



Children and families facing a future with Usher Syndrome

Louis is one of an unknown number of children in Australia with Usher Syndrome. "One of the first things I read after we got the diagnosis is that 80 per cent of adults with Usher Syndrome are unemployed. It's hard to comprehend your child will grow into a future where he is most likely to be unemployed."



Person-centered care has deep roots in China

During the Tang Dynasty, the medical master Sun Simiao began to advocate that a great physician should pay attention to all aspects of the patient and treat him or her with a holistic approach, especially addressing the psychological and social aspects.

This developed into traditional Chinese medicine, which values love, respect, support, and a warm, harmonious doctor-patient relationship, where decisions are made together.



Selina thrives in inclusive environment

Selina is a trailblazer, a strong advocate for the deaf community in Kuala Lumpur. Deafness, hearing impairment, special needs or possessing a disability were labels that society had tried to place her but she was not bound by such descriptions.

June is Pride Month

The size of Australia's deaf community is estimated that fewer than 10,000 people are native Auslan users. Dion says that can make information and resources about transgender issues difficult to access.

"America's way more advanced, people there are standing up and doing advocacy work, but in Australia, there's nothing."



Bringing answers to children with a little-known genetic condition

A University of Melbourne collaboration is helping to uncover the real needs of children and families facing a future with Usher Syndrome

By Sarah Marinos, [University of Melbourne](#)

Emily Shepard spent the first three-and-a-half years of her son's life searching for answers. Mother's instinct and closely observing Louis's interactions with his older sister, family and friends convinced her that her son had an underlying health issue.

"Louis was born in a private hospital in Victoria that was one of the last hospitals to roll out newborn hearing screening, so he didn't have that check when he was born," says Ms Shepard.



"I took him home and, because he was our second baby, my husband and I could tell there was something not quite right early on. We had a noisy three-year-old toddler but Louis didn't seem to startle or be impacted by her and at eight-weeks-old, he was diagnosed with profound hearing loss.

"He didn't tick off milestones either – he couldn't hold up his head and was late to roll and crawl and sit up. It was clear to us that as well as hearing loss, there was something else going on."

It was a complex journey, but eventually the Shepard family discovered Louis had a genetic disorder called [Usher Syndrome](#).

As well as hearing loss, children with Usher Syndrome develop an eye condition called retinitis pigmentosa that begins with night blindness and becomes tunnel vision or peripheral vision loss in adulthood.

Usher Syndrome also causes vestibular dysfunction in some cases, so children take longer to sit up and walk and have poor balance and coordination.

It occurs when both parents carry the gene associated with Usher syndrome. Together, they have a one in four chance of having a child with the syndrome. Neither Ms Shepard or her husband were aware they were carriers and neither had heard of Usher Syndrome before their son's diagnosis.

Louis is one of an unknown number of children in Australia with the syndrome. Getting an accurate diagnosis and information about the condition as well as finding the right kind of support for the child and their carers can be difficult.

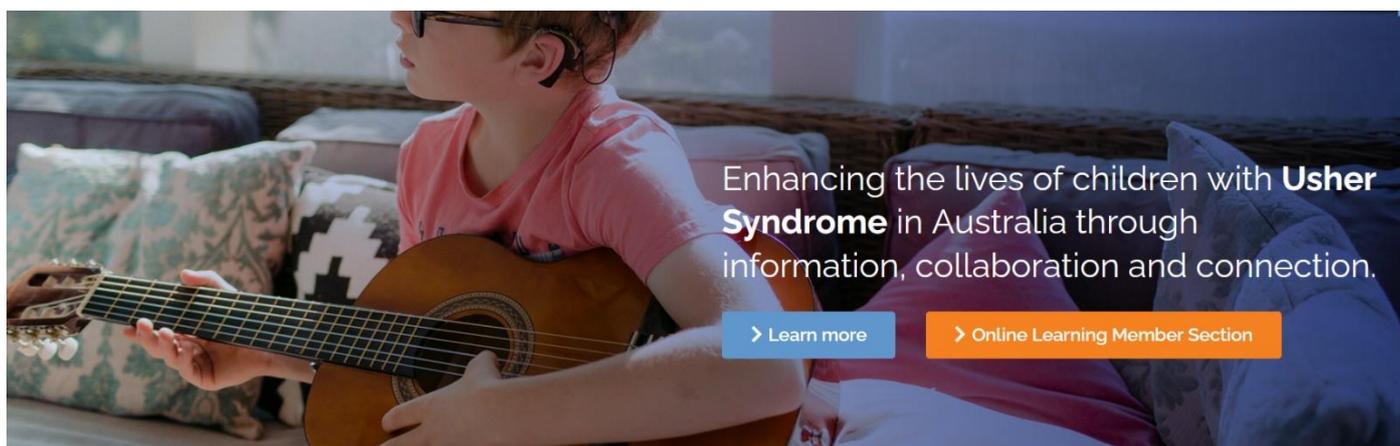
This is why Emily Shepard co-founded [UsherKids Australia](#) with another Usher parent, Hollie Feller.

"One of the first things I read after we got the diagnosis is that 80 per cent of adults with Usher Syndrome are unemployed.

"It's hard to comprehend your child will grow into a future where he is most likely to be unemployed," says Ms Shepard.

"I thought surely there must be skills we could start giving Louis to ensure he gets a good education and to help him cope with his vision and hearing loss. That was the motivation for starting UsherKids.

"We want to support other children and families to help them develop practical skills with their children in the early days to improve outcomes when they are adults."



This year, UsherKids Australia is being supported by the [Melbourne Disability Institute](#) (MDI) Community-Based Research program. The MDI initiative provides research support and evaluates community-based programs that make a difference for people with disability and their families.

The MDI program offers community groups, like UsherKids Australia, a direct link to University researchers – answering questions about a program's effectiveness and providing data that can be used to improve or grow program services.

Associate Professor Karyn Galvin, an audiologist and Principal Research Fellow in the Department of Audiology and Speech Pathology at the University of Melbourne, has partnered with UsherKids Australia through the MDI program.

She will help the organisation build links with researchers and more clearly define what supports are most helpful to children and carers at different ages.

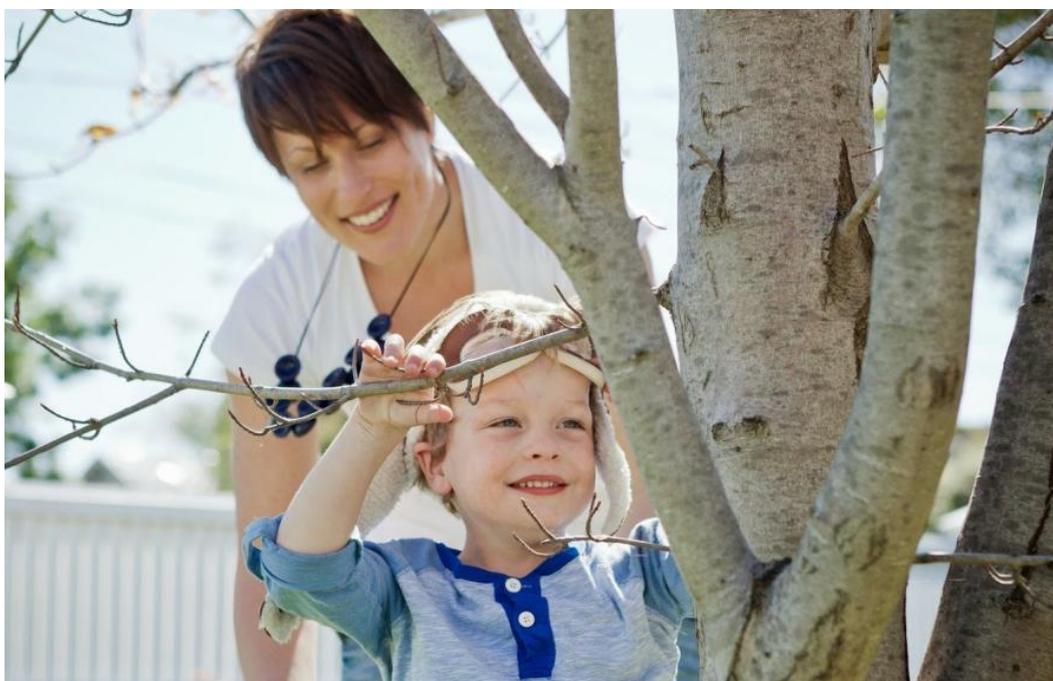
Masters of Clinical Audiology and Masters of Genetic Counselling students will support Associate Professor Galvin in her collaboration with UsherKids Australia.

“Including students means we can get more done and it also meets a longer-term aim of UsherKids Australia to educate clinicians more about Usher Syndrome – our students are the next generation of clinicians,” says Associate Professor Galvin.

The researchers will interview families of children with Usher Syndrome to ask them about their support needs and find out what needs are being met and where there are gaps. They will also work to identify barriers that slow the progress of children with the condition.

“The project wants to better understand the support needs of families of children with Usher syndrome so the organisation can provide support in a more targeted way,” says Professor Galvin.

“Clinicians don’t know what support to provide and families may not know what support they need. Families may know that vision loss is coming for their child, but how do you best support that family when they know that is what the future holds? The journey can change when people know what lies ahead.”



Ms Shepard says having the expertise of University of Melbourne researchers supporting UsherKids Australia is life changing.

“When Louis was first diagnosed the overall message from services we approached was ‘come back when he is vision impaired’. That was daunting. How do you sit with that for what could be years?” she says.

“I also remember the geneticist telling us they didn’t know much about the condition and to go home and Google it. I’m proud now that families who get this diagnosis don’t have to go through that – if they Google, they will find us.

“The University program will look at the impacts for families and build some evidence to inform better services for our families. It has been rewarding to go from being a Mum saying ‘please help us’ to having a university behind us so we can improve services to families that are so desperately needed.”

Worimi doctor Kelvin Kong awarded the prestigious Australian Society of Medical Research Medal for 2021



He has won multiple awards and he's been described as a true trailblazer in healthcare, now Nelson Bay (NSW) born and bred Dr Kelvin Kong is being honoured nationally for his work with Indigenous communities.

As associate professor with the Hunter Medical Research Institute, Dr Kong was awarded the prestigious Australian Society of Medical Research Medal for 2021.

Dr Kong has had a close affiliation with the Rotary Club of Nelson Bay, [which has donated around \\$30,000 to his research medical team](#) as they travel the country providing more efficient indigenous ear disease diagnosis, especially in indigenous children.

"This is great news for Kelvin, HMRI and the Nelson Bay Rotary," said the Rotary club's Chris Bartlett. "It's a great honour and Nelson Bay Rotary is proud to be associated with Dr Kong."

Dr Kong, a proud Worimi man, was the first indigenous Australian surgeon and is now one of Australia's leading ENT (ear nose throat) surgeons with a driving passion to reduce the disparity between health and learning outcomes for Indigenous and non-Indigenous Australians.

He regularly travels to remote Australia to provide specialist ENT services to indigenous patients, while his clinical practice is complemented by his ongoing research into the causes and treatment of ear disease, together with his involvement in community outreach programs designed to improve access to healthcare and break cycles of disadvantage for Indigenous Australians.

His mother Grace was a community nurse and women's health worker, his father Tony a GP in Malaysia, and his twin older sisters are also doctors.

His research focuses on diagnosis and treatment of otitis media, "glue ear", in children under three.

From [Port Stephens Examiner](#) (NSW)

Empathy and shared decisions: Person-centered care has deep roots in China



“People want to understand China. But 100 people will tell you 100 different stories.”

These are the words of Dr Mei, Dingxiang Feng, Ida’s China Consultant, who is working to expand understanding and implementation of person-centered hearing care (PCC) in China.

It’s a mammoth task, and not just because this is a country where, according to the most reliable estimates, [27.8 million people have a hearing disability](#), with the number of people experiencing hearing loss likely much higher. The country’s extreme diversity also makes it a huge challenge.

“Every city, every province is different,” says Dr Feng, who worked as a doctor, audiologist, speech therapist, and national hearing project leader in China for 30 years before coming to Ida. “From the economic resources available to the level of education to the standard of health or hearing care.”

Interest in PCC across the country

Yet the time seems ripe. In 2016, just one year after the World Health Organization urged leaders to build integrated, people-centered health services, the Chinese government published a strategy to achieve this by 2030 – and there’s excitement among the grassroots for more human-centered approaches too.

In April this year, Dr Feng organized a five-hour online seminar on person-centered hearing care, inviting hearing care professionals, academics, administrators in the healthcare system, and people with hearing loss.

Expecting around 50 attendees, Dr Feng was instead flooded with RSVPs. Nearly 300 people showed up from across China, including around 50 key opinion leaders from professional organizations, patient associations, universities, and industry.

‘The holistic approach runs deep’

Professor Ma Furong was among the attendees. An educator, ENT doctor, and surgeon herself, she is also Vice President of the Second Committee of the ENT Department of the Chinese Medical Doctor Association, and Director and Professor of the ENT department at the 3rd affiliated hospital of Beijing University.

Professor Ma has long been an advocate of a human-centered approach to care and, crucially, sees the modern concept of PCC as perfectly aligned with traditional Chinese medicine.

“During the Tang Dynasty, the medical master Sun Simiao began to advocate that a great physician should pay attention to all aspects of the patient and treat him or her with a holistic approach, especially addressing the psychological and social aspects,” Professor Ma explains. “This developed into traditional Chinese medicine, which values love, respect, support, and a warm, harmonious doctor-patient relationship, where decisions are made together.”

With empathy, active listening, shared decision-making, and an understanding of individual needs and preferences at its core, the modern concept of PCC could almost have been built on this ancient Chinese approach to medicine.

Dr Feng agrees: “The holistic approach – combining technical and medical aspects with human touch – runs deep in Chinese culture. Maybe we don’t call it PCC and maybe some people have forgotten about it, because now many people practice Western medicine. But I think once we can explain the modern PCC concept in an understandable and integrated way, people will accept it, because it’s not a completely new approach or way of thinking for Chinese people.”

Obstacles on the road

But that translation process is itself one of the key challenges.

“We need to bridge the culture gap as well,” she says, “We need to adapt the resources with the Chinese culture in mind. Only if people can understand PCC within the Chinese context, will they accept it.”

And although PCC is closely aligned with historical medical approaches in China, it will take some time for professionals to fully embrace and integrate modern PCC as a systematic approach.

“This type of PCC is very much at the beginning in China,” says Dr Feng.

Professor Ma also sees obstacles on the path to PCC becoming the norm in China.

“Sometimes there is more importance placed on technology than the patient and the psychological needs of people with impairments are ignored,” she says. “And in China, doctors and audiologists often have many patients – they are very busy and don’t have time just to talk with the patients.”

A further problem is that – as in many countries – the hearing care provided in public hospitals is driven by the biomedical model of diagnosis and treatment, while rehabilitation services are mostly the domain of private clinics. In cities such as Beijing and Shanghai, most people can afford to access this (often with the help of local or national government subsidies), but the percentage plummets in the smaller cities and rural areas.

Spreading information, tools, and knowledge

Both Dr Feng and Professor Ma see education as the path to a China where all hearing care, in both private and public settings, follows the biopsychosocial (person-centered) approach.

“First of course, education at the universities, because that’s the future,” says Dr Feng. “Second, continuing education, for people who are already working.”

By Judith Vonberg for the [Ida Institute](#). Professor Ma Furong and Dr Mei, Dingxiang Feng

Advertisement

Leading the future of Deaf Arts

FLOW Festival 2021



We are very excited about our amazing talented Deaf artists and performers.

FLOW festival will deliver a vibrant and unique festival of Deaf Arts by the Australian Deaf Community from 18 to 23 September 2021.

We will launch with a live event on the 18th with the fantastic ALTERBOY Band, which will also be livestreamed to all states. Each state will host the FLOW launch with Deaf Arts event. From 19 to 23, FLOW will be available via online. It will showcase Auslan, Australian Sign Language through many different artistic forms.

Auslan storytelling, Deaf Slam Poetry, dance, theatre, short films screening, children's art activities, workshops, artists talk, Deaf indigenous storytelling/art workshops, Queer Arts and DeafBlind Arts are some of exciting art events planned by FLOWFestival 2021.

We are now taking registrations for artists, performers, producers, facilitators/workshops and presenters. (Deaf/ Arts related organisations are most welcome!).

Please support our FLOWFestival 2021 by sharing this announcement/poster with your networks and contacts. We love to see all Deaf communities become ONE NOW!

It is very exciting, and we would love to see you there at the FLOW Festival 2021.

www.flowfestivalaustralia.com

flowfestivalaustralia@gmail.com

DEAFNESS FORUM OF AUSTRALIA

oneinsix

No Australian Left Offline: Australian Human Rights Commission

The Australian Human Rights Commission has heeded the Australian Communications Consumer Action Network (ACCAN)'s call for no Australian to be left offline, with the release of the [Human Rights and Technology Final Report](#)

The report, presented to the Attorney General, details the Australian Human Rights Commission's support for a concessional broadband rate for low-income households to make internet access more affordable and improve digital inclusion.

"The past year has demonstrated just how essential it is to be online," said ACCAN CEO, Teresa Corbin. "With Melbourne in the midst of its latest lockdown, and families forced back into remote work and schooling, we need to act now to make sure that our most vulnerable have access to a reliable, affordable broadband product."

The national human rights institution recommended that NBN Co should implement a reasonable concessional broadband rate for people with disability who are financially vulnerable.

"We know that not only are people with disability less likely to be digitally included in Australia, but they also spend a greater share of their household income on internet access than the Australian average and receive less data for each dollar of expenditure than the average," added Ms Corbin.

Ms Corbin said that ACCAN also welcomed the Australian Human Rights Commission's support for broadcasting content to be made more accessible through a minimum audio description requirement of 14 hours per week for national, commercial and subscription broadcasting services.

"People with disability have long been denied full and equitable access to Australian television. The adoption of minimum standards for audio description would be an important step forward to ensuring that vision impaired and blind Australians can enjoy the same TV shows as the rest of the nation and take part in national conversations."

The peak body for communications consumers has raised concerns that without any legislative mandate this inequality is at risk of being replicated on digital platforms, such as streaming services, where audio described and captioned content is not always available to Australian audiences.

"We're very pleased that the Australian Human Rights Commission has recommended that the Government introduce legislation to provide minimum requirements for audio description and captioning in respect of audio-visual content delivered through subscription video-on-demand, social media and other services that are not covered by the Broadcasting Services Act."

This recommendation echoes [ACCAN's submission to the Media Reform Green Paper](#), which is aimed at the future of television in Australia. In its submission, ACCAN expressed concern that the Green Paper proposes no provision for audio visual access features in its vision for a sustainable Australian free-to-air landscape. Deafness Forum of Australia contributed to ACCAN's submission.

"The Human Rights and Technology Final Report is a strong roadmap for Government to follow to allow Australians to enjoy the benefits of new technology, while protecting against potential human rights violations. We look forward to seeing the Government act on the recommendations put forward by the Australian Human Rights Commission as soon as possible."



Every June, Pride Month celebrates the diversity of the lesbian, gay, bisexual, transgender and intersex community. It's a time to reflect on just how far civil rights have progressed in half a century and an opportunity to protest discrimination and violence. Australia is at the forefront of the push towards true equality and inclusion for LGBTI people, but there is more to do.

History Of Pride Month and what it can teach us about moving forward

On June 28 1969, police officers from the New York City's Public Morals Division raided the Stonewall Inn, a gay bar in New York City's Greenwich Village. This raid wasn't unusual in New York (or many other cities). Back then, police could arrest and even force hospitalisation of gay people.

On this particular evening, however, the bar patrons fought back. It started when Marsha P. Johnson cried "I got my civil rights!" and threw a shot glass into a mirror (now known as "the Shot Glass that was Heard Around the World"). More and more patrons joined the fight, including people from neighbouring bars, and mayhem ensued. Hundreds of people resisted arrest.

Things eventually calmed down. But once the word got out, thousands returned the next night to continue the protest. It lasted six days.

Stonewall was not the start of the LGBTQ movement. LGBTQ activists have been organising since at least the 1920s. But the rage and fervour caused by the Stonewall riots helped catapult the LGBTQ movement to a new level.

Media coverage of the riots allowed others to see the LGBTQ struggle for themselves and to relate to and support those fighting for their rights. Events at Stonewall emboldened others to do what they could to help.

The following year, the anniversary of the Stonewall riots was marked by demonstrations in New York, Chicago, Los Angeles and San Francisco. At first, the New York City day of celebration was called "Christopher Street Liberation Day." In Los Angeles and San Francisco, these events became known as "Gay Freedom Marches," and the day was called "Gay Freedom Day." Chicago had Gay Pride Week.

The parades were a mix of politics and celebration. They promoted visibility of the LGBTQ community. They also served as a huge megaphone for LGBTQ needs and rights — like protection against harassment, raising awareness of the AIDS epidemic or fighting for marriage equality.

The culture shifted in the 1980s, as less radical activists began taking over the march committees in different cities. They dropped "Gay Liberation" and "Gay Freedom" from the names, replacing them with "Gay Pride."

The first few marches drew only a few hundred people, but the Pride Parades today include hundreds of thousands. In fact, the Chicago Pride Festivals have had crowds of more than one million people since 2013.

We've come a long way from the 1970s. We've also made it through the AIDS crisis of the 1980s and 1990s. The parades have long been the voice and coming together of the LGBTQ community to celebrate their lives. But while there have been some huge gains, we still have a way to go.

From by Forbes online.

Dion brings trans awareness to the Deaf community during Pride Month

"I am non-binary. It means I do not identify with either gender — man or woman. Sometimes, I am one or the other, both or neither of them."



Speaking to ABC's The Drum through an Auslan interpreter, Dion said the news they might be trans came as no surprise to their wife, who had been the one to first raise the possibility.

"I felt like I was the last one to realise my identity and everybody else had known well in advance.

"My friends all said they knew, that it had been really obvious. I think the deaf community is more accepting of diversity. Deaf people already know what it's like to be different."

More than a year into testosterone hormone therapy, Dion is feeling increasingly confident and comfortable in their body, which is slowly becoming more aligned with their trans-masc identity.

The size of Australia's deaf community is estimated that fewer than 10,000 people are native Auslan users. Dion says that can make information and resources about transgender issues difficult to access.

"America's way more advanced, people there are standing up and doing advocacy work, but in Australia, there's nothing."

They're helping fill that knowledge gap by creating video resources in Auslan and speaking publicly about their transition.

"I think I'm one of the few trans deaf people that are in the spotlight, saying 'this is OK' and trying to encourage the deaf trans community to come and share information and share experiences.

"I've been contacted by a few deaf trans people. A lot of them are not ready to come out. They are still not sure about where they can go and who they can talk to. It's going to take time."

Dion said they were encouraged by a growing awareness about the theory of intersectionality.

"It's about the layers that people have, for example me as a deaf person, a trans person, and a white person. I don't conform.

"I'm not here to make people happy ... that's not on my shoulders. There's variety and diversity and people need to respect that.

"I think it's important for all of us to identify the intersections that we do have and take them on and embrace them."



Devices Search



Click on Devices to search for phones, tablets, accessories or apps suitable for people with specific needs or disabilities.



Telecom Training Search

Click on Telecom Training Search to search for training about how to use telecommunication devices.

Use this free service to find independent and up-to-date information on telecommunication products and services that are suitable for seniors and people with disability.

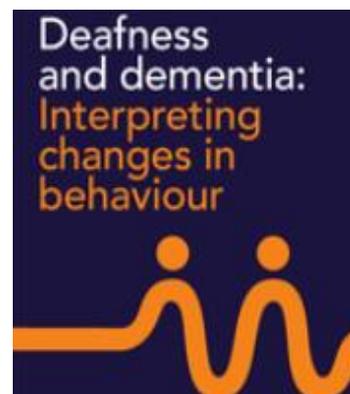
Go to <https://www.accessibletelecoms.org.au/>

Deafness and dementia: an information booklet for family and friends

The Dementia Centre and Hammond Care created a Deafness and Dementia booklet to give communication tips and some simple approaches in response to what might be happening for the person living with deafness and dementia.

The booklet also provides information about how you can enable a Deaf person living with dementia to remain engaged with their life and their community.

Click [here](#) to download the booklet.



Advertisement



**Supporting You On Your
Hearing Loss Journey**

DRC is a registered DGR Charity for Tax purposes

Deafness Resource centre offers a range of services to the Deaf Community in the ACT and surrounding region

Come to the ACT Deafness Resource Centre for confidential assistance with:

NDIS

- Need help applying to the NDIS?
- Preparing for your plan review meetings
- Support at your planning meetings
- Understanding your plan
- How to apply for the things you need.
- Need assistance with letters or other information from the NDIS?
- What will the NDIS help with?

Assistive Technology

- What Assistive Technology (AT) equipment is available
- What equipment will work best for you
- How to get AT equipment
- Assistive Technology sales

Other Support

- Reading and Understanding letters or other correspondence
- Paying Bills
- Assistance with Centrelink and others

Not sure if we can help you? Please ask and we'll let you know if we can. If we're unable to help you, we'll find someone who can. The DRC is a registered NDIS Provider. Provider Number: # 60297041. The DRC is located in the Grant Cameron Community Centre 27 Mulley St Holder, ACT. Drop in or appointment time available: Monday to Friday 9am-5pm
Email the DRC for more information: drcenq@actdrc.org.au

Selina thrives in inclusive environment



“Diversity is about our individual differences and acknowledging the unique blend of knowledge, skills and perspectives people bring to the workplace. Diversity can include characteristics such as cultural background and ethnicity, age, gender, disability, religious beliefs, language and education.”

Functional lead in human resources at UOW Malaysia KDU Kevin Lim said diversity and inclusion did not simply refer to valuing colleagues with respect to their ethnicity or religious belief. Diversity also included characteristics such as professional skills, working style, location and life experiences.

UOW Malaysia KDU (part of the University of Wollongong Australia's global network) values the contribution that special needs individuals bring to campus communities. A case in point is Selina Ooi, one of the private university college's finest graphic designers.

Deafness, hearing impairment, special needs or possessing a disability were labels that society had tried to place on Selina but her UOW Malaysia KDU colleagues know she was not bound by such descriptions.

She is a trailblazer, having been a strong advocate for the deaf community in greater Kuala Lumpur. She is the first deaf blogger in Malaysia (Deaf Boleh! Malaysia), founder of a community that builds awareness of deaf culture through sharing their success stories, a guest speaker at various non-governmental organisations (including YMCA) as well as an active game and tech geek.

Willis the Wallaby is Selina's latest creation for UOW Malaysia KDU. Willis has been adopted as the institution's official mascot. Willis is courageous and seeks to connect with a diverse range of friends, always seeing the possibilities that could be, rather than being overwhelmed by life's challenges.

“Besides being a mascot, Willis will also bring sign language awareness to the public as Willis will be using some sign language in the animated social media posts/stickers that I do. This can be a fun way for the public to be exposed to sign language. For example, Willis will say ‘thank you’ in sign language,” Selina said.

From [The Star](#) Malaysia

Become a member of Deafness Forum of Australia

An individual member of Deafness Forum of Australia can be person who has a hearing issue, is Deaf, a member of their family, or someone who provides support such as teachers, researchers and audiologists. To join, download and complete a membership [application form](#)

An organisation member can be an organisation that is of and for consumers; or a service provider association, which provides support to people with hearing loss, who are Deaf or who have a balance or ear disorder. Annual membership fees for organisations start at \$105. To join, download and fill in a membership [application form](#)

<https://www.deafnessforum.org.au/about-us/become-a-member/>



Miss a hearing? You can watch them on the Royal Commission [website](#).

Go to the relevant Public hearing page, look under **Documents**, then click on **Video/Auslan**. Each video has captions and Auslan interpreters.

Know someone who deserves their own copy of One in Six?

Drop us a line: hello@deafnessforum.org.au



Deafness Forum is a Registered Charity

All donations over \$2 are tax deductible.

To donate, go to

<https://www.givenow.com.au/organisation/public/534>

We acknowledge the traditional owners of country throughout Australia and their continuing connection to land, sea and community: we pay respect to them and their cultures, to elders past, present and future. We want to be part of the effort to overcome the unacceptably high levels of ear health issues among First Nation people; and we understand that it is an essential component of Closing the Gap. We understand the risk of the disappearance of indigenous sign languages and the cultural loss it would cause.

Items in Deafness Forum communications may incorporate or summarise views, standards or recommendations of third parties, which is assembled in good faith but does not necessarily reflect the considered views of Deafness Forum or indicate commitment to a particular course of action. We make no representation or warranty about the accuracy, reliability, currency or completeness of any third-party information. We want to be newsworthy and interesting and our aim is to be balanced and to represent views from throughout our community sector, but this might not be reflected in particular editions or in a short time period. Content may be edited for style and length.