Submission by Amy McGinniskin and Millie Burrows

We are two young women who are profoundly deaf as a result of a genetic disease called Neurofibromatosis Type 2. In response to the public inquiry regarding disability support and care we submit the following thoughts and ideas:

Amy McGinniskin

I grew up as a hearing person in a small town in country Victoria. When I was 18, I began to lose my hearing in one ear. I was in the middle of year 12 when a diagnosis of Neurofibromatosis type 2 was made to explain my hearing loss. Neurofibromatosis type 2 is a genetic disease characterised by bilateral acoustic neuromas (tumours on the hearing nerves). I am now 24 and have subsequently become profoundly deaf. I also have other disabilities because of the complications of this disease. Becoming deaf has brought into stark relief the challenges and barriers that not only deaf people, but all people with a disability, face in their everyday lives. It was a massive adjustment, for example, to go from being a hearing person at school, to a profoundly deaf person at university. The gap between what I could learn as a hearing person and what I can learn now as a deaf person in a hearing environment is, I believe, large. The gap between how easily I could interact with the world around me as a hearing person and how difficult it is now as a deaf person is large. The gap between what was accessible to me as a hearing person and what is accessible to me now as a deaf person is large. I believe we can close the gap.

I believe the mental well-being of people with disabilities and their carers should be a priority. I believe the well-being of the whole person should be taken into account. When I first became deaf, I was having therapy with a speech pathologist (to help with facial paralysis resulting from the operation to remove the acoustic neuroma which left me deaf) and she said, “Don’t despair. You have so much to offer the world.” I wanted to believe her, but I found it incredibly hard and was at my lowest ebb. But I believe now that I, and all people with a disability, have good things to offer the world, if only given the opportunity.

I have seen firsthand how disability impacts upon a life, in both myself and my family. Both my father’s brothers have recently passed away due to complications resulting from lung disease. They were both in their early 60’s, and in the last years of their lives needed to wear oxygen masks constantly. They could walk only a very short way without getting out of breath and needing a rest. This meant that my uncles, who grew up with my father on a grape block in the Mallee on the Murray River and were active, outdoorsy people, were cut off from their usual activities which gave them so much joy – such as fishing and camping. They kept up their spirits remarkably well, but it inevitably took a toll. I believe in the old proverb which states that the rules for happiness are something to do, someone to love, and something to hope for. If we can try to ensure these rules are applied to people with disabilities in taking into account their care and well-being, it would be a great thing.

These are a few thoughts I had in regard to the Disability Care and Support public inquiry:

Supports for people who are deaf and hard of hearing:

- Live remote captioning is provided at my uni for people who are deaf and hard of hearing where a stenocaptioner types up everything a lecturer says and it is sent to a laptop in their possession. It is really good for me. I think widespread use of this for deaf and hard of hearing people in education settings would be very beneficial. It provides deaf people with all the information exactly as the teacher presented it and can be used in any setting where most of the people are hearing, so deaf people can gain information as it is available to hearing people. It can be used where subjects are complex and Auslan interpreters do not have the depth of knowledge to fully convey the material as it's presented. It gives the user a degree of independence over their own learning. It makes it easier to engage with the subject material. It would be most beneficial in settings such as lectures, seminars, forums or meetings, where there is one or a few speakers and the length of duration is more than half an hour, and so could probably be used also in the workplace. It requires technology, though, and training for the user and for the stenocaptioners. I saw on the TV show The New Inventors recently, that a deaf person has invented a similar device where a teacher wears a microphone and the audio is received by a person listening in, who re-speaks everything and it is converted to words on a computer, which is then sent to the student who receives the text with only a few second delay. I think the use and development of such a device would be greatly beneficial to deaf and hard of hearing people in a learning or workplace environment. The inventor made the point that Auslan interpreters are expensive and also that deaf and hard of hearing people do not always have good English writing skills due to Auslan being their first language. Live remote captioning could help in both these instances.

- At uni, sometimes there are things outside the academic framework that I feel I might like to be involved in that I don't have access to, such as counselling workshops (where students learn how to stop procrastinating or deal with stress) or career forums. It would be good if the counselling service, career service or other university services, whatever they may be, at any university tries to include at least one or a few programs a year that are accessible to people with disabilities, as these things enrich your experience at uni.

- The last thing I thought of was about Auslan interpreting. I do not know how it is funded but I do know that in many situations, such as at doctor's appointments and in hospital, when interpretors aren't provided I rely on my family for communication. I think it's really important in those situations too, for your peace of mind, to know that you are getting all the information. Ensuring funding and provision of Auslan interpretors is important to me.

Supports for people with disabilities in general:

- I think there should be more places available to disabled children in schools with specialist care, and I think these places should be government funded. The British have a good system for funding such places. I don't know exactly how it works, but every child with a disability has a right to a place at a school with specialist care, funded by the government (I think). We should try to emulate this.
- Less reliance on charities to provide basics such as education
- I think the new support system should focus not just on the everyday needs of people with disabilities, such as food, housing, etc but also ensuring their time is employed in such a way that they can contribute to society and therefore build a sense of self-worth. Ensuring that mental as well as physical needs are met is important.
- I think more support should be in place, for those in aged care, to contribute to society in a meaningful way. My grandfather had a stroke a few years ago and so needs supported living. He lives in a hostel. Because of his stroke, his driver's licence was taken away. He lives in a rural town on the Murray River where cars are the only means of getting around as there is no public transport. As a result, his independence, very important to him, has been taken away. He used to be a farmer and still owns a bit of land on which he would love, now, to keep his mind active and

give him something to hope for, to put in a crop or keep some cattle. He would need support, however, and transport to achieve this.

- I don't think any child should be the full-time carer for a disabled parent - support from outside in such a case as where this may occur.
- Funding for specialist support, where required, which will greatly enhance a person's chance of reaching their potential, such as kinesiology/brain gym in cases of learning disabilities such as dyslexia.
- Identifying early and putting in place adequate support for people with learning disabilities.
- Greater support for people with disabilities in rural and regional areas.

Millie Burrows

The key issue with deafness is always communication barriers, stemming from that is potential social isolation. I used to be a very social person, since I lost my hearing I've had a fair amount of problems with this. All of a sudden I lost almost all my friends who I could no longer communicate with easily.

I have found deafness, isolation and my inability to partake equally in society to be highly detrimental to my mental health, social skills and thus also self esteem. When I do socialise I find I don't quite know what to do with myself and how to approach people socially because I'm so used to being on the outside, just minding my own business. I have been diagnosed with depression. For me, a trigger to a depressive episode seems to stem from being alone for long amounts of time and my lack of sense of belonging somewhere in society, as well as loss of hope in being able to progress with my social networks and even a career. I know a key issue for many deaf is something of an identity crisis, of where do I fit in.

How interpreters or other means of access can be provided in ways to overcome this I do not know.

With regards to primary school and childhood, I was not deaf then myself so I'm not sure of current provisions and associated issues with them. I think it's important to receive language assistance in some way to socialise. This could be by way of interpreters available not only in class times but also for social purposes and/or other students learning to sign, perhaps sign language being incorporated into the compulsory curriculum.

Currently I'm a University student. Universities by policy only provide assistance in class, this means I haven't been able to join clubs and things like other students, nor partake in study groups organised by other students so I'm left out. By the end of the first few weeks of a new semester everyone is walking around in little groups except me. I still barely know the names of any other students in my course two years on. I've given up trying to make friends, my fellow students don't want to write stuff down all the time and it doesn't work for group situations. Not having friends has made it hard to find partners for compulsory group work and this has been detrimental at times to my belief that I hold any hope of obtaining work once I finish my degree.

I think it would be essential, arguably more so for a young mind of primary school age to feel included, to learn how to make friends and build teams socially. To feel they are of equal worth, equal contribution and thus equal potential to everyone else.

It’s not discrimination to not provide means of social interaction, that’s my problem but I've found no way out though I've tried and tried. Perhaps this could be something that could be combated by having my own 'allowance' to use for interpreter provision for extra curricular activities of my choosing. I think deafness would need to be raised as an individual issue, that is, an issue unique from other disabilities in order to be considered for this. There’s currently nothing.

Within my own time, I have no access to most extra curricular activities. Community events, for example council run festivals, workshops, activities at the library or tours at the museum, public lectures, and so on. Chances are there will be no interpreter. This is a huge barrier to community involvement. I think it’s possible to make an application for provision if its council run, or alternatively by an organisation that is financially able but I’m not going to undergo a huge legal process every time I want to go out for the afternoon. If it’s late notice that I hear about the event from a friend, which it frequently is, then of course it’s not possible. Again, having my own allowance, some sort of easy, immediate access to funds could begin to break down this barrier.

Another issue is assistive technology that is adapted for hearing impairment within the home. This includes smoke alarms, flashing lights for the phone, an alarm clock that vibrates, a baby alarm for parents. As far as I’m aware it’s all paid for by the individual. There was a one off opportunity some time back to get smoke alarms with a light fairly cheaply, I grabbed one. The thing is I’d have to be in that room to see it. Ideally I should have one in every room, if I’m asleep the house would burn down around me. Given it’s a life or death issue one would think the Government would provide but they don't.

The above leads me to wonder about the situation in rental properties. Properties must by law be fitted with a smoke alarm, but if the tenant is deaf, must that alarm have a flashing light? I think it unlikely and I highly doubt the landlord would fork up for it by choice! If they had to pay by law I think we'd just see another case of indirect discrimination in landlords not accepting deaf tenants without them admitting this as a basis for their decision. I don't have lights for my TTY, I can't afford to purchase and have them installed so I usually don't give out my landline number as I always miss the calls. This makes is hard for many people, such as the hospital to contact me as many do not use email nor have mobiles for communication with patients. This limits my independence which affects my self esteem.

The treatment of my medical condition involves periodic surgery for my entire lifespan, frequent MRI’s and frequent outpatient appointments. Naturally, I spend a lot of time in hospital. The hospital I attend is terrible with interpreter provision for outpatient appointments. I'm forever turning up and there has been some muddle up with the booking even when I've called several times to remind them. I'd like to do the bookings myself through a private agency to make sure I can always have an interpreter there and thus not have to waste 2+ hours travelling to and from the hospital, missing my classes at Uni and other things, waiting for ages in the waiting room, all for nothing, time and time again. I can't be given the funds to do it myself, that’s not how it works. Many times I have considered making a DDA complaint and I may at some point do this. However, I feel this will be a time consuming and stressful endeavour. It would be nice to avoid it and just get on with my life, I’d much rather spend the time studying. Again, easier, faster and more reliable access to provisions would assist.

When I'm admitted for an operation there’s no interpreter, they’re only booked for outpatient appointments. Doctors come on rounds, they tell me how the surgery went, ask how I am, I have no idea what’s going on. I recall once being surrounded in my bed by a group of 10-15 doctors all at once. My mum was speaking to them and all of a sudden they all looked at me and laughed, evidently due to something my mum said about me. I would like to know what it was. My mum’s not very good with this sort of thing, she still sees me as the child and at 24, in situations like this I still feel like one. I think an interpreter should be there.

Alternatively, how hard is it to have just one staff member on every shift who, as a work requirement, has learnt some sign language?

If my mum didn't fly over from her home in New Zealand every time I have surgery I'd have no access at all, this means I'm not able to be completely independent from her. This is again, detrimental to my self esteem. Its somewhat difficult, I will admit, when the doctors come for a short time only every morning very early and its not always the exact same time. However rights are rights, I shouldn't be being spoken to, or spoken about without knowing what is being said about me, my care and my body. When I was 18 years old I underwent an operation that I now severely regret. I had not been properly informed of the potential outcome as I was relying on my mum to explain.

I have a small dog. He's a great help to me as he alerts me to sounds and is good company, deafness can be isolating. He's assistive technology on four hairy legs; I need him. However, during my stay in hospital there's no one to look after him. I cannot afford a kennel so I must constantly ask friends or housemates for help, as I do when I need communication assistance and there's no way to seek provision, when I move house (I can't drive due to my disabilities) and countless other occasions. This isn't what friends are for and I feel like a burden.

When I'm discharged, the hospital don't provide me with care or support. I had surgery on my spine while undertaking my VCE at the age of 21. I wasn't allowed to lift more than 1Kg which is less than a carton of milk. I couldn't cook, do my washing, and certainly couldn't get my text books off the shelf. My mum came over from NZ for a little while but she had to go, I strained to do things myself. With much trouble meals on wheels were organised and sometimes my housemates helped, though this turned out to be reluctant on their part. They suggested I move out because they didn't want to be in the position of looking after someone. I talked them out of it as it was only temporary.

Funding for disability support, as I think would apply not only to deaf people but those with other disabilities also, is limited to public education. This means that there is plenty I have no access to. I can request provision, and under the DDA, so long as an organisation can't prove they are not financially able they must provide it. However, as already stated this is a long and arduous process, one that I have always walked away from, accepting that the door is closed to me. It would be nice to have a user friendly, easy way of enforcing the Disability Discrimination Act.

In summary;

The greatest support required by deaf and hard of hearing people are language and communication aids, greater provision of Auslan interpreters in clinical settings and more ease in setting this up, greater inclusion in community and extra-curricula events (through provision of Auslan interpreters and/or captioning), and a greater focus on the mental well-being of people with disabilities. In an ideal world, we might hope that the things we could achieve in a given week are on a par with people without disabilities. When we go to uni we might hope that we have access to all the information and activities available to all people. We might hope that we have a supportive social network at uni, as most people take for granted. We might hope that we can attend a doctor's appointment without anxiety at missing vital information. We might on a whim decide to go out to a community event with friends and, in an ideal world, we might hope the program will be accessible to us. These things we hope for, if only an ideal world were accessible to us. Thank you sincerely for your time.