learning to talk like everyone else in their families. Characteristically these only manage to survive in the early years through huge family sacrifices, never-ending community fundraising, philanthropic grants and perhaps, in time, government assistance. Usually all this is carried out entirely by such families but in other cases CI surgeons and other professionals have also been a driving force. This certainly makes life easier especially if a hospital, university or school is providing administrative and clinical support – but it is no guarantee of ongoing sustainability.

Examples of family/community-initiated centres within First Voice include the Cora Barclay Centre in Adelaide (now part of the Can:Do Group); Taralye in Melbourne (now part of NextSense) and The Shepherd Centre in Sydney. Examples of CI surgeons involvement include The Hearing House in New Zealand and Corel du Toit in South Africa and AVUK was started up by an AVT specialist. All these approaches are evident within First Voice membership.

It can take years to build a client caseload large enough to be financially viable and support the range of specialist professionals required to achieve optimal outcomes for client families and their children. Depending on where you are in the world (given the variability of birth rates), in a city of 1 million people there may only be 20 to 30 deaf babies born each year and, in the absence of newborn hearing screening and established referral pathways, only a fraction of these will find their way to a specialist EI service provider. Small caseloads are a major barrier to sustainability even for the very best services and survival may necessitate merging with a larger, stronger organisation (as with the Cora Barclay Centre and Taralye), or expanding and diversifying their hearing and listening services (e.g. into child and adult audiology, CI implant programs and paediatric speech pathology), or diversifying into other childhood disability and developmental areas such as autism disorders, developmental delay and complex learning difficulties.

SPECIALIST STAFFING: Another ongoing threat to sustainability is the scarcity of registered Auditory Verbal Therapists (AVTs) who are the very highly specialised lead therapists in EI listening and spoken language programs. To fill these roles, most centres need to recruit speech pathologists, deaf educators and audiologists and support them through their 3-year training with the Alexander Graham Bell Academy.

AWARENESS: Specialised speech and language services provided by First Voice member centres and other organizations also remain vulnerable without a reasonable degree of professional, political and public knowledge and understanding of what they do and the outcomes they routinely achieve. ***First Voice research shows that 94 % of Australians do not know that children born deaf in Australia can achieve speech, language and education outcomes equal to or better than those of children hearing with typical hearing of the same age.*** First Voice is actively involved in raising public awareness, political advocacy and informing relevant health and education professionals through published academic research and clinical conferences. But there is much work to be done in all these areas to achieve the security that comes with an informed public and key decision-makers.

Telethon Speech & Hearing:
Support Beyond the Screen

Covid-19 has brought a whole new dimension to so many lives across the world. In particular, for families of children with hearing loss already navigating an unexpected path, the pandemic has raised even more questions along their journey: Will my child be able to attend their necessary appointments? Will we still be able to access services? Can they have their scheduled surgery? However, thanks to technology and a dedicated team, Telethon Speech & Hearing has been able to provide ongoing early intervention supports to families despite the physical challenges that Covid-19 has imposed.

Groups are an important component of our program, providing families with a much-needed sense of community and support. We, therefore, wanted to ensure families had ongoing access to this resource by giving them a space to connect online. Our multidisciplinary team used teletherapy to engage with families – answering questions, discussing goals, providing support, and modelling listening and spoken language strategies online – which could then be carried over to the home environment by parent and child. After sessions, we encouraged families to remain online for a virtual coffee. This allowed many parents to build social relationships and connect with one another – continuing one of the benefits our families get from our groups.

In addition to online sessions, our multidisciplinary team also developed educational resources, such as short video clips around ear infections and troubleshooting devices, that have been useful in continuing to engage families and assisted them to support their child at home. Topics and resources are based on parent feedback, providing a flexible family- centred approach that meets the needs of the child and whole family.

Honing our ability to use teletherapy during COVID means that now we can help families access the regular support they crave at different times, including when a parent or sibling may be sick, or just not able to come to our centre.

In a very challenging time, there is not always a perfect solution to ensure continuity of service for families. However, we are fortunate to have access to technology which does ensure the sustainability of services for families, even when we are unable to come together in person.

Telethon Speech & Hearing: Outpost School Support program

The Shepherd Centre: Online Telehealth services

The Shepherd Centre: Online Telehealth

With COVID-19 restrictions causing organisations to quickly pivot their service delivery, The Shepherd Centre was well placed to continue providing quality care through Online Telehealth. With over ten years' experience servicing our Tasmanian and rural NSW families this way, our clinicians are skilled and confident in engaging children online. Importantly, children who have accessed our Online Telehealth services achieve the same outcomes as children who have attended centres in person.

'The reassuring part was that it was business as usual for us, the sessions just went straight online. Families still had access to their team and I think they trust that we are still there for them because we do online very well. We've been doing it for many, many years,' says Child and Family Counsellor Natalina Canon.

The Shepherd Centre's model of empowering parents to be their child's teacher also lends itself naturally to Online Telehealth. Parents continue to receive expert advice in paediatric hearing loss, guiding them to support their child's listening, literacy, language and social development using everyday equipment and daily life routines.

We are also always happy to hear that Online Telehealth more often allows both parents to be actively involved in a child's journey to speech and sound. Tasmanian father Stuart said, "Interactive Online Services made sense in terms of availability, flexibility and frequency of sessions. It also allowed me to call in from work while Caroline and Ted were at home and his specialised team were in Sydney. That potential for us all to take part together was very important."

Learn more about our Online Telehealth services here.

NextSense: CE Chris Rehn on Sustainability

Off the back of Hearing Awareness Week (HAW) and World Hearing Day, it's a good time to talk sustainability. It's important we stay the course when it comes to raising awareness of the impact hearing loss has on Australians. Partnering with like-minded organisations with shared goals is how we will achieve this, and it was fantastic to see this in action at the Australian Hearing Hub last week (3 March) and during HAW.

We take our responsibilities of being around for the next generations of Australians seriously and have invested in good governance to that end. After all, a child that is implanted today and needs support may need support for many years to come—our services are for the whole of life.

The sustainability of NextSense is thanks to long term relationships with government, donors and a variety of funding sources that have enabled us to ride out storms such as the pandemic. For us, sustainability is not only about fiscal responsibility but strategic partnerships, growing and evolving to meet the needs of people with hearing and vision loss, constantly innovating (as we do through NextSense Institute and service delivery) and a clear roadmap to the future—our strategy. Core to our roadmap is the NextSense brand, designed to drive our 160-year-old organisation into the future. It's also our people—people who stood by us in trying pandemic times and enabled us to pivot services to offer tele-practice (thanks to the existing tele-practice expertise in-house). And it's about investing in the future of our sector by educating the next generation of experts.

NextSense client journey - Read Valentina's story here

Medicare funding for remote programming of auditory devices contributes to our ongoing sustainability, as does our move to Macquarie University. The relocation of our largest education and service centre at North Rocks to Macquarie University next year heralds a new era for NextSense. It brings with it opportunities for deeper partnerships and knowledge sharing. We see this as a critical investment that will make sure we continue to thrive and help for the next 160 years.

The Hearing House: Going Virtual Kept The Hearing House and Families Connected Amid Lockdowns

The restrictions imposed during New Zealand's Delta outbreak in August 2021 made it particularly difficult for many clients of The Hearing House who received implants leading up to the lockdown - and the 16 switched on through it.

The Talaciro family was among those who anxiously awaited news on whether six-month-old Leo could undergo cochlear implant surgery. It was soon decided important elective surgery could go ahead at Gillies Hospital, so Leo's surgery was rebooked.

Restrictions meant Mum Charlotte spent an anxious wait at home, while Dad Tony braved face at Leo's bedside during the three-hour operation.

A week later, Leo's implants were switched on at The Hearing House with mum and dad by his side, and in front of a screen with his wider family watching on via Zoom.

"It was something fun and positive in what's been a challenging journey," Charlotte says.

While the virtual experiences have been unusual and the road harder than normal, The Hearing House CEO Dr Claire Green says the resilience and determination of these people will result in great outcomes.

As well as utilizing Zoom for switch-ons, with most of the team working from home, The Hearing House also delivered many appointments and therapy sessions virtually.

Speech and Language Therapist (SLT) Stephanie ran fabulous weekly Zoom playgroups with a variety of fun and interactive themes. She and fellow SLT Victoria also created a suite of Tip of the Day videos to help whānau develop language for children under five years of age. Visit their YouTube channel here.

The Hearing House: Charlotte and Leo

Can:Do 4Kids: Music Matters – No Matter What Comes

It is no secret that the COVID pandemic has created lots of changes in recent times and our need to be able to pivot to online services was one of them. Although we have provided online individual therapy for quite some time, the previous lockdowns meant that we also needed to adapt some of our group programs the same way.

Our music group, Music Matters was one of those and required some quick training about delivering to a group of children and families rather than an individual. We also had to consider the audio signal in a group, as well as ask families to mute their microphones when the group was singing (except for the Music Matters leader), and we had to communicate with families prior to the session to let them know what props were required.

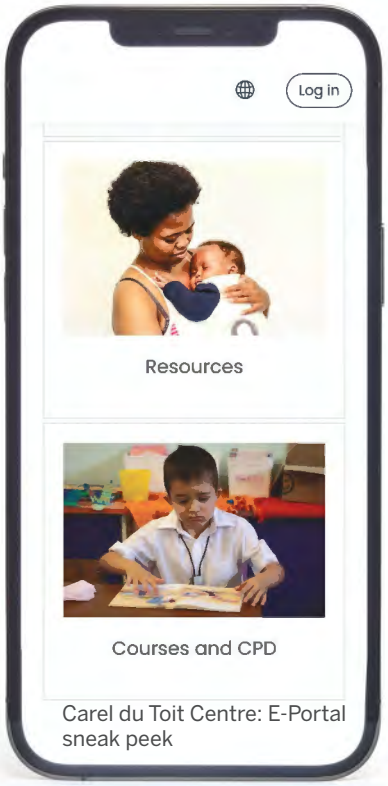
Fortunately, throughout the sessions the children were able to remain engaged and were still able to contribute song ideas.

The ability to quickly adapt to online group therapies allowed the continuation of the routine that we would normally follow in Music Matters, ensuring that families had a consistent service and maintained important connections for children and parents throughout the lockdown. It also means that if another lockdown were to happen, we will be ready to make sure that no child misses their vital therapies.

Carel du Toit Centre: Childhood Hearing Gets a Boost in Africa

Covid-19 brought many challenges but also forced organisations, such as us, to think out of the box to expand our communications strategy. For the staff and children at the Carel du Toit Centre and Trust, social distancing and lockdown forced us to find new ways to communicate remotely with the same efficiency and effectiveness as we do in face-to-face situations.

This was the birthing of our E-learning hall for childhood hearing, which promises to become a valued archive of our existing material and a great learning tool for Africa.



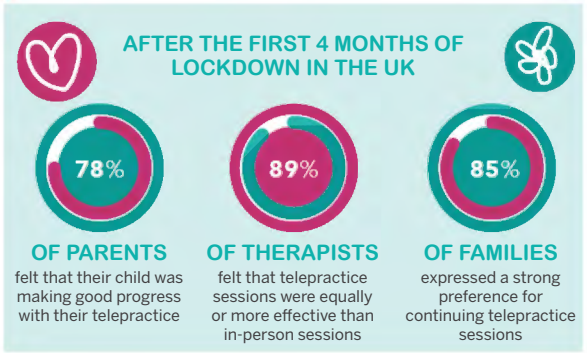
Carel du Toit Centre: E-Portal sneak peek

Our e-learning strategy was catapulted from a vision into a reality as WhatsApp, Zoom, videoing and sharing using all kinds of online and distance communication suddenly became commonplace during lockdown.

Currently we are nearing the date for our soft launch dubbed 22 for 22 = 22 valuable lessons on hearing loss in 2022. This launch will provide the much-needed boost that is needed to raise awareness about childhood hearing and to offer solutions and guidance to many 1000's of families and professions on the continent.

We look forward to taking virtual hands with families in need of support, professionals in the field who will benefit from our specialist training, and the community. As we look to the future, we see trained hearing screeners from the communities working in their own neighbourhoods to identify hearing impairments early and, with this detection, positively change the lives of these children.

For the staff and children at the Carel du Toit Centre and Trust, social distancing and lockdown forced us to find new ways to communicate remotely with the same efficiency and effectiveness as we do in face-to-face situations.



AVUK: Telepractice Study

AVUK launched their Position Paper which uses the latest international research to outline the current landscape of the Auditory Verbal (AV) approach and paediatric deafness. It includes how social policy, hearing technology and early interventions have advanced; raising the potential for deaf children to learn to listen and speak alongside their hearing peers. In this paper AVUK explore the global picture of Auditory Verbal therapy and what more we can be doing to make this intervention accessible to families across the UK.

"Over the last 21 months, the majority of our Early Intervention has been via telepractice. We have been delighted to see that the effectiveness of AV intervention has been rated very highly by parents and therapists alike and that the children on the programme continue to make excellent progress with their listening and spoken language development. Many families have joined the programme since March 2020 and together we have been able to bring the AV strategies to families who have only ever accessed their programme remotely. While we are looking forward to playing and learning together in person, it is reassuring to know that effective early intervention for children with hearing loss is still a reality." Sarah Hogan, Senior Auditory Verbal Therapist and Bicester Clinical Lead

Part of the telepractice study was also published in the peer-reviewed journal of the American Speech Hearing Association "Perspectives". Read more here.

Centre Highlights

Telethon Speech & Hearing: LEGO holiday program

Telethon Speech & Hearing (TSH)

- Harry Potter LEGO holiday program – Applying the evidence-based LEGO Therapy approach by David LeGoff, TSH therapists and teachers used LEGO building projects and activities to help students from TSH's Outpost School Support program build their social competency and communication skills. Students spent a fun-filled morning practising problem-solving, negotiation, turn-taking and collaboration in this whimsical, Harry Potter themed morning!
- Remembering Jack Bendat – This February, TSH sadly farewelled one of its most enduring local philanthropic supporters, Dr Jack Bendat OAM. Most known for his successful business ventures, philanthropic interests and ownership of the Perth Wildcats basketball team, Dr Bendat's generosity included supporting TSH's revitalisation and expansion project back in 2011.

Counsellor Hazel Benson-Dawe (right) is available for anyone connected to The Hearing House

The Hearing House

The Hearing House now offers counselling through their newly-appointed in-house counsellor Hazel Benson-Dawe. Hazel is available for anyone connected to The Hearing House, including family, partners, those on our waiting list and those who aren't.

Sessions with Hazel can help people gain clarity about their experience. She can also act as an intermediary between clients, their audiologist and speech and language therapists. When further questions arise during a session, Hazel is able to pass them on to the clinical team to answer.

"I've received feedback from a client who expressed their appreciation of being able to gain further information about their journey in this way," says Hazel.

The Shepherd Centre: (L to R) Dr Mike Freelander MP, Stephanie and her daughter Natalia, The Shepherd Centre Chair Susan Turner-Kapsanis, Camden Mayor Therese Fedeli, Peter Sidgreaves MP, CEO Jim Hungerford, Melanie Gibbons MP and Tanya Davies MP at the Oran Park opening

The Shepherd Centre

We are pleased to announce our brand-new clinic at Oran Park is open. With the Camden Council population set to increase dramatically in the next 20 years, including an increase of 46,800 children aged 14 years and under, The Shepherd Centre is proud to offer local families world-class care close to home.

23 children are already enrolled across the Early Intervention Program, school-age services, regular therapy and groups as the team look to at least doubling the number of Listening and Spoken Language Specialists, Audiologists and Child and Family Counsellors in the future.

AVUK: Launched the #HearUsNow Campaign

With children at risk of falling further behind as a result of the COVID-19 pandemic, AVUK are calling on the Government to invest in early and effective support for deaf children in the UK.

AVUK launched the #HearUsNow campaign on World Hearing Day (3rd March) asking the Government to make an investment of £21.5m over the next 10 years, so that they can provide a sound future for deaf children and unlock an economic benefit of £152m. This will enable all families who want their child to learn to listen and talk to be able to access Auditory Verbal therapy through publicly- funded services, close to where they live. Find out more.

Carel du Toit Centre Audiology Department dressed up for Word Hearing Day workshop

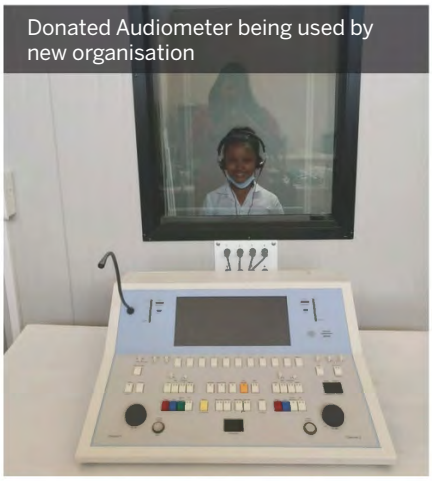
Carel du Toit Centre learners in Audiology ear health and hearing workshop

Carel du Toit Centre: Celebrating World Hearing Day

World Hearing Day, 3 March was great fun for our Carel kids! Our Audiology Department dressed up with big animal crafted ears and held a workshop on ear health and hearing. The day included song and dance which was the cherry on top for the littlies who eagerly joined in.

Paying it forward

We were blessed with a generous donation of a new audiometer which meant we were able to donate our previously-loved audiometer to another organisation whose machine stopped working. The cost of annual calibration for equipment not being used means it is far better used at another organisation.



Donated Audiometer being used by new organisation

New Audiometer being delivered at Carel du Toit Centre

Hear and Say: Dimity and Julia

30 Years of Hear and Say

As Hear and Say celebrates its 30th year, Executive Director and Founder, Dr Dimity Dornan AO, reflects on all that Hear and Say and First Voice have achieved.

"The listening and speaking outcomes for children who are deaf or hard of hearing is what has driven my passion all these years," said Dimity.

"The changes that I've seen are huge. When I started in 1992 if you were born with severe or profound hearing loss, you usually needed sign language to communicate. Today, thanks to the advances in hearing technology and listening and spoken language therapy, we know that communicating through spoken language is a very real option for most babies born deaf."

Dimity knew that Hear and Say could not maximise these ground-breaking outcomes working in isolation, so turned to like-minded organisations for support.

"Forming First Voice was extremely important for children in Australia who were born with hearing loss. As the numbers of families choosing listening and speaking outcomes grew, it was really important for us to gather research and funding so that these children could receive an intensive education in their earliest years," said Dimity.

"I believe that First Voice has spearheaded the gathering of pertinent evidence that will prove that by starting early with children who are born with, or acquire, a hearing loss then you can achieve wonderful outcomes. The sky is the limit not their hearing loss."

Hearing Awareness Week 2022

First Voice's national campaign for World Hearing Day and Hearing Awareness Week was focussed on directly challenging negative and uninformed public perceptions of the outcomes possible for today's generation of children born with hearing loss. The truth is that, thanks to modern hearing technologies and evidenced-based speech and language early intervention, it is now possible for children with hearing loss to learn to hear, listen and speak as well as children with typical hearing of the same age. Indeed, for the past 15 to 20 years, a significant proportion of Australian children with permanent hearing loss have achieved fluent speech, attended mainstream schools and gone on to further education and employment. But hardly anyone knows this. A recent First Voice survey revealed that 94 per cent of Australians are unaware of this life-changing reality and 84 per cent of Australians don't know where to turn for support if their child is born with, or develops, hearing loss.

First Voice Chair, Mark Fitzpatrick, says he is on a mission to educate Australians about timely and effective interventions. "For parents, a hearing loss diagnosis can be full of unknowns and uncertainties about the future, so it is critical that we educate them on the options available to encourage informed decisions that can enable their child to embrace a world of sound," said Mr Fitzpatrick.

Our Key Campaign Messages

- Achieving spoken language through listening is possible for children born with hearing loss
- Every child born with hearing loss should have access to evidence-based early intervention services to make sure they reach their full potential
- Early intervention is fundamental to providing children with hearing loss with the listening and spoken language skills necessary for mainstream schooling, choice of employment and a life unlimited by hearing loss
- Informed family choice and control is critical when making decisions for their child, and therefore guided support and effective early intervention pathways are vital.

The campaign has had strong media attention with a feature segment on Studio 10, coverage from ABC Radio National, Daily Mail, New Idea and 9Honey Parenting, as well as metro newspaper features in – The Courier-Mail, Daily Telegraph and The West Australian.

400% increase
In visits to the First Voice website

400 thousand
People saw the television spots on Studio 10

Over 4 million
People heard the radio segment on ABC

Over 22 million
People saw the earned media coverage across digital and print

Telethon Speech & Hearing
Releasing children's potential

The Shepherd Centre
Giving deaf children a voice

Hear and Say
Opening worlds

AUDITORY VERBAL UK

THE HEARING HOUSE

Can:Do 4Kids

Next Sense

Carel du Toit
Waar dowe kinders leer praat
Where deaf children learn to speak

firstvoice
THE FUTURE IS HEAR

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