



Australians anxious about end of phone captioning service

The average age of people using the CapTel service is 80. They are devastated by the Government's decision to axe the service early next year. Users are concerned about the quality and convenience of the alternative services and are uncomfortable about learning to use a new technology.



Disability Royal Commission will bring forward the hidden stories of abuse in indigenous communities

"People are bringing up vulnerable experiences and what support is after that? They haven't talked about, or funded appropriately, healing programs and support for before or after."



What it's like to be the only person in your family who can hear?

Jodee is a CODA — child of deaf adult — a hidden minority in a minority community. She describes Australian sign language (Auslan) as her first language, and English as her second. After all, in her home no-one actually spoke English. Ever.

Hearing loss still a challenge for kids

Children born with hearing loss are now routinely diagnosed within weeks of birth and having hearing aids and cochlear implants fitted well before school. So why are they still lagging behind their hearing peers in spoken language?

'Can't do without it': deaf Australians anxious about end of phone captioning service

By [Fergus Hunter](#) for The Sydney Morning Herald

Paul Philippa started to go deaf ten years ago. The 86-year-old business consultant on the NSW Central Coast signed up to CapTel, a telephone service that provides live captioning on a special handset.



"I can't do without it," Mr Philippa said. "Because with normal telephone conversations, I might only understand what someone is saying about 50 per cent of the time."

Mr Philippa said the service is particularly important for the regular emergency phone calls he needs to make because of his wife's health issues.

But an unwelcome change looms for Mr Philippa and 2000 other deaf and hearing-impaired people who use CapTel – which has been available under Australia's [National Relay Service](#). The handset will not be available from February next year as it is not supported by the new contractor.

Some CapTel users are concerned about the quality and convenience of the alternative services and are uncomfortable about learning to use a new technology. The average age of people using the service is 80.

Labor communications spokeswoman Michelle Rowland said the government has ignored the concerns of elderly Australians and their families.

"Their decision to cut CapTel outright, without consulting the community or making any reasonable attempt to find middle ground, is not befitting the sensitivity and care we should be showing to elderly deaf Australians," she said.

Paul Philippa said it doesn't seem reasonable and he doesn't trust the government to deliver an adequate alternative. "Why disturb a system that is working and working well? What reason is there?" he said.

<https://www.smh.com.au/politics/federal/can-t-do-without-it-deaf-australians-anxious-about-end-of-phone-captioning-service-20190923-p52u1g.html>

Government dukes it out with the company that manages the National Relay Service: no change to decision to scrap CapTel



Ministers for Communications, Cyber Safety and the Arts



The Government has registered a formal legal instrument to give it additional powers to compel the outgoing provider of the National Relay Service (NRS), Australian Communications Exchange (ACE), to support CapTel captioned telephone handset users to transition to alternate services.

The *Telecommunications (Consumer Protection and Service Standards) (National Relay Service Rules) Determination 2019* requires ACE to provide information to the Department of Communications and the Arts on request to help transition CapTel users to the new NRS provider, Concentrix, including information about current CapTel users. Despite repeated requests from Government, ACE has not provided details of CapTel users to the Commonwealth.

“It is surprising and disappointing that it is necessary to take this step” the Hon Paul Fletcher, Minister for Communications, Cyber Safety and the Arts

“I would have expected greater cooperation from ACE in either providing the information or seeking it from other parties, to allow the Government to give comprehensive information to CapTel users about the wide range of service options they will have under the NRS as we transition from ACE to a new provider”.

The contract with ACE was originally negotiated by the Telecommunications Universal Service Management Agency (TUSMA), established by then Labor Communications Minister Stephen Conroy in 2013. TUSMA failed to include a contractual provision giving the responsible Minister, or the Commonwealth, critical information detailing the location of CapTel handsets and contact details for current CapTel users.

“The Morrison Government is committed to maintaining a world-class relay service that meets the needs of key user groups amongst the hearing and speech impaired communities – those who speak, those who text and those who communicate through Auslan” Minister Fletcher said.

The Determination also provides that the Commonwealth may request ACE to communicate to CapTel users about the handset being discontinued as part of the NRS from 1 February 2020 and to recommend they contact the NRS Helpdesk to explore alternatives to meet their individual needs. <https://www.minister.communications.gov.au/minister/paul-fletcher/news/government-takes-action-support-national-relay-service-transition>

The plot sickens. Just days after the federal Communications Minister threatened legal action against the organisation that formerly had the contract to deliver the National Relay Service (see previous page), his department is on the front foot with a fresh strategy. The following was received in an email late yesterday.

Support for CapTel users

Thank you for contacting the Government about the upcoming withdrawal of National Relay Service support for the CapTel handset on 1 February 2020.

For the latest information about alternative communication options for CapTel users from 1 February 2020, please see [Frequently Asked Questions: Withdrawal of National Relay Service support for CapTel handsets](#).

The Department of Communications and the Arts is committed to helping CapTel users to fully understand the NRS call options that can be used. Support will include written instructions, demonstrations and one-on-one sessions using communication devices.

To help us best meet user needs, we are inviting CapTel users to complete a questionnaire. Responses to this questionnaire will help us to help CapTel users transition to another device before support for the captioning service of the CapTel handset is withdrawn.

CapTel users can complete the questionnaire in a number of ways:

- online at this [link](#), or
- by downloading and emailing a completed questionnaire available at this [link](#), to the [NRS Helpdesk](#) at helpdesk@relayservice.com.au, or
- contacting the NRS Helpdesk on 1800 555 660. The Helpdesk staff can record verbal responses to the questionnaire and provide the response to us.

If responses to the questionnaire include interest in receiving some support, we will get in touch with CapTel users to make arrangements for the delivery of that support. It would be appreciated if surveys could be completed and returned by no later than 21 October 2019.

Thousands of vulnerable and elderly Australians are about to be shafted by the axing of the CapTel captioned phone service. It doesn't matter whether it's the fault of the Government, the Department, Australian Communications Exchange, or the Man in the Moon – CapTel must be saved. While they are sorting it out, we have questions for the decision-maker:

- Noting that the average age of CapTel users is 80, does s/he think that people will be jumping onto their laptops and smart phones, calling government call centres, queuing to do this web survey, and embracing the inferior alternatives?
- Has s/he considered how many elders will even be aware of this decision to axe CapTel until they try to make a call to their families in February?
- Is s/he aware that this decision to axe CapTel is likely to come under scrutiny by both the Aged Care Royal Commission and the Disability Royal Commission?

Disability Royal Commission will bring forward the hidden stories of abuse in indigenous communities

“People are bringing up vulnerable experiences and what support is after that? They haven’t talked about, or funded appropriately, healing programs and support for before or after.”

June Riemer from First Peoples Disability Network Australia (FPDN) said First Nations people are 1.7 times more likely than their non-First Nations counterparts to live with a disability.



“In traditional groups and languages, there isn’t a word for disability.”

“People, not always but in most groups, looked after one another. If someone was born with an impairment you just went along with the mob and you were looked after.”

“In colonial areas, our groups were marginalised, put on the edges of towns – not being allowed to work or have an education.”

“We were at a disadvantage, if you were a person with a disability you were fighting alongside everyone else,” Ms Riemer said.

Ms Riemer said service systems and Indigenous Australians didn’t connect well as they were government-based initiatives.

“If it was to do with government, it meant they had business with your family and sometimes people were scared to bring forward, for example a mother with a child who had a disability, because she would be then seen as a bad mother.”

“Generally, our mob has never connected well with the service systems because it has never been culturally appropriate.”

“The general block funding around service system support was that people worked nine to five but what if you needed help after five? Or if there are geographical boundaries, if you lived outside of a serviced area there was no flexibility to include you.”

“It’s only been in recent times that there has been that larger disability focus in general so most of the programs across different states came under the umbrella more so of ageing services – so there weren’t appropriate supports available.”

From National Indigenous Times, <https://nit.com.au/first-nations-disability-support-historically-neglected/?fbclid=IwAR1TsiE1v-WJCgajFBtC-X8yWWi0jbXAH4bpx7gFHN0qWApG9NN8NZ5wZx8>

What it's like to be the only person in your family who can hear

By [Patrick Wood](#) for News Breakfast and [Georgia Moodie](#) for [Earshot](#). Illustrations by [Luke King](#)



Jodee Mundy was just five when she got lost in Kmart.

Separated from her mum and discovered by a friendly staffer, she was taken to the front desk and a call was put out over the loudspeaker.

A few minutes passed but no-one showed up. Another call was made. Another no-show.

Suddenly her exasperated mum Gillian was beside her, demanding to know why she had run off.

"I said: 'But the lady made an announcement on the microphone'. And my mum looked at me, and signed: 'I'm deaf. You know that!'" Jodee says.

It was a moment of sudden realisation for Jodee: she'd never really understood what it meant that her two older brothers and both parents were deaf.

"I didn't see what they could not do, I could only see what they do," Jodee says. "Suddenly, I realised there were two camps. My family were in one camp, people who hear were in another, and my feet were in both. Ever since then, I've been trying to bring those two worlds together, and find a sense of peace."

Capital D Deaf

Jodee is what you call a CODA — child of deaf adult — a "hidden minority in a minority community".

She describes Australian sign language (Auslan) as her first language, and English as her second. After all, in her home no-one actually spoke English. Ever.

Her family is what's known as culturally deaf — capital D Deaf. Instead of thinking of deafness as a disability, being Deaf is seen as a difference and something to be proud of.

"It's like Italian is spelled with a capital I. A Deaf person sees themselves as part of Deaf culture, and that's a capital D Deaf," she explains.

"It's not just that I'm medically deaf — I'm Deaf! I sign, I'm proud, I roar, I am not ashamed of my language."

The Mundys even had two deaf cats — white cats with blue eyes, which have a genetic tendency to be deaf.

"A lot of Deaf people get them. It's a thing!" laughs Jodee.

In many ways Jodee's childhood was like anyone else's: family holidays, backyard cricket, birthday parties and chasing around after her brothers — much of it captured on old Super 8 film.

In other ways, however, it was markedly different, as from a young age Jodee became a conduit and interpreter for an entire family.

Some interpretations were simple, like making appointments. But others were more complex.



"Things like 'tell your father there's no work for two months', or 'your great aunty has died'. Big things for a child to tell an adult," she recalls.

Jodee would often sit next to the TV and interpret the news for her parents, and remembers doing so as the Berlin Wall came down.

Sometimes dark scenarios would play on Jodee's mind — like what would happen if someone broke into their home at night.

"I used to get really scared because if someone broke in no-one could hear me scream," she said. Lying in bed at night Jodee developed a plan. She would crawl down the dark corridor to her brother's room and wake him up, writing out the letters B.A.D — M.A.N — I.N — H.O.U.S.E on his hand.

By the time Jodee hit her teens, she'd had enough of interpreting for her family.

"I used to fight a lot with mum. I used to scream, 'I'm not your secretary. Find someone else to do it'," she recalls.

"When I look back, it was pretty hard. But I think I've forgiven myself for being such a terrible daughter. And I was a good kid, I just didn't understand the system."

Jodee says music was her saving grace.

"It was my link to the hearing world and pop culture. I could play it as loud as I wanted," she says — adding with a smile that one time, the neighbours complained.

Jodee was about 15 when she first heard about the term used to describe kids like her, CODA.

"I suddenly had an identity. I wasn't just this kid in a Deaf family. I had a home, I had a name," she says."

It's a feeling she believes is expressed in Auslan itself.

"To sign deaf, you get your index finger and your middle finger, and you put them over your ear and then over your mouth," she explains.

"To sign CODA, you take the deaf sign but you take your two fingers from your ear onto your heart. So when I introduce myself, I say I'm a CODA, I have deaf heart."

When Jodee tells people her story their response often falls one of two ways: those who exclaim how interesting it is, and those who exclaim at how hard it must have been.

"I guess in a way two camps of people — some people are more about glass half-full and others are a bit more glass half-empty," Jodee says.

The Mundy family did look into it, but there's no discernible reason why Jodee can hear and her brothers and parents cannot.

"We don't know, we have no idea why. It's just the beauty of nature," Jodee says.

Trailblazing technology

When Jodee was growing up in the 1980s, services for deaf people were very limited.

"You could only get a free interpreter for a funeral or wedding," she says. "My mum went through labour three times without an interpreter in hospital. Can you imagine giving birth and not knowing what the doctors are saying?"

New technology, in particular phone and internet developments, is breaking down barriers of communication and offering a freedom like never before. Jodee was never able to call her parents for a chat, but now she can video-call them. She says the first time that happened, she wept.

"I could [communicate with] my mum on my own phone. Not through a service, not out of necessity, not through pen and paper," she says. "It was my mum and dad, in real time, on my phone. People forget how special that is."



Cochlear implants have helped other hearing-impaired Australians, and brain-scanning hearing tests are now common in the first days after birth to address any early issues.

Captioned TV — which Jodee first saw on the soap show *Neighbours* — is now standard.

Jodee welcomes the technological shift and advances in medicine, but not if it comes at the expense of Auslan. For the Deaf community, Auslan represents more than just a means of communicating — it is a language of itself that is integral to Deaf culture.

"So while able-bodied people and the medical model may say, 'Hooray! We have fixed everyone!', we're actually at a serious risk of losing a beautiful language," Jodee says.

"There is a very high risk that Auslan could be extinct in about two or three generations, which is a real tragedy. For me and my family in the Deaf community, Deaf is to have a culture of speaking with hands, to use light as a way to signal. I'm really proud that I'm bilingual and that I can speak with my hands but also with my tongue."

"We are just as diverse as anyone else and [want people] to see beyond disability and to see our culture is about inclusion," she said.

Her mother Gillian goes further, and says while societal attitudes towards Deaf people have improved in her lifetime, there is still a long way to go.

"Many things still need to improve around education for deaf children," she says. "We need more awareness in the mainstream about our community, our struggles, strengths, our culture and our language."

From ABC online, <https://www.abc.net.au/news/2018-04-21/jodee-mundy-is-a-coda-hearing-daughter-in-a-deaf-family/9676300?fbclid=IwAR1H6iXcduoK3vrQWjbF7Iftz299W-001PHboGFptukF-KcITL-DKGcKWuE>

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The Congress theme, *Power of Connection*, will centre on the following topics over 4 days:

- Hearing and deafness – audiological and neurological perspectives on development and functioning
- Language and communication development and skills – spoken, sign and written language
- Technology – new developments for identification, access and education
- Education in classrooms, schools and systems
- Early childhood, primary, secondary and post-school education
- Curriculum, instruction, assessment and achievement
- Families, peers and friendship groups
- Parent advocacy, associations and support
- Resilience, wellbeing, self-advocacy and mental health
- Communication access through technology, interpreting, environment and media
- Deafness, disability and diversity in society, law and politics (national and international)
- Specialist teachers – their role, training, continuing education and professional associations

Interested in interpreting for ICED 2020? Expressions of interest are now open for Auslan and International Sign interpreters: www.iced2020.com/access

Want to be part of the Program? Submit your abstract by Friday 25 October: www.iced2020.com/abstract-submissions

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DEAFNESS FORUM OF AUSTRALIA

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Hearing loss still a challenge for kids

Children born with hearing loss are now routinely diagnosed within weeks of birth – having hearing aids and cochlear implants fitted well before school. So why are they still lagging behind their hearing peers in language?

By Dr Valerie Sung and Dr Peter Carew, University of Melbourne

In the last 20 years, we've made dramatic advances in the early detection of hearing loss in newborn babies and in providing early access to hearing aids and cochlear implants.

For example, since 2012 in Victoria, the median age at which hearing loss is detected in newborns is measured in just weeks; this compared to a median 20 months of age back in 1989.

And in 2018, [more than 2,800 Australian children were fitted with either a hearing aid or cochlear implant](#) for the first time, many within the first year of life, and the majority prior to starting school.



Children are being diagnosed with hearing impairment within weeks of birth, allowing hearing aids and cochlear implants to be fitted much earlier than in the past. Picture: Getty Images

Given this massive improvement in early detection and intervention it could have been expected that hearing impaired children would have quickly come to enjoy the same language and educational outcomes as their hearing peers.

But, this hasn't happened consistently for all children and we don't know why.

The big improvements in early detection have been driven by the widespread adoption in Australia of [universal newborn hearing screening](#) (UNHS), which was first rolled out in New South Wales in 2002 and 2005 in Victoria.

This involves playing soft clicks into the baby's ear while they sleep. Small recording pads on the baby's head and neck measure the baby's electrical responses to the sound.

But, while we have seen some improvements in language outcomes for hearing impaired children, according to a [recent study](#), they still have much poorer outcomes compared with their hearing peers.

What's more, the same study showed that for those children with mild hearing loss, there has been no clear improvement in language outcomes.

This is a major problem.

Globally, up to three in every 1000 babies are born with some level of hearing loss. In Australia around 350 children a year, or the equivalent of one child every day, is diagnosed with a permanent hearing loss.

Systematic reviews of published evidence suggest we have a long way to go with understanding what works best for children with hearing loss.

For example, there is no consensus on what intervention works best for developing spoken language in children with hearing loss.



A baby undergoes a hearing test. Picture: Courtesy of the Victorian Infant Hearing Screening Program (VIHSP)

The evidence that does exist hasn't been validated by experimental controls, and is somewhat focused on the outcomes of children with cochlear implants – those children who have the greatest level of hearing loss.

Yet, the majority of hearing-impaired children have a milder degree of hearing loss.

It may be then that a 'one size fits all' approach may not be the most effective way to assist impacted children achieve language outcomes that match their cognitive potential.

Indeed, babies and young children identified with mild hearing loss have, until recently, gone undetected.

Historically, prior to the introduction of UNHS, these children didn't receive a diagnosis until much later, usually when problems arose at school. Now that we are identifying them early, we need more research to identify the best ways to help these children.

Is it possible that children with mild hearing loss don't benefit from hearing aids to the same extent as children with more severe hearing impairment?

Do we have an issue with terminology, where parents consider a 'mild' hearing loss as something not to be concerned about and, therefore, they may feel early intervention is less important?

(Ed: are children who might benefit from learning Auslan not being given access to this second language?)

Is the impact of hearing aids cumulative, where each and every day the child consistently wears their device it adds to a 'bank of benefit' for their language development overall – helping them to reach their potential through this cumulative auditory experience?



There may be no "one-size fits all" approach to helping hearing impaired children learn language. Picture: Getty Images

And how do we help families persist with consistent device use, if this really helps, when their child seems to respond normally even when not wearing their hearing aids?

(ED: Are children who would benefit from Auslan not getting access to learning it?)

These are just some of the many unresolved research questions around hearing loss in newborns.

To help find answers to these questions, we need large observational studies representative of children with all degrees of hearing loss followed over long periods of time to capture their outcomes, as well as rigorous population-based intervention trials. To date, these are lacking internationally.

This is why the [Victorian Childhood Hearing Impairment Longitudinal Databank \(VicCHILD\)](#) is so important. It is a unique statewide databank of hearing-impaired children designed to help researchers all over the world understand why some children with hearing loss adapt and thrive, while others struggle.

The databank has been developed over the past eight years, and has been built on a body of work going back 25 years by researchers and clinicians from the Royal Children's Hospital, the Murdoch Children's Research Institute and the University of Melbourne.

More than 800 children and their families have now provided baseline hearing, clinical, sociodemographic, health service and quality of life data along with saliva samples – with most families consenting to have other personal data linked into the database and agreeing to be re-contacted for future research projects.

The children in VicCHILD are assessed at key developmental timepoints – around two, five and 10 years of age – for their language, developmental and quality of life outcomes. To join the VicCHILD study visit www.mcri.edu.au/vicchild or email vic-child@rch.org.au

From *Pursuit*, The University of Melbourne, <https://pursuit.unimelb.edu.au/articles/hearing-loss-still-a-challenge-for-kids>

Comments on Facebook



"Hearing aids, cochlear implants do not equate to language acquisition - they are medical aids to assist. One size does not fit all of course that's true. A holistic approach for each individual is so important. Parents are given minimal information about Auslan and the Deaf Community for example. Maybe it's time for the medical profession to open their doors to allow this to happen so parents can make a holistic pathway for their child."



"My takeaway from this article is that concern is not so much in this case towards Deaf children but towards finding out why children with mild loss are struggling. These would not be children getting CI, they may not be getting much help at all because they retain fairly good hearing levels which they can get by with. I don't think this is an argument between signing and CI for these children. This research shows a need for parents to be aware of the impact a mild loss can have."

Free Auslan posters

These free, colourful posters provided by the Western Australian Association of the Deaf are available to be downloaded and printed for display in schools, childcare centres, workplaces, in the home, and to share with friends and family and more.

2019 FREE AUSLAN POSTERS



<https://www.waad.org.au/free-auslan-posters?fbclid=IwAR1IkoDzX7BnJm53R9UwE-jRvktaET31XQxGyirJ4mOgoqNbUVh5xCQh1vU>

When Elizabeth Karn gives evidence to the Aged Care Royal Commission she will tell them how she is falling through the cracks

Along with her husband, Walter, Mrs Karn is profoundly deaf. She would have been eligible for financial support under the NDIS for an Auslan interpreter to help her at her appointments or other occasions but by the time it was rolled out in the Wollongong region, where she lives, Mrs Karn had passed the NDIS age threshold of 65.

Now 68, Mrs Karn doesn't feel old, but is struggling to navigate the aged-care system. So far, to no avail, as the system does not fund government-funded Auslan interpreting services, which run to about \$240 for up to two hours. This is despite a government commitment to "consumer-directed care" in aged care.

"We feel like we don't belong in the same category as people accessing aged-care services. We are still active, many of our friends are still working," Mrs Karn said, through her daughter Tina, acting as interpreter.

"We don't need help with our shopping, cleaning or personal care, like others in aged care. But at the same time we feel excluded, neglected and isolated from our community because we can't access an interpreter, a service that would mean so much to our quality of daily life."

"Where do we belong? When are we going to be included and accepted as being valued as other Australian citizens?"

The 2016 census identified 871 deaf people over the age of 65.

They are not the only ones who feel they are falling through the cracks in the aged-care system, as the Aged Care Royal Commission will hear when it examines the aged-care needs of people with diverse backgrounds, experiences and characteristics.

From an article in *The Australian*.

Mrs Karn will give evidence to the Royal Commission on Friday 11 October (after lunch). Watch the webcast from 9.30am Melbourne time, <https://agedcare.royalcommission.gov.au/hearings/Pages/Webcast.aspx>



Are you a cochlear implant recipient in the NDIS?

Cochlear is collecting information about the experience of cochlear implant recipients with the National Disability Insurance Scheme. All responses will be anonymous.

Sharing your feedback is easy – simply go to <https://www.surveymonkey.com/r/CochlearNDISSurvey>

Advocacy Conference

Monday 21 October 2019. 10:30am - 3:30pm. Jasper Hotel, 489 Elizabeth Street, Melbourne

Presented by Australian Federation of Disability Organisations.

Keynote Speaker - Senator Jordon Steele-John, Disability rights advocate and member of the Australian Greens.

Book your FREE ticket at

<https://www.eventbrite.com/e/afdo-next-wave-advocacy-conference-2019-tickets-71639376303>

Registrations close Friday 11 October at 5.00pm.

For enquiries, email Helen at helen.cameron@afdo.org.au



Annual General Meeting

Members and friends of Deafness Forum of Australia are invited to attend the Annual General Meeting at 3:00pm Friday 15 November 2019. The venue is the Australian Hearing Hub at Macquarie University, Sydney.

Main business: approve the minutes of the previous annual general meeting; matters arising from the previous meeting; confirm appointment of directors; receipt of the audited financial statement; and to appoint an auditor for the next financial year.

Consumer organisations that are current financial members may nominate a person to represent hearing-impaired people on the board. A nomination must be received by cob 15 October. To learn about making a nomination, contact us on info@deafnessforum.org.au

Know someone who might like to get their own One in Six?

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

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, and to elders past, present and future. We acknowledge the challenge of overcoming high levels of ear health issues among First Nation people and its role in Closing the Gap. We acknowledge the risk to indigenous sign languages and the importance of Auslan.

People with disability have and continue to be subjected to isolation, exploitation, violence and abuse in institutions. We thank the Australian Parliament for its bipartisan support of a Royal Commission into the evil committed on people with disability.

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.