

Reimagining education with Dorothy Taare-Smith: Takiwātanga and community-based support



Haere mai, Dorothy. Tell us a bit about yourself and what brought you to this Takiwātanga mahi?

Ko Hikurangi te maunga

Ko Waiapu te awa

Ko Horouta te waka

Ko Ngāti Porou te iwi

Ko Dorothy Taare-Smith tōku ingoa

No Tūranganui a kiwa ahau e noho ana

I'm married to Tuhi and we have a blended family of three grown daughters and eight mokopuna. My number five mokopuna is our taonga takiwātanga. My journey began way before my mokopuna was born; the takiwātanga journey began for me when I was teaching. The skills and knowledge I acquired came from the tertiary institutes I had studied at, and the PLD I received as a classroom teacher. Both approaches were very Western, and this suited most but not all families. At the time when I was teaching, I had children in my class who were from different ethnic backgrounds, and for some English was not their first language. I was interested in looking at indigenous approaches to autism, approaches that are different from a Western approach. I enrolled in the postgrad Specialist Teaching Programme through Massey University, then I went on to do my Master's degree, hoping to learn a little bit more about the indigenous approaches to autism in pre-colonial times. I was blessed to have Jill Bevan-Brown as my lecturer when I did my postgrad; she paved the way for what I'm doing in the space today. I was curious to learn about autism, first and foremost, and then later on in my career, I became interested in indigenous autism, particularly Māori autism.



Can you tell us a bit about pre-colonial understandings of autism?

There isn't much in the way of research. The information that I've read comes from Elsdon Best, but from what I've read Māori weren't willing to give information to Pākehā and so there aren't accurate readings on disability. Another thought that I've had is that our people aren't singled out for being different. *Difference* is, in my opinion, a Western construct.

Can you talk about what that shift would look like if we really thought about it as Takiwātanga rather than autism?

I think for me, it's acknowledging the relevance of indigenous knowledge. Quite notably, the absence of research and literature that reports on Māori perspective of autism needs further attention. If we are to progress, if we're to learn, we need to know more about it. I would like to see Māori-led research in the space. What we've seen is that Māori typically don't lead the research – that Māori are the *researched* but we are not the *researchers*, so that needs to change.

I really like what you said about Māori feeling like the research rather than the researchers, and probably autistic people would say the same: that they've often been under the gaze rather than the ones that get to bring their lens. You're sitting at that intersection, where you're trying to amplify Māori voices and autistic voices. How did your experiences with your mokopuna shape you as an advocate and as an ally?

I'm in a privileged position, where I have a sound knowledge of the system and have many connections nationally and internationally. I have been in the autism space since probably the mid-90s so I'm quite privileged in that sense. And I'm able to use my knowledge and my networks to not only support my mokopuna, but to support other whānau who need advocacy support, or just to have a kōrero. What I'm finding is that whānau have trouble navigating the health and disability sector, as well as the education sector. There's confusion around processes and limited knowledge of the community services at the grassroots. The years and years of work that I have done have put me in a position where I can use that, and I freely give it to our whānau. The way I communicate with them is non-threatening. What I've created here is a 'no red tape system' – so if anyone wants to ask a question, I'm only a phone call away. I think the red tape, the barriers, are huge for whānau. There are long wait lists, waiting times ... and what we do is that if you've got a question, and I can answer it, I'll answer it. I have the luxury of time and so I freely offer my services to go along and advocate for whānau if they need me to. It's about ensuring that our people have a voice, helping them get the entitlements they are entitled to, and walking alongside them to navigate the system.

It's a daunting task for a lot of our whānau. They are given a diagnosis, in most cases a label, and it sticks. For some of our kids, some of our whānau, they become 'the autistic person' and they in some sense lose their identity. They don't become Johnny or Mary or Sara; they become 'that autistic kid'. Autism is not a kupu of our people; it's not even a kupu of this land. Yet, in order to get the support that you need, it's a prerequisite that you have an autism label. Some of our families struggle with that label, but, in order to get the support that they desperately need, they have to take it. For me, that's not fair. That's not fair at all.

My whole purpose is to raise awareness, and to wrap a korowai around our whānau. To say “there’s nothing wrong with your child; it’s society that needs educating”. The work that I do in our community is sad. You’ve got parents who refuse to go out, because they’ve had bad experiences. They’ve been told to leave shops. And so that’s something that that I’m wanting to change. As far as I’m concerned, our whānau and our children have a right to access anything in the community. They’re part of an iwi, they’re part of a whānau, they have a whakapapa. On our marae as well, I’ve had whānau share with me that their child’s making too much noise, they need to go. I have concerns about that.

The notion of ‘no red tape’ support – what a lovely metaphor. Another thing we talk about is being mana-enhancing and strengths-based. What might that look like, especially for mokopuna and whānau, if we were genuinely were strengths-based and mana-enhancing?

Well, I think that’s simple. Kaua e takahia te mana o te tangata – don’t trample on the dignity of the people. And I’ve lived by that. I know that people come from different backgrounds; they’ve got a different story to tell. There are several examples, but specifically the absence of karakia, whakawhanaungatanga, manaakitanga, tautoko, aroha and hūmārie. Not all whānau want to begin with karakia, but to ask is always a great start. Choosing your own team; getting rid of the jargon. Something as simple as jargon could put them off; they won’t want to engage anymore. Because they felt whakamā, because they didn’t understand the question that was being asked of them.

Gone are the days where you walk into someone’s whare and you’re holding a clipboard, and you’re looking around the home and you’ve been offered a glass of water or a cup of tea and the mug might be paru, and you’re putting your nose up at that. Whānau pick up on that. And again, will be less likely to engage. A practice that I adopted years ago was: the first day, leave all the business stuff behind, you go in there and get to know who they are. I would take probably three hours, maybe a day or two, just to get to know the whānau. Later on, you get into the business stuff. I’m very much passionate about getting to know the whānau – “What’s your story? We’ve all got a story”. Trust is a huge thing. Whānau have shared things with me, and they have my word that it wouldn’t go any further. On a couple of occasions, I have had to say, “Look, I need to take this further”. But trust is huge, absolutely huge, especially in Tairāwhiti.

If there’s a way that I can help them manage whatever it is they going through, I’m happy to do that. No money is exchanged. None. That doesn’t even come into the kōrero. Funding. No. When I was studying, in Auckland with Massey, I always felt that I was going home to help my people. I’ve always had that mindset; it’s not about money for me. In this day and age, everything is about money, you pay for your time. Whānau can’t afford that. I’m blessed that I’ve been given this opportunity. I’ve got the tertiary qualifications that I need. I’ve worked in some really good places. I know my way around the system. And that’s my koha back to my community.

Thank you for giving us a sense of the principles that drive everything you do, and also those really practical examples that every single one of us could do. Because you don’t want it to be about money, and that notion of koha to your community is so powerful, how did all of that inspire the Taonga Takiwātanga Charitable Trust?

I guess the Taonga Takiwātanga Charitable Trust was born out of frustration. The questions I pondered was 'who was looking after our community in terms of autism support? Where is the specialist ongoing support that we need?' It was almost as though our community was forgotten. The kaupapa was about creating local solutions for our community with kaupapa Māori at the forefront. Tairāwhiti is isolated but resilient; access to specialist autism training was very minimal. As a community, our options were pretty thin. We had to source our own training, refer to Google, and go to the library and find books around autism. In some case, education practitioners would pay out of their own pockets and carpool to attend autism PLD which was usually outside of Tairāwhiti. We had providers come to Gisborne, but they would seldom go to our rural communities such as the East Coast and Wairoa, which meant families from rural communities would either miss out, or they would have to figure out how they would get here, and if they would be back home in time to pick their children up, to make sure tea was on. ... So it's all those practicalities that we often forget about when we look at PLD. Our community is approximately 53% Māori; however, the autism training being delivered failed to include content that reflected our Māori population. In addition, our whānau Māori were not given a Māori equivalent explanation of what autism was, and a lot of our whānau struggled. Families have shared with me that they were given a brochure, the paediatrician didn't know who was in the community. ... One lady said it felt like she was on a conveyor belt: you go from one service, they put you onto another service, and you go to another service. Another whānau said that they were overwhelmed with the people who are in their lives. They knew their names but they didn't know what they did. They would see them once a year if that. Medication was a big thing; they didn't want their kids on medication. There was a whole raft of issues that we had to contend with here in our community. It's social, it's the environment, it's housing, it's no kai in the cupboard, it's getting access to specialist services, relationship issues with parents ...

The nature of our Trust is to provide autism awareness and advocacy training for professionals and whānau. And we talk about takiwātanga and autism. Yes, takiwātanga is a Māori word for autism, but when you really dissect the two, they're very separate. Takiwātanga has nothing to do with autism, and vice versa.

My work varies. It's seen me working with the likes of police and lawyers, business people, community organisations, NGOs, iwi, gang families. The pleasure I get from my work is working alongside whānau and guiding them through the system. Helping them, lessening the load on them. It's very emotional, but rewarding mahi at the same time. I'm privileged to be working in this space.

What we do here is that the beneficiaries of our trust are whānau takiwātanga in Tairāwhiti. The mahi that I do, presenting and that, comes into our trust account. The putea that is in there is for Christmas parties for our families, therapy sessions for our families. ... Each term, we start term activities that happen every Thursday. During Term 4 our trust has paid for families to go to Kiwa pools. Yesterday, I trained the lifeguards at our local pools. We do lots of good stuff in our community.

Any events we have, our community and local businesses are bending over backwards to donate items. Community engagement is key for us, and that's something there's a dearth of research around: community engagement and the voices of grassroots initiatives such as what we're doing

here. But it's working. It's working for us. We're changing the narrative here in Tairāwhiti. We don't have any waiting. We do have a rule around families who come through our Facebook page for help – 24 hour turnaround. We either acknowledge the message, or we will help them depending on what it is.

I created the Tairāwhiti takiwātanga Facebook page to initially support our whānau here in Tairāwhiti. But it's actually blown up! Our Facebook page has gone international – it's whānau from Australia, Canada, America ... coming to our page and asking questions and sending private messages. I never thought that this would blow up like it has. It's a different way of doing things. What's been in place historically hasn't worked for our people; this is just a new way of doing it. We're cutting all the red tapes, there are no gatekeepers. It's just honest support, there are no hidden agendas. If you need help, and we can help, we'll help you.

You're not just changing the way we think about takiwātanga; you're changing the way we think about what support looks like. You've crafted a role wherein you identify need, and engage with others to meet the need, whatever it is, from the police force to the lifeguard to the schools. Dorothy, I'm in awe of everything you've done. And I know a lot of people that read or watch or listen to your whakaaro are going to say, 'How can we support? How can we do better in our communities?' So just to conclude, what would your challenge for all of us be? What's your challenge to the education system in particular?

I guess my challenge to the education sector is: we need more specialist training at an undergraduate level. It doesn't make sense that beginning teachers are coming in to a brand new classroom, and they don't have that training at the undergraduate level. I would think that, we would be growing our teachers by giving this training. We have seen an increase in tamariki. In the education sector, and in the health and disability sector with ADHD, foetal alcohol, takiwātanga ... and I don't believe our beginning teachers are ready for it. That's one challenge I'd like to put to the education sector.

Also, mandatory specialist training for education practitioners, including teacher aides. In most cases, teacher aides are responsible for children with high and complex needs. They are the most inexperienced, but they are responsible in most cases for supporting our most vulnerable tamariki. They receive minimal training. I have been a teacher aide and I struggled with what I was allowed to do and what I wasn't allowed to do. Back then, we started having conversations about not being able to hug the child. As a teacher aide, how do you measure what is appropriate and what is inappropriate? There are professional boundaries that teacher aides can't cross, like picking kids up on the way home and taking them home in your car. But you know, that's what we do as caring people not knowing that we may get in trouble for it. So I would love to see that.

Lastly, that ORS scheme needs a major review. I have been involved in ORS applications and it's a derogatory process. You're looking at what the child can't do versus what they can do, and that certainly is not mana-enhancing. An example I have had is when my mokopuna went through the ORS application. He had been going to the toilet since he was two years old, and that's something that we were really proud of as a whānau. I was told to say that 'wearing a nappy at night' will actually get me ORS funding. For me, that's not right; that's not how we need to be practicing. The

ORS applications also gets sent out to the ORS Verifiers, who have no idea who the child is, who the whānau is. It just doesn't sit well with me, the ORS scheme as we know it today.

I think it's so interesting to hear you say, as a teacher aide, you didn't know what you were allowed to do. But you knew what needed to be done. And in a way you knew exactly what needed to be done, and then you've turned that into your whole life's work. It wasn't about you figuring out the rules; it was about you figuring out what the rules should be to meet the needs of every child, which is beautiful. Thank you, Dorothy. Thank you very, very much for your time.

INTERVIEWEE PROFILE



Dorothy Taare-Smith

Dorothy is the founder of Taonga Takiwātanga Charitable Trust (TTCT) which was established in 2020 to address the unmet needs of whānau Māori seeking authentic Kaupapa Māori support for their Taonga Takiwātanga. Dorothy has worked in the disability sector for well over 20 years as a teacher-aide, teacher, specialist teacher and advocate. Dorothy has a particular interest in the area of Takiwātanga – Autism from a Māori perspective where she has identified key implications for Te Whānau Takiwātanga seeking cultural authenticity in the Education, Health and Justice sector.

Website: <https://www.taongatakiwatanga.co.nz/>

Email: takiwatanga.facilitator@outlook.com