

## "Parents like us"

### A story of allyship after isolation, and payment after consultation 😊

REBEKAH CORLETT MNZM

JUN 20



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It's [National Volunteer Week](#) here in Aotearoa - a time to celebrate all the people who give their time and energy to support causes and/or groups for free. So **Thank You** fundraisers, workers, and supporters who keep not-for-profit organisations going; **Thank You** volunteer surf lifeguards, firefighters and all the other vital-but unfunded services in our community.

**Thank You** also to disabled people and whānau who VOLUNTEER their time, voice, experience, energy (and often trauma) to projects for the benefit of their community - and more often than not receive nothing in return, other than the satisfaction of being a voice for the otherwise forgotten.

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**Thank You** disabled people and whānau on advisory groups, who provide a valuable perspective of accessibility and inclusion. Our vulnerability and lived experience in health, education and in the community is a valuable commodity to some, but often not handled with the care it should be.



Fellow mums on our way to change the world...

## "Sacred and Triggering A.F Mahi"

Back when I was tentatively dipping my toe into the world of advocacy, I totally believed the hype being swirled around me at the time.

“You are your child’s voice, Rebekah.”

Oh FFS.

Yes, my daughter is non-speaking. Yes, my background is in journalism. Yes, I won school speeches at Naenae College in 5th form. But no, I am not her voice. She has her own voice, she has the ability to communicate, she has a human right to communicate. Lets brainstorm some ideas on how you can include her voice in a meaningful and accessible way for everyone. I can speak as a parent, of my own experiences, but I am not her voice. I’ll hold the mic for her until she is ready to speak.

This is a lesson that takes time to absorb for us parents, and back in the early days (say 10 years ago??) I totally thought I was her voice. I held the mic, and controlled the volume.

My journey with advocacy started with my original blog. It still exists online, its incredibly cringey at points and is a reminder to myself how far I have come... and how desperate for understanding and allyship. It serendipitously connected me to an online community of parents interested in equitable opportunities and outcomes for our disabled kids. We started pooling our collective skills from the careers we had to park due to the unsupportive education system that found us homeschooling, attending school part time, being unpaid teacher aides, attending meetings with the principal and filing Human Rights complaints.

It was an odd, but necessary extension of our parenting duties, as much a part of caring and protecting our kids as was clothing and feeding them. It was our strange new world, but it felt good to connect with other parents who just got it, and got on with it.

I would willingly give full days of my time to be involved in conversations with ministry around inclusion, education and accessibility and expect absolutely nothing in advance. Because I wanted to see change in the world for the betterment of my daughter, and other families like ours. I never thought of it as voluntary work, that was a more selfless, closer-to-god kind of pastime. but in hindsight, it totally was/is.

The investment of time, goodwill and cold hard cash was significant. This was well before covid, so no hybrid option for attendance - it was an hours train trip to the big smoke each way, leaving the house before 7am and arriving home hopefully before 6pm. I had to arrange a babysitter, and keep to our rigid daily routine that my daughter relied on as well.

Unlike the people being paid to attend representing organisations, I was constantly out of pocket. I didn't care because it felt like a giant swindle to get in the front door and spend a day watching people much more experienced than me swing their advocacy nunchucks in a room full of policy makers and rule changers. That was my payment. Hearing about disability from multiple different perspectives to my own helped me become a better ally to my daughter, to families and disabled people. I never once complained, maybe I should have.

This carried on for years, the meeting invites increased, and changed in topic and exclusivity as I gained more experience, and found myself on more contact lists as a 'voice' for whānau. It quickly became the equivalent of a part (sometimes full) time job, averaging about 20 hours a week - which was a lot when I was still juggling parenting on top of that. It was always the same - no payment for time, transport or energy, which was quickly becoming exhausting. The conversations were heavy at times, but I was still happy to be included.

It filled the void of social exclusion that parents of disabled children are familiar with. I found friends and allies in other parents, all similarly in the same boat - many of who continue to be a part of my every day life to this day. We plotted to change the world, through building networks of likeminded people and relentlessly lobbying for change through writing submissions. We shared our many ups and downs - supported each other through relationship breakdowns, school stand downs, teacher/doctor/family dramas with no judgement, and always laughter. So it's not all bad.

It's 100% true what they say about finding 'your tribe.' They become your shipmate, your anchor, and your compass - all in one.

## “Gold Nugget Trauma”

Parents like us are like gold nuggets for ministry types wanting to ‘engage’ with the wider disability community. We are clear, confident communicators. We can push out a well formatted submission with little effort. We turn up with pen and notebook already in hand, we know the Education & Training Act, we know the UNCRPD. And most importantly, we have the ultimate street cred - lived experience, usually involving trauma of some description. Exclusions, bullying, discrimination - you know the stuff.

The WORST experience I had was actually an online meeting where myself and another parent were put into a ‘random’ zoom break-out room to discuss (without sharing the specifics) the stuff of 2am panic attacks for parents like us. Like, imagine the worst possible topic to ask parents of non-speaking autistic children. We were outnumbered by ministry staff. We both ended up crying - because of the pressure to offer up our greatest fears for the future on a plate, for six ministry staff to furiously write down and present in their next team meeting. The zoom ended and that was it; there was no offer of after-care, not even a follow up email to check we were ok in the days following. It was brutal. That was when I truly understood the meaning of the māori concept of ‘Pouri.’ I had a heavy, sorrowful feeling that followed me around for days and weeks afterwards. It eventually left, but I never forgot. It was an absolute masterclass on ‘how not to engage with parents.’

In recent years (under another government that actually valued public engagement) there have been opportunities for paid work, doing the same things I did voluntarily for years before. Some co-design even! It felt good to feel valued, and know that finally disabled people and families were being compensated for the time and effort it takes to be there.

Being disabled and/or a parent is not an excuse not to ‘pay’ somebody for their contribution. Yes, we are volunteering our time, **but please don’t abuse our kindness**. We sacrifice a lot to be in the same room, both financially and emotionally.

I know full well how marketable my vulnerability as a parent and caregiver is. More importantly, I know my worth as a person, and the importance of my

wellbeing, **and I hope you know yours too**. I willingly use my platform to share my good, bad and ugly experiences to raise awareness and empathy, for the good of my community - for people like my friends who don't have the privilege of time or energy to lend to this sort of mahi.

But I wish they knew that every single time, without fail, it triggers a part of me. It chips away a little bit of my battle weary armour that keeps my wairua safe. I can mend my armour, it takes time but I'm used to constant patch ups nowadays.

I enjoy working with groups that are open to learning more about what life is like for families, and open to learning more about assistive technology like AAC, like my daughter uses. It fills my cup to meet people genuinely engaged and open to listening and learning new ways to include and engage with families and rangatahi like my daughter. That's what keeps me going. That, plus the friends I have made along the way.

Take good care of our people, volunteering their time for the betterment of all of us. We often hear the concept of 'manaakitanga' bandied around our schools and workplaces, but do we extend this as far as we should?

Acknowledge the many and varied lived experiences that disabled people and whānau bring to the table. Make sure they leave knowing that their contribution has been valued. They deserve it. And you never know how long it has been since someone has extended them an act of genuine kindness.

Thank you to all the helpers in our community 

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