I would like to start by extending my deepest sympathies and strong support for the families, the victims and of course, the Muslim community in Christchurch and around New Zealand.

I also want to acknowledge and pay tribute to the work of people in the health and disability sector in Christchurch - the first responders from St John, and the amazing staff, both clinical and non clinical, at the DHB, who have been nothing short of outstanding in dealing with the injured and offering support to their families. I also want to acknowledge the disability providers and local NASC, Lifelinks, for ensuring continuity of support to the disability sector at this difficult time.

As a reminder, if over the following days and weeks people feel their distress or stress symptoms are escalating, or feel they are not coping, early access to help and professional support is important. A GP is a good starting point, or for support with grief, anxiety, distress or mental wellbeing, people can call or text 1737 – free, anytime, 24 hours a day, 7 days a week – to talk it through with a trained counsellor.

The new Disability Directorate team is back into its work programme for the year and focused on delivering on a number of high priority areas. These include System Transformation, Funded Family Care, High and Complex bed management and Financial Sustainability.

The directorate is aware of recent media stories about underfunding in the disability sector. This has led to worry about funding changes to Disability Support Services. I understand how concerning the prospect of changes to people's supports can be.

The Ministry is needing to look at its funding in order to ensure services are sustainable into the future and ensure fairness and equity for all who access them.
Whilst we are committed to providing support for disabled people and their whānau in a fair and equitable way, the increasing costs in recent years needs to be addressed.

As you are aware, System Transformation will provide us with insights on how the long-term disability support system can be improved, to both meet people’s desired outcomes for a good life, and remain within a sustainable funding path.

We will keep you informed of any changes that arise as a result of our priority work areas.

And finally, a warm welcome to our new Deputy Director General – Disability, Adri Isbister. Adri joins the team on 25 March to lead the new Disability Directorate. We are looking forward to Adri joining us and want to thank Mathew Parr for his support to the Directorate in the interim. More about Adri in our next newsletter.

## Enabling Good Lives

### Christchurch

Hannah Perry, Enabling Good Lives Lead, Ministry of Health

Kia ora koutou

The key outcome of the Enabling Good Lives approach in Christchurch is that young people leaving school have great opportunities, choice and control over how they live their good lives.

We also aim to make it easier for service providers and others involved in supporting young people to work collaboratively, be of service to disabled people, and enable citizenship, connection with and contribution to local communities.

Project SEARCH is a wonderful example of achieving these aims and much more. Project SEARCH is a one-year, employer-led internship programme for students with learning disabilities in their final year of school. It is targeted at students whose goal is competitive employment.

The host organisation for Project SEARCH Canterbury is the Canterbury District Health Board (the largest employer in the South Island), and the collaborative partners include CCS Disability Action, the Blind Foundation, the IHC Foundation, Workbridge and Riccarton High School.

The eight Project SEARCH interns begin their day learning employability skills in a training room at Burwood Hospital and then move to their work placement on the hospital site. The placements are specifically chosen to match each intern’s skills and interests, as well as the likelihood
of leading to transferable skills for paid employment following the internship. One young woman is washing dishes in the café and packing theatre bags for doctors’ lunches. A young man is checking and changing air-conditioning filters around the hospital, and another intern is sorting and delivering stores to the wards. At the end of the day, the interns return to the training room to reflect on their day, discuss challenges and evaluate progress. Throughout the year, they undertake employment planning and mainstream employment is actively sought for each intern.

Competitive employment for young people with disabilities is enough of an outcome to make a programme such as Project SEARCH worthwhile, but an added benefit has been the positive impact on the CDHB. Already they have learnt how applying for jobs could be made easier and more welcoming to a wide range of people (for example several of the interns did not have the identification required to complete a Ministry of Justice police check). The CDHB departmental staff working alongside the interns have been really welcoming, with employees appreciating the richness of, and interest in increasing the diversity in their hospital teams.

It is a privilege to be a part of the steering committee of Project SEARCH Canterbury and I look forward to sharing stories of success and challenges as these amazing young people work towards their journey of open employment.

Ngā mihi nui

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**Waikato**

*Kate Cosgriff, Director, Enabling Good Lives Waikato*

One of the real highlights of our work has been the number of people who have been able to plan and budget for a rest, break or holiday. Often this has taken 1–2 years to percolate: believing it could be possible, dreaming, detailed planning, ‘saving’ within personal budgets, organising flexible supports, trusting the supports put in place and taking the step away.

We have seen disabled people achieving life goals such as holiday experiences, visiting relatives and attending conferences. A significant number of parents who have high care responsibilities have had their first holiday break in decades. The impacts on wellbeing, hope and resiliency have been marked.

As we need to manage the number of people accessing EGL Waikato, the team has refocused on maximising local relationships and solutions. Collaboration is occurring with the Waikato DHB on increasing their responsiveness to disabled young people and adults once they leave the coordinated care of paediatric services, inputting into the DHB’s first Disability Responsiveness Plan and some joint work is in the planning stages with the Population Health team.

We are also contributing in the housing space. Like many regions, Waikato faces significant housing issues. We provided feedback to the Waikato Plan Housing Initiative Working Group on disability prevalence data, accessible housing, predicting the future housing need and the case for universal design. We want to ensure accessibility in its widest sense is included in the Waikato Plan and raised a number of questions for the working group to consider.

The final results of the third phase of the developmental evaluation of EGL Waikato are due in late March. The evaluation team connected with 60 disabled people, families and whānau participating in EGL Waikato, focussing on their outcomes. A summary of the evaluation findings will be included in the next DSS newsletter.
Wendy Illingworth, Programme Lead, System Transformation, Disability Directorate

Six months in, Mana Whaikaha is continuing to see great results for disabled people and their whānau. Over time people are becoming more comfortable with the idea of thinking differently when engaging with the new system.

Director of the Kaitūhono/Connector team, Lorna Sullivan, says ‘I am finding myself quite overwhelmed by the opportunities that sit within the prototype that would never have existed before and that are now being taken up by people and families.’

A recent example of this was a young man and his family, who made a decision that they wanted to work with an independent Connector from their local community. They worked with this person to build a comprehensive plan around his life aspirations. These are aspirations that are no different from any young person of his age: a desire to find a paid job, support to enable him to increase his independence from his family, and the ability to maintain his connections to family and friends. They then brought their proposal to the funding team at Mana Whaikaha so that they could talk through their aspirations and present why they believed the funding they were seeking would lead to reduced support and a better quality of life over the long term. After the funding proposal was discussed, modified and approved, the young man chose to work with a personal budget. This means he has control over who is employed to work for him.

Stories like these continue to motivate the Mana Whaikaha team to work collaboratively with disabled people and their whānau to achieve better outcomes.

MidCentral Governance Group

A key part of Mana Whaikaha is greater system accountability, with disabled people and whānau having a role in making decisions, monitoring and evaluating the system. The MidCentral Governance Group is made up of disabled people and whānau from the MidCentral DHB region, one workforce representative, one provider representative and two people who have experience with governance. Their main role is to make recommendations to the Minister for Disability Issues and Associate Minister of Health on changes to improve the MidCentral prototype, based on the evidence gathered through the ‘Try, Learn and Adjust’ cycles.

As well as providing recommendations for improvement, the Governance Group meets regularly to provide strategic oversight of the prototype. They have made decisions about the priorities for the prototype, endorsed the focus for the first Try, Learn and Adjust cycle, and agreed to test market stewardship initiatives through seed funding and market intelligence within the MidCentral region. The Directors of both the Kaitūhono/Connector and Tari/System teams report to the MidCentral Governance Group.

Peter Allen, MidCentral Governance Group Chairperson says, ‘Because all of our MidCentral Governance Group disabled people, whānau and providers are either representative or directly connected to people with impairments, we bring a life experience to the decision table. Nevertheless we are also very aware that our personal and arm's-length connections to others are not the only experiences. The physical, sensory and learning impairments cover a tremendous
width and depth and we need to make decisions that will positively impact as many of our peers and colleagues as possible’.

‘So now it is our turn to shoulder the burden and carry it forward. A privilege – definitely, and a challenge. Gen X, Y and Millennials, we are always looking to the future and new upcoming leaders to share this responsibility. It is not only today that counts, tomorrow is also very important.’

If you would like to find out more about Mana Whaikaha call 0800 626 255 or visit us online at https://manawhaikaha.co.nz/

Funded Family Care

Lauren Jones, Manager Disability Policy

In September 2018 the Government announced the intention to make changes to Funded Family Care (FFC), which included the intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000.

The Ministry has undertaken targeted stakeholder engagement on FFC, with meetings and an online survey that attracted over 900 responses.

The results of this engagement were published in late December 2018 on the Ministry of Health’s website (health.govt.nz/publication/targeted-engagement-funded-family-care-and-paid-family-care), and included feedback on eligibility, pay rates, employment and Part 4A, and is helping to inform advice for Ministers.

The Ministry has been working hard to provide the government with information and advice on the next steps regarding Funded Family Care. More information will be provided in the future on any changes to the current policy.

Contact Disability Support Services

Email: disability@moh.govt.nz

Phone: 0800 DSD MOH (0800 373 664)

Web: www.health.govt.nz/disability

To be added to or removed from the email list for this newsletter, please email disability@moh.govt.nz
The Chief Ombudsman’s investigations into the Ministry of Health

Lara Penman, Manager Quality Team, Disability Support Services

In February the Office of the Chief Ombudsman announced the commencement of two investigations into the Ministry and its services for people with intellectual disabilities.

I. One investigation covers the ability of the Ministry to resource, coordinate and plan services for intellectually disabled people under the High and Complex Framework. The overall aim is to consider whether people with an intellectual disability are able to live in facilities that are suitable for their individual needs.

II. The second investigation relates to the quality of data collected by the Ministry relating to the deaths of intellectually disabled people in residential care. The overall aim is to understand the Ministry process when a death is reported and make recommendations on how this could be improved.

‘The Ministry of Health welcomes the systemic investigations announced by the Office of the Ombudsman,’ says Acting Deputy Director-General Disability, Mat Parr. ‘It’s important to share and learn from any experiences that will help improve the outcomes provided to intellectually disabled people supported by our services. The Ministry will continue to work constructively to share information, and respond to any final recommendations.’

As part of these investigations the Office of the Chief Ombudsman has requested information from the Ministry of Health, and indicated that they may also ask for information from third parties, such as providers of community residential services.


Death Notification to the Ministry of Health

Disability providers delivering community residential services (including services under the ID(CC&R) Act) are reminded that they need to report the death of a service user to the Ministry of Health as soon as practical within 48 hours. A Death Notification form needs to be completed and emailed to dsscomplaints@moh.govt.nz

The death notification form has recently been updated and is available on our website at: health.govt.nz/our-work/disability-services/contracting-and-working-disability-supportservices/reporting-critical-incidents-and-death-service
Monitoring and audit of claims for hearing aid funding and subsidy scheme

Linda Rundle, Audit Manager, Audit and Compliance, Ministry of Health, (03) 974 2325

The Ministry’s Audit and Compliance Risk and Intelligence team are currently running data analytics over audiology claiming data to assess compliance with the Hearing Aid Services Notice 2018.

All audiology providers have been advised of the monitoring programme and reminded of the claiming rules.

Once the data analytics are complete and the results are assessed, we will develop an audit programme to support, and potentially improve, the current process around compliance.

News from the sector/our providers

Auckland DHB, second organisation in New Zealand to sign up to the Accessibility Tick

Auckland DHB received the Accessibility Tick at a presentation on Wednesday 5 December 2018.

The Accessibility Tick programme helps New Zealand organisations become more accessible and inclusive of people with disabilities. It is managed by Access Advisors, a subsidiary of New Zealand Blind Foundation.

Auckland DHB is only the second organisation in New Zealand to sign up to the Accessibility Tick and the first DHB in the country to achieve the tick. In signing up, Auckland DHB is committed to becoming a place where barriers are removed and people with a disability are enabled to do their life’s best work.

Getting the Accessibility Tick is just the start for Auckland DHB. We are also working towards the Rainbow Tick as part of our commitment to providing an inclusive and equitable workplace for everyone. There is a lot to do but we are making good inroads and we have a plan. With the support of the Access Advisors and our own people within the organisation, we will continue to make Auckland DHB a more supportive and inclusive place for anyone living with a disability.
Songs tell of struggle and pride

Their songs come from their struggles. Their music defines who they are in the world.

Wairarapa kapa haka group Te Roopu Manaaki took the stage at the Te Anga Pāua o Aotearoa Kapa Haka Festival in December 2018 with a selection of original songs composed by the group. The songs tell some hard truths – of feeling excluded, being invisible or experiencing discrimination. But kapa haka has transformed these experiences. Performing has built confidence and connections with people and group members show instead their joy, pride and a sense of being whānau.

The kapa haka group was formed in 2016 when tutor Tama Biddle, from community education provider REAP Wairarapa, and his wife Trina began to teach kapa haka to IDEA Services clients. They practise for four hours every Thursday and stage performances throughout the Wairarapa.

The group was one of 17 IDEA Services kapa haka groups, including more than 300 performers, participating at Hamilton’s Claudelands Arena, on December 5, 2018. The festivals are all about participation not competition, though the performers have their sights set on one day competing at Te Matatini, the national performing arts festival. The goal of the festival is to support our people to be part of the community and to have Māoritanga and culture as part of their everyday lives.

Te Roopu Manaaki started out with popular songs, but now increasingly showcases its own songs.

Tama says composing songs gives the group a sense of ownership. One of its latest songs is about discrimination. ‘It’s something that the group has talked about a lot. So we spoke about it and we developed a mōteatea waiata – like a chant. We have also incorporated sign language into that. I always like to remind them that this is our song.’

Caleb McNamara, Kaitātaki tāne (male leader) of the group, says they sit down with Tama and brainstorm. ‘We put words together and that is how we do our songs – what we have been through – like the real negative stuff that we have all gone through – being put down, picked on, treated like we don’t exist. So we decided that we wanted to have a voice and speak up for others like us.’

Kaitātaki wahine (female leaders) Faith Konia and Ameria Wallace form a strong partnership. The group takes their lead in the actions from Faith, while Ameria’s powerful voice rises above all the others. ‘The role as leader is to also be humble. I do care about the group around me. If they can give 100 percent then everything is kapai,’ Faith says.