

Disability Directorate e-newsletter

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From Adri Isbister Deputy Director-General Disability



Kia ora koutou

Welcome to the final newsletter of 2019! It's been a huge year for us in the Disability Directorate, so I want to take a moment to reflect on some of our highlights.

One of the most important milestones was celebrating the Disability Directorate's first year since being re-established in October 2018. This is a significant and positive step for us, as I believe that this elevates disability within government.

While the Directorate has been back together for more than a year, I have only been in my role as Deputy Director-General Disability for eight months. I want to thank all of you for making me feel so welcome. It's probably no surprise that nearly every day has felt like drinking water out of a firehose – there's always so much to learn and do.

For the past year, the Directorate has gone through a lot of change. This includes standing up a new sector-facing structure so that we can deliver the best outcomes for our disability community.

We've also been developing a strategy so we can build a sustainable disability system over the next three to five years. You have been an integral part of this strategy, and I had the privilege of working with you on this at the community conversations we hosted around Aotearoa in September and October.

When I started, one of my goals was to meet with as many of you as I could. It's important for me to understand how disability supports and services impact disabled people and their whānau, so that we can embed these experiences and voices into our work.

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It was really heartening to hear about the pockets of innovation happening around the country and meet communities working together to wrap support around each other. We also visited regions that don't have this level of support. Our challenge is to learn how we can transform the system together, so that everyone can access the supports and services they need, no matter where they live. I am really looking forward to working with you as we make this happen.

We shared our strategy with the Director-General of Health, Ashley Bloomfield, in November and will be sharing it with Minister Salesa in the New Year. Thereafter we will have it up on our website.

I want to thank everybody who came to our community conversations. It was truly a humbling experience for me and my team. If you couldn't attend in person, I hope you were able to participate in our livestream. If you haven't already, you can still watch the livestream on our website: health.govt.nz/our-work/disability-services/disability-projects/disability-community-conversations

We've had several other highlights this year.

Investing more in Child Development Services

In May, the Government announced its commitment to increase funding to Child Development Services. This will provide improved access to early intervention and support for children and their whānau and promote greater independence in their future lives. I want to thank everyone who has worked to integrate services and make these important changes happen.

Making changes to Funded Family Care

The government also announced changes to Funded Family Care this year, to recognise the value of family carers. We've worked hard to develop policy options that reflect what people told us they want to change about the system. These changes will come in 2020 and you can see more about what they are and what they may mean for you and your whānau at health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care/funded-family-care-changes-2020

Transforming the system

We've had some early positive feedback from Mana Whaikaha, the prototype to transform the disability system in MidCentral. Already we're seeing more people access and choose the supports and services they need. Next year, we'll be able to share more information about what we've learnt from this prototype. In the meantime, we're still monitoring the outcomes.

We're also seeing great outcomes from Enabling Good Lives in Christchurch and Waikato and continue to get positive feedback about the impact that Enhanced Individualised Funding and Local Area Coordination have on peoples' lives.

Exits and arrivals

As we have been standing up our new Directorate, we have welcomed several new faces and roles. Our Contract Relationship Managers are now Portfolio Managers. For most of you, these people will be the same as those you have been engaging with.

We've also said farewell to Toni Atkinson, who was an integral part of the Directorate for more than seven years as Group Manager of Disability Support Services. I want to thank Toni for her invaluable support and work – we truly wish her all the best for the future.

Where to next?

I have no doubt that 2020 is going to be a big year for all of us. At the Ministry, we'll implement our new strategy and roll up our sleeves on the work programme. We will keep you updated and involved as this work progresses.

This year, we tried new ways to engage with the sector, such as livestreams, so that we all head into the future in one waka, steering in the same direction. These efforts will continue, and I look forward to being in touch with you all next year.

I would like to wish everyone a safe and happy holiday season.

Enabling Good Lives

Christchurch

Rawa Karetai, Enabling Good Lives Christchurch

Approximately 430 people now participate in Enabling Good Lives Christchurch, with over 50 young people leaving school this year. Over the last few years, young people who left school are continuing to grow and develop, moving out of home and flatting, turning work experience into paid employment, developing a hobby into a business or completing a course and joining a group for further connection with others. It has been encouraging to speak with families about the successful outcomes of Enabling Good Lives in Christchurch.

Enabling Good Lives Christchurch was involved in the launch of Project SEARCH, a one-year, employer-led internship programme for students with learning disabilities. The project targets students in their final year of school who want competitive employment. Some of our first participants have found jobs throughout the city.

The Regional Leadership Group met with Hon Jenny Salesa to discuss the success stories of the people who are part of Enabling Good Lives. Three families attended to talk about their experiences with Enabling Good Lives. The Minister appreciated hearing from the families. The leadership group expressed their concern about the lack of change for Christchurch. They pointed out that they felt Christchurch was in a holding pattern by only being able to serve ORS (ongoing resourcing scheme) funded school leavers. The leadership group explained that the current pilot creates a two-tiered system of those who fit the criteria and those that do not. They also expressed that they would like to see the Christchurch pilot expand so more people can participate in Enabling Good Lives.

We have also discussed Enabling Good Lives with the Ministry of Education and their Waitaha Parent Advisory group. There was a general desire to expand the MoE's defined geographical boundary. Enabling Good Lives currently only has a reach from Rolleston to Kaiapoi and those who are ORS funded. One family in Timaru could be considered as a trial.

We have also discussed helping disabled persons transitioning into adulthood with Oranga Tamariki. If Enabling Good Lives Christchurch works with transitioning young adults, we will start to have some school leavers who are not ORS funded but have support until they are 25 years old.



It has been inspiring to bring meaningful, positive outcomes for people living with disabilities and their whānau into the realm of possibility. Our independent facilitators and their practice supervisor have been crucial to the success stories that our participants have to tell. They walk alongside our Enabling Good Lives participants to help connect them with services and activities individualised to their needs, dreams and aspirations.

Waikato

Kate Cosgriff, Director, Enabling Good Lives Waikato

The Waikato demonstration of Enabling Good Lives has entered its fifth year, with 402 disabled people participating along with their families and whānau. There is optimism growing for a wider future for Enabling Good Lives in Waikato.

Recent highlights included visits from Minister for Disability Issues Hon Carmel Sepuloni, local MP Jamie Strange and Associate Minister of Health Hon Jenny Salesa. The Ministers met with members of the Leadership Group, the lead evaluator and a group of diverse disabled people, families and whānau who are participating in EGL Waikato. They shared compelling stories with the Ministers about the benefits of increased choice and control, with self-management, flexibility, the ability to do things differently, the role of the tūhono and better outcomes highlighted.

Enabling Good Lives had a great win at the Spirit of Service Awards in mid-September. The Spirit of Service Awards celebrate outstanding public service delivering great outcomes for New Zealand. The Ministries of Social Development and Health, in partnership with the Enabling Good Lives Leadership Groups, won the inaugural award for Leadership in Governance. This award is the culmination of many people's hard work over the last decade and required the commitment, perseverance and leadership of the disability community, including the Waikato Leadership Group.

We have learned a lot in EGL Waikato, with many lessons identified in our three evaluations. One big observation is that some families with young children don't choose to have respite or short breaks when given control of their budget. Many purchase items or regular supports that mean family time works well for everyone. The following story illustrates this:

A family in a small rural town spent their small first year's budget on an outdoor wooden playground to help their young son have fun, grow his confidence and develop motor skills. This has been fantastic, however, since moving to their new home he's been unable to use the playground without an adult present as the outside area is exposed to the road, several creeks, gullies and bush. This has been really stressful for the family. The connector assisted Mum to apply to local community funders for fencing, with no success. The family chose to use their year two EGL budget on fencing, as this supports their son to have freedom to play outside at home, without constant adult vigilance.

System transformation

James Poskitt, Programme Lead

Hamish McNeill is a young man with Down syndrome who has begun the process of starting his own small paleo baking business called 'Hungry Hamish'. Hamish loves baking and has always dreamed of having his own business in the food industry.

About 16 years ago, Hamish and his mother Christina, came up with the idea of Hamish having his own business. They first thought Hamish could open a café called 'The Hungry Hungry Hamish'.

Fast forward to present day, Hamish and his family have been working with kaitūhono/connectors from Mana Whaikaha and using the Enabling Good Lives principles to determine what a good life could look like for Hamish. The insights and



Hamish McNeill and his mother Christina

experience of the kaitūhono/connectors helped Christina realise the importance of building a network around Hamish that would help him achieve his goals.

'If you want Hamish to be a baker, you need a support worker who is a baker.' This simple statement resonated with Christina, who previously had only thought about a support worker being a 'safe' person for Hamish. Hiring Damian, a qualified baker, as Hamish's support person has opened a whole new world of opportunities for Hamish and set him on the path towards having a good life.

youtube.com/watch?v=uu8M9rGY_dU&feature=youtu.be

Baseline study of the disability support system in the MidCentral area

Marianne Linton, Senior Advisor, Quality & Performance

What is happening in MidCentral?

A prototype disability system, Mana Whaikaha, was introduced on 1 October 2018 in the MidCentral DHB region, which includes Palmerston North, Horowhenua, Manawatu, Otaki and Tararua districts.

Mana Whaikaha is based on the Enabling Good Lives vision and principles and aims to:

- provide disabled people and whānau with more flexible support options
- give disabled people and whānau greater decision making over their support and lives
- improve outcomes for disabled people and whānau
- create a more cost-effective disability support system.

More information about Mana Whaikaha can be found on their website.

manawhaikaha.co.nz/about-us/mana-whaikaha/

Why was a Baseline Study done?

The Baseline Study was undertaken before Mana Whaikaha began. It tells us what things were like before Mana Whaikaha started and will provide a reference point for understanding the difference Mana Whaikaha makes for disabled people and whānau over time. The Baseline Study is the first stage in a longitudinal outcomes evaluation.

The Baseline Study involved:

- interviews with disabled people and whānau and a survey of service providers and support workers
- mapping the disability support system before Mana Whaikaha started
- analysis of outcomes using administrative information.

There are four Baseline Study reports available on Mana Whaikaha website.

manawhaikaha.co.nz

- A Summary Report which summarises information from all the interviews with disabled people and whānau, the surveys of service providers and support workers and the system mapping. There are Easy Read and New Zealand Sign Language versions of the Executive Summary available.
- A Disabled Peoples Report which provides more in-depth results from interviews with 172 disabled people who took part.
- A Whānau Report which provides more in-depth results from surveys of 152 whānau about their experiences of the disability support system.
- A report providing the Survey Tools used.



What's happening next in the evaluation?

Baseline reports about outcomes for disabled people and whānau using administrative information and a social cost/benefit analysis will be published when they are completed.

Evaluation activities are happening to help support the ongoing development of Mana Whaikaha (the 'Try, Learn and Adjust' approach).

The Baseline interviews and surveys with disabled people, whānau, providers and support workers will be repeated in April 2020 and September 2021 to help us understand what has changed since Mana Whaikaha started on 1 October 2018.

Any questions

If you have any questions about the Baseline Study, please contact STFeedback@health.govt.nz and include 'Baseline Study' in the subject line.

Launch of Disability Action Plan 2019–2023

Stuart Parkinson, Senior Policy Analyst, Disability Policy

Minister for Disability Issues Hon Carmel Sepuloni launched the Disability Action Plan 2019–2023 on 14 November 2019. The Ministry of Health will lead important work programmes on behalf of the health and disability sector.

The new action plan responds to the main issues identified by disabled people, the Disabled Persons' Organisation (DPO) Coalition and government agencies working together. Most work programmes in the package are expected to continue beyond 2023 and new programmes may be added.

The six work programmes for health sector leadership are:

- repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992
- reduce the use of seclusion and restraint
- improve health outcomes and access to quality healthcare for disabled people
- transform the disability support system
- protect bodily integrity of disabled people against non-therapeutic medical procedures
- change Funded Family Care policy.

Overall, the Minister for Disability Issues will lead the action plan, coordinating with the Office for Disability Issues (ODI).

The New Zealand Disability Strategy 2016–2026 (Disability Strategy) and the action plan are part of New Zealand's realisation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

United Nations Convention on the Rights of Persons with Disabilities
Purpose: to ensure that disabled people have full and effective participation in society on an equal basis with others



New Zealand Disability Strategy 2016–2026
Outcomes: education, employment and economic security, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control, and leadership



New Zealand Disability Action Plan 2019-2023

Monitoring and measurement of progress includes six-monthly status reports, Ministerial Leadership Group on Disability Issues bi-annual meetings and DPO Coalition meetings.

Further information on the action plan is available from ODI's website
odi.govt.nz/disability-action-plan-2/#Summary

Pacific update

Bella Bartley, Portfolio Manager, Operational Performance, Central

The Pacific Disability space has had a busy year!

We are in the third year of the Faiva Ora Plan 2016–2021. The plan sets out priority outcomes and actions to support and improve the lives of Pacific disabled people of all ages and their families.

To support the implementation of this important plan, a leadership group was established to provide advice to the Ministry.

The leadership group held its first meeting for the year on 19 February 2019, focused on setting priorities for the coming year. They identified sector engagement and coordinating with DHBs Pacific disability advisory groups as key priorities.

The leadership group has also provided a Pacific perspective to the Ministry on several key policy developments, including Funded Family Care, the Respite Strategy, System Transformation prototype, changes to carer support, Tamariki Ora review, Disability Strategy, Pacific Health Plan and the Health Standards review. They also hosted Associate Minister of Health Hon Jenny Salesa at their last meeting on 23 August 2019 in Auckland.



Members of the leadership group are actively involved in their communities with various projects to raise awareness of disability, including promoting and supporting the Faiva Ora Community Innovation Funding initiative which opened in 2017. The innovation fund supports community-based initiatives that enable Pasifika people with disabilities to enhance participation, reduce stigma and increase access to support. They created videos about projects funded in the first year of the programme which were shared widely on social media. You can view these on Le Va's website (leva.co.nz/our-work/disability-support/innovation-fund). Successful applicants for this year's round of funding will be announced soon.

Other initiatives include the establishment of the 'Engaging Pasifika' cultural competency training programme and engagement across Pacific church groups about supporting people with a disability and being inclusive. They have also established circles of support that bring together Pasifika disabled people with people to support their planning, decision making and thinking about their future. We have made inroads engaging with government agencies and DHBs.

The Ministry has monitored progress against the action plan and is pleased with the level of engagement from across the sector and progress on implementing the Faiva Ora Plan.

Child development services

Noreen McMahon, Portfolio Manager, Operational Performance, Central

Child Development Services (CDS) provides therapies to children with disabilities to maximise their potential and promote their independence. In Budget 2019, the Government allocated an additional \$35 million over four years to CDS (\$8.75 million per annum) to address waitlists and modernise the service.

The CDS teams and their respective shared services agencies submitted implementation plans to the Ministry in September 2019. In addition to recruiting additional staff, the CDS teams were asked to submit initiatives that would help to shape the future model of care. We received 26 proposals outlining great initiatives that would help with the development of pathways, seamless processes and delivery of services in isolated regions. Unfortunately, not all the proposals could be funded this year. The Ministry is delighted to support 14 initiatives in addition to allocating funding to increase capacity. Several of these initiatives involve partnership with other agencies, such as the Ministry of Education and Ministry of Social Development, to help identify children in the community who would benefit from CDS. We hope to share the key findings from these projects in the future.

Recent publications on health website

health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guidelines-supplementary-paper-effectiveness-sexuality

health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guidelines-supplementary-paper-school-transitions

Spotlight on quality

Christina Curd, Senior Advisor, Quality and Performance

We are excited to announce that the updated Disability Directorate complaints and feedback webpage on the Ministry of Health website is now live.

We have updated the page to include a feedback mechanism so we can hear about people's experiences, and have organised translations into easy-read, New Zealand Sign Language (NZSL) and Te Reo. This is so we can make it more accessible to the people we fund and their families/whānau. The easy-read, NZSL and Te Reo translations will be on the website in the next few weeks.

We hope that the updated webpage will encourage people to share their experiences with us so we can use this as an opportunity to improve our services for the people we support and their families/whānau.

Check out the link to the updated page: health.govt.nz/your-health/services-and-support/disability-services/disability-support-complaints-and-feedback.

As always, we are keen to hear any feedback you have. Feel free to email disability@health.govt.nz if you have any questions about the complaints webpage, or the complaints and feedback process more generally.

From the community

Two letters were received by thankful recipients of hearing aids funded by the Ministry's hearing aid schemes.

Please note: some information has been removed to protect the identity of the recipients:

Good day to you,

I am writing to express my appreciation & gratitude, of the precious gift you have 'enabled' me to have – HEARING!!

Unbelievable – wonderful – scary (at first) – but it has given me so much more confidence to communicate with 'life'.

At first even a leaf blowing outside, fridge turning off/on, indicator in car, having input at our board meetings, doing volunteer work and having the confidence to speak/report any suspicious activity would give me panic attacks, having never heard them before. But now – wow!! I'm 'onto it'.

How can I ever REALLY THANK YOU? Please know I will be eternally grateful and say so, each time I put my aids in. Once again THANK YOU! You do a wonderful job & I am one of the lucky recipients.

Truly you are "STARS!" ★ ★ ★

Hello

I am writing to say thank you for the hearing aids which have been truly transformational. I have just finished the trialling period and they are helping me so much. My heartfelt appreciation.

My very old ones were next to useless – had been for years, and I was becoming quite despondent at times as it had really affected my ability to communicate also my confidence had taken a big knock.

Also, the TV had to be up too loud for me to hear which was very antisocial, and still clarity of speech was missing! Now I am not annoying the neighbours!

I still mishear some things, but mostly everything is so much better I feel like a new woman. It is such a relief.

THANK YOU. With a voice challenge as well, it is truly wonderful to think I can be much more 'normal' than I thought was possible.

Please pass this on to any other pertinent people.

Kind regards

The gift of music benefits Robert's protégés

Robert Mullen of Hamilton is a music teacher with a gift which sets him apart from other musicians. He knows how to bring out the best in students with learning or intellectual disabilities, so much so that many of his protégés have arguably become better than their master. He has helped unlock hidden treasures within them.

'The research into how well creative arts such as music, dance, drama, art etc. can assist those struggling with traditional classroom subjects and settings is so much clearer now than a generation ago,' says Robert.

Take Alex Johnsen as an example. Alex is a 27 year old with Down syndrome which several years ago would have seen him institutionalised and written off. Not now, insists Chris, his support worker from Community Living. His life changed earlier last year when Chris contacted Robert to say she thought Alex had some real talent musically. Robert agreed to give Alex guitar lessons. But halfway through the first lesson 'we discovered guitaring wasn't his strength, it was singing and rapping! We just started mucking around with some stuff and I said to his mother:

"Can I just work with what he's got in other areas?" They wanted to bring out Alex's talents and ensure he was happy and could express himself. They gelled. Alex's focus heightened and after one of the lessons the two filmed 'Chasing Cars' by Snow Patrol and put it on Facebook. It went viral and



Robert Mullen (in cap), Alex Johnsen (with beard), and Cameron Gregory.

resulted in international media attention – CBS News, People Magazine, NBC, Metro UK and many other publications in Europe and even in Asia.

About a month after Alex's first lesson, Robert took on another student, Robyn from Idea Services. She wanted to be able to play guitar in a kapa haka group.

Robert does not call them music lessons. 'It's mentoring expression through creativity. I just want them to see that they have the ability to express themselves.'

He has worked with people with disabilities for nearly 18 years, has a Diploma in music and knows how the power of music can improve people's lives.

Earlier this year, Cameron Gregory came on board with learning the keyboard along with Glen Terry and Julian Godfery learning drums. The group of friends and students formed Robert Mullen Junior and Friends.

Alex, Robert, Julian, Cameron and Glen all work on their own goals and projects but come together on occasions. One of these occasions was on World Down Syndrome Day when the team provided entertainment at a fundraising barbecue outside The Warehouse in Hamilton Central.

'They are benefitting from the fact there is now more awareness around people with disabilities, that they can do anything. It's a "so what" attitude and that anything is possible,' says Robert.

Their Facebook page continues to attract viewers as does the group's YouTube channel and Instagram account (look for Robert Mullen Junior and Friends).

Other big events they have performed at include Community Living's Got Talent in Hamilton and the opening ceremony of the International Special Needs Taekwondo Games in Napier ([facebook.com/International-Special-Needs-Taekwon-Do-Games-New-Zealand-5th-October-2019-2320819314797945/](https://www.facebook.com/International-Special-Needs-Taekwon-Do-Games-New-Zealand-5th-October-2019-2320819314797945/)).

'I'd rather work with these guys than the general public, they're way more interesting,' says Robert.

Live Your Best Life!

Geneva Healthcare's annual Ball is the social event highlight of the year for people supported by Geneva Healthcare to lead an independent life with disability.

This year's 'Dance of Nations' themed Ball was one of the biggest yet with over 250 people from all over New Zealand celebrating diversity, culture and inclusion at the Pullman Hotel in Auckland City.

Rt Hon Jacinda Ardern and Hon Jenny Salesa helped light up the night. The Prime Minister astounded everyone at the Ball by arriving unexpectedly – talking to as many people as she could, posing for photos and addressing the crowd with an impromptu speech to kick-start the event after the Karakia. She thanked Geneva's clients who put together a personalised video invite and said it brought tears to her eyes and she felt she just needed to be a part of the event, even if it was only a fleeting appearance.



Hon Jenny Salesa

Hon Jenny Salesa, Associate Minister of Health expressed her delight to see so many people wearing spectacular outfits, stating how amazing everyone looked. 'We make who we are, and tonight's event reminds us how important it is to honour Aotearoa's diverse cultural backgrounds and show our respect and support for disabled people. The Minister was very impressed by the dancing prowess of Geneva's own staff in the dance medley. 'I thought you had hired people in to come and dance tonight! My gosh, you are so talented, and you all look so fabulous,' said Minister Salesa.

Josephine Gagan, New Zealand Health Group Chief Executive, and Minister Salesa presented the Geneva Pillar Industry Award in recognition of organisations who have gone above and beyond to remove barriers to services, allowing for inclusion. The Cookie Project took this year's award, while the nominees included Will&Able and Recreate NZ.

The dance floor was packed for hours and there was a lot of fun, laughter and good times. Everyone left with smiles on their faces, having enjoyed a fabulous evening of celebration, dancing and food. It was certainly a night to remember.



Contact Disability Support Services

Email: disability@health.govt.nz

Phone: 0800 DSD MOH (0800 373 664)

Web: health.govt.nz/disability

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