

## System failures

There are a number of system failures which could prevent complaints if fixed.

One of my jobs is marking assignments for a Uni paper in Australia called 'Auslan (Australian sign language) and Deaf community health and wellbeing'.

The unit teaches them some Auslan. But in my role I have the privilege of marking the written assignments. They must identify barriers for Deaf in their area of health. Summarise and analyse 3 pieces of current (last 10yrs) research relating to Deaf and their area of health. Then they must recommend improvements and challenge their own recommendations.

Research indicates many Deaf health and wellbeing issues are the same in Deaf communities all over the world.

Briefly from my lived experience and as a marker, the biggest problem is communication access and cultural awareness, and lack of [health, education, rights, English] literacy. These are the issues constantly repeated. Recommendations are always to add more funding and make sign and Deaf culture compulsory for all health professionals.

While that would be nice, if we want a successful outcome a more realistic approach might be considered.

If we had hubs for Deaf to access primary health care and advocacy services in NZSL. It might be provided online, and/or in main centres where larger populations of Deaf gather. A safe place to connect.

Having a number of health professionals specifically trained in NZSL and Deaf culture awareness who could be first point of contact for Deaf, in person, or online would help. They could be a go between for the Deaf person and the health system who might not know how to provide access. All hospitals should be equipped with a device specifically for connecting to the VIS relay in a situation where a Deaf person arrived in need of immediate support. That device could be loaded with some simple keyword signs that can be used in a health setting.

A register of health professionals fluent in NZSL who would be prepared to communicate in NZSL would be helpful. Not to replace an interpreter role, but to have a language and cultural understanding is so important for the trust relationship. I know of 3 doctors who are fluent in NZSL but it would be good to have a register so Deaf know who can connect in NZSL.

Deaf health and well being is more than just knowing the language. The culture, and the barriers need to be understood to be able to offer proper support.

Offering a paper/unit at med schools in NZ like the one I am working on in Aussie would be a great start to helping educate the wider medical profession about working with Deaf NZSL users. I don't think we can ask for it to be

compulsory, but surely we can ask for there to be that training available for those Med students who have the compassion and interest in it.

The reason Med students are so important to reach and educate, is because the Deaf community, those who have the lived experience know the solutions better than the hearing people trying to impose their own solutions.

From birth Deaf children are given a message that they are broken, not fully perfect, defect and need fixing to be like the hearing kids.

Some people look at Cochlear implants as a miracle of science that allows the poor deaf child to become hearing. Or at least 'better' in some way.

I don't support that message for deaf children. I want them to grow up knowing they belong to a rich culture, with a valid language which is their taonga, the keys to their empowerment.

Some view CI as child mutilation. Drilling a hole in a child's head and poking an electronic device which will force noise pollution through their skull, giving them a lifetime head injury, with some children being expected to wear them all day, causing a hideous kind of noise exhaustion which can result in nausea and vomiting. While 95% of what hearing people complain about is noise.

The health system pushes the lip reading myth, that Deaf can lipread. The best lip reader in the world can only pick up 30% and that's someone skilled in English (which most Deaf are not) and assuming the person is speaking clearly, when most don't. The real 'lipreading' is not lip reading at all, it's predicting what might be said, and looking for visual cues or words you might know, and seeing facial and body expression, etc, there is a huge range of skills used to determine what is being said, and with 1000's of words having the same lip pattern, reading postage stamp size lips is a very inexact science even for those skilled in English. The health system peddles the lipreading myth leaving hearing people believing its a real thing.

Because of the cultural/linguistic disconnect between deaf children born to hearing parents, many deaf children never learn NZSL at all. Current stats show about 10% of children with severe/profound hearing loss are learning NZSL. Some Parents tell me they don't need to learn NZSL because their deaf child can speak. How disempowering for those kids left without their language of empowerment, while they put in all the speaking, listening and 'lip reading' effort, missing vital information for the rest of their lives, while their families carry on in blissful ignorance of the information they aren't getting through tech aids.

NZSL is given a backroom tokenism type of acknowledgement delegated 'not as valuable' as speaking and lipreading, yet it is the language of empowerment for any person with hearing below the speech banana. The fact that only 10% of Deaf are learning NZSL is alarming. Interpreters

become unavailable to them in any of life's many situations where aids don't provide enough information.

Speaking to literacy.... English is extremely difficult for Deaf to learn, and the easiest way is to give them strong NZSL education and teach Deaf English as a second language. Everything about English is hearing orientated, and most born Deaf don't have English literacy beyond 12-13yr level.

Part of the reason for that is because the teachers of the Deaf aren't able to stretch their comprehension and vocabulary because they don't have enough NZSL fluency. Also a problem because deaf children are being taught English as a 1st language and not as a first language.

I really appreciated what Kylie said about needing a partnership between the Deaf community and the hearing 'experts' who are guiding parental choices. Why would anyone deny NZSL to their deaf child? Who would advise that? Its nonsensical.

But if most of the advice is coming from the hearing medical profession who believe deaf kids need to be fixed, then thats the only perspective parents have.

We have 6-10 Deaf teachers, (myself included) who have done teacher training because they want to make a difference to deaf kids education and teach through NZSL, but when they get to the end of their training they are told they have to work 2yrs in a hearing class before they can train as a teacher of Deaf, and the people training teachers of the deaf can't sign. I lasted 1yr in a hearing class with no interpreter support and burnt out and never went back.

Zero credits for NZSL fluency/ability in the Teacher of Deaf course (meaning there is no requirement to be fluent in NZSL), and when Deaf teachers apply for positions, hearing teachers are given preference. I passed in the top 5% in my degree, but hearing people decided hearing teachers who could not sign had more to offer deaf students. 25yrs deaf kids have been without my skills because the hearing people in power positions don't 'value' NZSL in Deaf education. Plenty of lip service but little **action**

All of these systemic failures are important because they are the root of repeat barriers Deaf experience every day, and are the root cause of most complaints.

**UNCRDP**

The UNCRDP principles are founded on nothing about us without us. Implying a 2 way conversation/discussion, yet the Deaf DPO who claims to be the voice of Deaf, has secret 'non disclosure' conversations between 2 hearing men in positions of power, discussing Deaf issues under 'obligations of confidence'. I understand this is allowed under OIA legislation, and the lack of real legislation around the UNCRDP principles, allows it to happen.

## **Voice of Deaf**

Deaf Aotearoa claims to be the 'voice of the Deaf community', yet their membership is barely 2000, and of that only 500ish use their even though they monopolise funding for most of the services. I removed my membership when I was told my membership means they get to be my voice.

I can't speak to the experiences of others, but my experience is that I get told from Deaf Aotearoa what is happening and don't get asked. I'm consistently victimised and lied to when I try to stand up for my rights, and actively prevented from supporting my community and silenced when raising issues of concern, as part of the victimisation.



This action clearly showed the board chose business interests (which is what it is required to do under the constitution), over and above the DPO role of putting the Deaf community interests first. Which is their absolute right to do so as a business. But not as an organisation representing the community who voted this person to the board of the DPO 'Voice of the Deaf' community

During covid lockdowns, DANZ actively voiced to government (apparently on behalf of Deaf but I never knew about it) telling government who select service providers, that they have an obligation to chose Deaf Aotearoa for all of the funding and they will decide on any sub contractors if any.

They told MOH that other service providers, including valid and capable Deaf owned businesses should not be used by government and only Deaf Aotearoa should be used for all things related to the Deaf community.

## **Choices**

Having a monopoly business acting the dual role of DPO/business robs the community of their own voice (because DANZ doesn't engage with the community except to speak at us in a paternalistic manner. There isn't any 2 way conversation allowed, and anyone who objects to the decisions of the hearing management is quickly silenced.

The board is bound to the benefit of the business, so that is their priority.

Having choices is the natural way for business to thrive and survive.

When there is a monopoly of funding, and a control of the 'voice' driven by business and profit, it encourages corruption and robs service users and providers of experiencing a world of choices.

Just like not all Disabled people are the same, All Deaf are not the same either. Currently most of the funding goes to one company, masquerading as the 'Deaf voice'

Sharing the funding with other Deaf run businesses is important. We don't want a DPO that excludes Deaf who are in business, but we can't have one business that is solely recognised as the 'Voice' of Deaf'.

Enable good lives funding is a good way to help Deaf have more choices about the support they need, and helps to ensure healthy competition for support without one company monopoly, and external people deciding for us. Sadly only 2 regions in NZ offer EGL funding access so it's a postcode empowerment lottery.

Some legislation or better systems to prevent monopoly biz interests being able to capture the Deaf 'voice' would be great.

## **Education NZSL**

Deaf kids. The Deaf community has been asking government for decades to improve the access to NZSL education for deaf children. I have a letter from the government in 2001 telling me that all deaf children would have access to NZSL if their parent chose it. There was the Human Rights report in 2008, and recently the ombudsman report on failures of deaf children accessing NZSL education.

Despite all this 25yrs later still only 10% of Deaf children accessing NZSL education. Its worse than it was 25yrs ago, even with NZSL having been an official language for nearly 20yrs.

Deaf teachers are training, and then can't get jobs working with deaf students unless they teach 2yrs in a hearing class first. Mainstream schools have a ratio of 1:30+ and Deaf schools operate on a bout 1:7. So every Deaf child placed in a mainstream school is losing by 1/4 in attention of teacher/student ratio, without factoring in all the other challenges like background noise, and visual distractions, and the noise exhaustion that all creates.

For the Deaf community, the Deaf school is the hub of the culture and the language. Its the Marae of the Deaf world. Its where deaf kids go to escape the label 'broken' and deficient' and they discover their tribe vibe. Others who the same as them and speak their language.

Deaf schools are where the connection, the identity and the communication begins for Deaf. Just like Maori whakapapa back to their waka, Deaf will whakapapa back to their Deaf school. Once that happens more connections are made around who was at the school at the time. Deaf schools are rich and meaningful taonga for the Deaf community but there is a huge effort to shut them down.

Mainstream deaf kids miss out on those connections, although KIT (keep in touch day) has helped. As well as being in a difficult learning environment, where they are different, there are also the challenges of having teachers who can't speak in the natural language of deaf children (NZSL), and are forced everyday to communicate through their weakest senses. (Aural/oral)

One of the reasons learning NZSL is so vital for deaf children, is because if they ever find themselves in a difficult situation where they can't pick up all the information required (aids and CI are not perfect hearing), they can't access a NZSL interpreter if they don't know NZSL

This is complete and utter disempowerment, and unnecessary vulnerability. Every person with hearing below the speech banana should have access to NZSL learning, because it is so empowering! Disabled doesn't have to be disabled by the system. Deaf kids don't have to miss out on Deaf school, and NZSL access. It should be for all those who might be missing speech sounds.

NZSL in schools is vitally important for any hope of empowering UNCRDP. NZSL needs to be promoted in high schools for hearing students. They are the key to building better bridges between the hearing and Deaf communities. Those who are fluent in` NZSL can really make a huge difference, and they become the bridges between Deaf and hearing worlds.

NZSL is an ideal language to suit visual tactile students who are often labeled as mischief in schools. NZSL is a language they could gravitate to, providing more job opportunities, and maybe some will end up as NZSL interpreters which we are badly lacking, and we can't keep relying on CODA (children of Deaf Adults)to fill those roles.

Having NZSL taught in mainstream schools to hearing students also improves the mainstream environment for deaf students who might be trying to learn in mainstream. Its a win/win. But 20yrs later, the government is still so slow with progress.

Legislation is required so that those who prolong or stall the process can be held to account when they deliberately disable.

## **NZSL Interpreters**

Every government interaction with Deaf should have a qualified NZSL interpreter, especially when they instigate it.

The Deaf community needs and values NZSL communicators (unqualified), but not in the interpreting role.

Complaint systems need to be a safe environment for Deaf and interpreters.

## NZSL empowerment

Knowing NZSL, empowers Deaf to access interpreters, and learn about their culture, and form their identity in a healthy positive way. Drilling a hole in a babies head and poking an electronic device with constant noise (not the clarity you might enjoy) all day, sends a very strong although unspoken, message that you're not right and need fixing. Many in the Deaf community would prefer the deaf child grow up with a communication platform based on strengths (visual/tactile), as opposed to communication platforms which require deaf kids to rely on their weakest sense.

Its quite ridiculous. Have never seen a blind child asked to 'look harder'? Absurd!

Yet deaf kids are required to forgo their education time for speech therapy to learn to 'speak', even though speaking helps everyone else except them. They still can't hear, regardless of being expected and demanded to try, while their formal education in NZSL is almost totally neglected.

Many hearing Teachers of Deaf (ToD) can barely sign a simple basic sentence in NZSL, yet are given the position of teaching deaf students over and above Deaf teachers fluent in NZSL.

Its literally the same as having an English speaking person who can barely speak Maori, teaching in a kura kaupapa Maori school. Most Teachers of Deaf who do sign, use sign in English grammar which is completely different to NZSL structure. Deaf want to know the topic first so we know what is being discussed first. In English the topic comes last. A river of words to wade thru before you know what's being discussed.

'Best practice' is what they call it in Deaf Ed, yet even an idiot can see there is no meaningful progress, few good learning outcomes. Many deaf kids have no language access at all until well beyond language learning ages, and most don't get past 13yr reading age. Not because they can't, but because the ToD don't know their language and can only take them to 13yr level with limited NZSL. Imagine the equivalent of putting someone who could barley speak English in charge of a mainstream class? Having ToD who aren't



fluent in NZSL produces the same result, but it's deaf who are blamed and assumed not to be clever.

All of these issues mentioned end result in higher mental health issues for those in the Deaf community, largely due to communication issues/access.

## **Educating the Public**

Educating the public is a huge part of achieving better outcomes. Its super hard advocating for you rights when others aren't aware of them.

Example: thru covid mask wearing the NZSL messaging from MOH was all about being respectful of people who wanted us to wear masks, yet mask wearing (its written on the box that they don't protect from viruses) was an exemption for Deaf who needed to communicate. But no messaging teaching Deaf they have a right to ask people to remove their mask or education for those who might need to remove their mask for a Deaf person

Most of the positive/negative in NZSL is fully on the face. 'I understand' and 'I don't understand' uses the same hand sign but the difference is found in the facial expression. NZSL uses the face and the hands to communicate.

The ridiculousness of having masks with clear windows for lip reading was just ridiculous. I guess its what you expect when 1 organisation, managed by hearing people, are deciding outcome for Deaf.

If I had a dollar for every time the person 'hung up' on me thru the relay, I would be rich. Zero public education around why they should accept a relay call from a Deaf person. I have never seen any public education about the Deaf ph relay service.

Maybe MOH could siphon some of the advertising money from the failed vaccine and use it to put some valuable messages in the minds of the public about how to treat a ph call thru the relay? How about making the daily news NZSL accessible.

## **Accountability**

Here we come to the foundation of all of the failures.

Without proper systems of accountability, there is no change.

Without legislation which supports the principles of the UNCRDP, there can be no proper accountability for failures and Ground hog day continues for the Deaf community.

Things only change when/if the accountability process leads to the system changes which prevent it being repeated.