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"A Different Light"

A Different Light - 15 January 2022 - "Jonny Wilkinson looks at Disability Sector and Covid"

Let's celebrate the home-grown rock stars of the pandemic – Michael Baker, Siouxsie Wilcox , Amanda Kvalsvig , Amanda who? Indeed- Kvalsig has been a leading epidemiologist advising the Government on New Zealand's pandemic response alongside her Otago epidemiologist workmates including Michael Baker and Nick Wilson. Maybe she's missing the punch of Baker's spectacular spectacles..? No, unfortunately it appears that it's more to do with the fact that she *is* profoundly deaf, meaning that phone and radio interviews have not been readily accessible to her.

When I found this out, I immediately wanted to write about her, emphasizing the inequality of media coverage and disability. As soon as I started writing about her, however she immediately appeared on TV news that night. And then again! My theory and my story was severely diluted. Nevertheless, her story had captured me and I pushed on. I emailed her (using deaf friendly communication) and asked her a few questions. I wasn't confident that she would reply, as I was sure she is currently up to her armpits creating a virtual model of an Omicron tsunami. She did, however, reply very promptly and below is our question and answer repartee:

Have you been approached to be interviewed in the media to speak about Pandemic issues?

Yes, I've commented in the media over 100 times during the pandemic. That's been mainly as written comments for print and online media, because being deaf makes it difficult to access radio or live TV

interviews. That's meant that I have a much lower media profile than my close colleagues.

Do you use Sign Language?

I don't. I'm not from the Deaf community; instead, I'm 'small d' deaf, having lost my hearing completely as an adult. I now have cochlear implants. It's fantastic technology but while the implants give me a lot of sound information, I'm still quite dependent on seeing faces to communicate.

Years ago before I came to NZ I learned British Sign Language (BSL) to help me communicate better with Deaf patients; I loved being in a classroom that didn't require me to hear, but I was very much a new language learner and my knowledge of vocabulary and grammar was always fairly basic. I'm keen to learn NZSL when things settle a bit.

Do you feel you are you adequately supported in your role in regards of being Deaf?

Even before the pandemic, my role was demanding from the communication point of view. The pandemic has made some aspects harder, including lots of time on Zoom and battling to follow what's going on when people are wearing masks. My colleagues have been very supportive and the University has helped with technology solutions. People I interact with, including journalists, are good at taking my communication needs on board. But people will often underestimate what you're capable of if they know you're disabled. In many ways I have to find my own solutions, as I don't know anyone doing similar work with similar hearing. It can be pretty exhausting at times.

Has your research into syndemics included Covid19 and Disability?

Although the syndemics research programme was designed before the pandemic, we're linking it up with our Covid-19 research as there are so many crossovers between the two. I'm leading a syndemics project about people with underlying conditions and the added risks they face from infectious diseases. That's certainly one aspect where my work life and my disability come face to face.

Some of Amanda's answers were not what I was expecting. I realised I was jumping to my own conclusions. My initial impulse was indignant on her behalf- "Why aren't they interviewing her on TV, surely they can provide a NZ Sign Language Interpreter", not considering that she may not know Sign Language. I overestimated the power of television as opposed to written media, in which she was frequently quoted. I gormlessly didn't consider that the pandemic would make it harder for her to communicate because of Zoom and mask wearing. Disability is diverse and complex and it pays not to make any assumptions, even when you are sure you know what you are talking about. There is however an assumption one can safely make -and that is that disabled people can and do add value and a point of difference. In this case Kvalsvig holds a uniquely important disability perspective, as well as being a worthy additional expert in the rock star pandemic pantheon. Go Amanda, you're my Pandemic Rock Star hero!

Jonny Wilkinson is the CEO of Tiaho Trust - Disability A Matter of Perception, a Whangarei based disability advocacy organisation.