

Disability Directorate e-newsletter

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From Adri Isbister Deputy Director-General Disability



It's certainly been a very busy summer! Hot and dry in some regions and not in others. Christmas is like a distant memory, but was lovely – plus in early February I went to see Elton John and was lucky enough to go to the concert where he belted out the songs for three hours!

Within the Directorate we continue to recruit to vacant FTE (full-time equivalent) positions and our next newsletter will have introductions to new people coming on board. The changes to Funded Family Care are under way and we welcomed Wayne Skipage to lead the implementation of these important changes. I've met with various providers to talk about what's coming up in 2020 and listening to ideas of innovation and some issues to see how we can support providers to deliver the very best care for disabled people and their whānau.

I've also met with a large group of small providers in Auckland and discussed improving communications with the Ministry of Health, flexible contracting and the sustainability of providers. I know that these are meaty issues, but I can assure you that we are collaborating with providers to ensure we can all support each other and best serve our communities. We would appreciate providers coming to us proactively with any issues they have. I want to extend my sincere thanks to those that have done this already, we really appreciate your honesty and willingness to work with us.

I was invited to present to the Health Workforce Advisory Board in February 2020. This group works in partnership with the Ministry of Health to provide strategic advice and sector leadership for New Zealand's health workforce. If you attended one of our community conversations, you know that we are keen to explore health workforce issues and ensure that carers and support workers get the help they →

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need to do their jobs well. My main topic of conversation was enabling greater participation of disabled people in the health workforce and how best to partner with DHBs to better understand the needs of this workforce.

I was pleased to present at the New Zealand General Paediatric Forum 2020 in early March. I presented on system transformation and Madeleine Sands presented on the Directorate's work with Child Development Services. This was a great opportunity to highlight the great work to support our children, particularly in early intervention and integration programmes.

Last year I had the opportunity to travel around Aotearoa and present to 22 community conversations. As you all know the feedback can be found on our website at health.govt.nz/our-work/disability-services/disability-projects/disability-community-conversations. What we heard has genuinely made an impact on us and we are so grateful for everyone who shared their stories and experiences. The main themes were flexibility both from the disabled person, family and whānau and from our providers. Enabling flexible services and contracts is one of the key themes from system transformation and we're looking at how we can apply these learnings to the rest of New Zealand.

I want to share a good story with you all. I spoke to a family member at one of the community conversations about how best to support a person who was in dire straits at the time. The operational team in the Disability Directorate were very responsive, as was the provider tasked with providing the best environment for this person. Just this week I heard from the parents via a portfolio manager and the person we spoke about is thriving. This reminded me of how very privileged we are to be working in the Disability sector and how our communities – particularly our providers – do some amazing things. Thank you all.

We have already sent out sector wide communication regarding COVID-19. I urge you all to stay updated via the Ministry's website, which is constantly updated. However as COVID-19 is constantly emerging, so are our planning and response needs. Sector-wide leadership and coordination will be essential to this if things escalate. The Directorate is commissioning a Sector Leadership Response Group where we (remotely) meet to work through planning and response as it unfolds. We will produce a sector information sheet that can be published and distributed. Lara Penman is the Disability Directorate's lead person on the response and our key connection to the response team. She will also be the key contact for this group so we can have consistency of communication.

COVID-19 is a reminder to take care of yourselves and those around you. Please remember to be vigilant about washing your hands, protect your sneezes and check in with whānau, family and friends. I wish you all the very best.

Ngā mihi nui

Adri

COVID-19

Please refer to our website as the best source of information about COVID-19
health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus

Information from other sources can lead to inconsistent messaging or become out-of-date, and it may not be relevant to New Zealand. Our page is updated frequently, often several times a day, and includes videos of our media stand-ups which take place most days. We have also set up a Ministry Facebook page at facebook.com/minhealthnz to get messaging out to the public and help to counter misinformation about novel coronavirus. Please share this with your networks.

There is a dedicated Healthline 0800 number for COVID-19 health advice and information. The number is 0800 358 5453. It is free and available 24 hours a day, 7 days a week. People calling that line will be able to talk with a member of the National Telehealth Service. They have access to interpreters. You should call this dedicated number:

- to register if you have self-isolated yourself
- for any coronavirus health advice and information and any questions you have about coronavirus, self-isolation etc.

Healthline's main number is still the one to call for non-coronavirus health concerns – 0800 611 116.

Whichever number you call, you will get professional health advice and information.

Importantly, we all need to follow the Ministry of Health's public health messaging, in particular:

- washing hands regularly for at least 20 seconds and dry them for 20 seconds – or use an alcohol-based hand sanitiser
- covering your mouth and nose with a tissue when you cough or sneeze – then putting the tissue in a lined bin
- coughing or sneezing in to your elbow if a tissue is not readily available
- avoiding touching your eyes, nose and mouth
- cleaning surfaces regularly
- staying home if you are sick.

It is critically important that we all work together to protect New Zealanders from COVID-19 and play our part in the global effort to contain it.

Enabling Good Lives

Christchurch

Hannah Perry, Enabling Good Lives Christchurch

Kia ora, Talofa Lava, Kia orana, Malo e lelei, Bula Vinaka, Greetings from Enabling Good Lives (EGL) Ōtautahi Christchurch!

The disability community and those of us who are privileged enough to work alongside it are familiar with the Enabling Good Lives principles. We understand that all people should have choice and control over their own lives, that support should be easy to use and available in a way that enhances the mana of the person and that the EGL approach aims to make it easier for disabled people and their whānau to build strong relationships with the local community.

In Waitaha/Canterbury, EGL have been working alongside young people, their families and schools since 2013. We assist students as they transition from high school to live good lives of their own choosing in communities that truly value who they are and what they have to offer. But what does this look like in real life?

I recently posed this question on our private Facebook group and was overwhelmed with the response I got from young people, their families and supporters. I am grateful to those who were keen to share their stories of how they live their good lives. It is exciting to see what a difference working in a way that is consistent with the Enabling Good Lives principles has made for the young people, their families and the communities in which they live. There were too many stories to share, but here are a few examples.

- Olivia gains confidence and strength at the gym. She was unsure about the machines at first, but her gym buddy Anita won her trust and was able to scaffold the activities.
- Nevie has a busy and full life, with animals, kayaking, travel, camping, cooking and using the ride-on mower!
- Jesse is supported to live a good life like any other young man in his 20s; flatting, playing foosball and biking.
- Claudia loves the gondola, the spa, being on stage, music classes, train trips and exploring Christchurch on the tram.
- Oskar catches up with his old mate Kerry (AKA Captain Long John Knickers) at the local market on Saturdays.
- Janelle loves art work and dancing and is now too busy to attend a day service!
- Lilian is gearing up for another busy year at university.
- Jacob hangs out with people his own age to go mountain biking, to flip out and go swimming.
- Callum has started a business combining his love of calendars and photography!

The EGL Christchurch team is thrilled to be beginning early with students in their last few years of school, to assist them and their families to live good lives. We look forward to sharing more good life stories throughout the year.

Ngā mihi mahana

Waikato

Kate Cosgriff, Director, Enabling Good Lives Waikato

Waikato Demonstration update 03.03.20

Enabling Good Lives Waikato is in its fifth year of doing things differently in disability support. The initial two-year demonstration commenced in July 2015, hosted by MSD. More than 430 disabled people are now currently participating, 35 percent of whom are Māori and 40 percent aged under 15 years.

Much continues to be learnt and disabled people and families are achieving excellent outcomes. The three Waikato evaluation reports provide lots more information about the learnings and outcomes.

For those of you who may not know much about the EGL Waikato approach, here is a summary of some of the key things that have contributed to success:

- a strong local leadership group of disabled people, families, Māori and providers who have held a clear and consistent vision
- investment in capacity building, especially in disabled people's and family leadership and networks
- solid local relationships and working together through the ups and downs
- all disabled people and families who join EGLW work with a tūhono/connector who gets to know them well and assists them to plan their good life and connect to their community
- people don't have a usual needs assessment instead talk with their tūhono/connector to describe their life and where disability support funding can assist them to achieve their good life
- people and families then receive a personal budget that they have full control over and can use flexibly. Tūhono/connectors support people to use their disability support funding creatively and effectively
- many people use their budgets differently to the usual supports and services provided
- evaluation results consistently show that most people and families achieve their ideal outcomes and think the demonstration has made a lot of difference to them and their whānau
- disabled people and whānau particularly value their tūhono/connector relationship, having the flexibility and freedom to direct their own lives, manage their personal budget and choosing the what, when and how of their supports.

EGL Waikato is very much looking forward to decisions about the future being made and more people being able to choose an EGL approach.

From the ACC treatment safety team

Pressure injury prevention and management

In partnership with the health sector, the ACC Treatment Safety team has a programme of work under way aimed at reducing the incidence and severity of pressure injuries.

Roughly 55,000 people develop a pressure injury every year in New Zealand, even though evidence tells us that 95 percent are preventable. These injuries come at a significant cost to the health system and impact quality of life for people who are affected. In the most severe cases they can cause death.

Over the past few months the Pressure Injuries team has been working closely with its Community Design Group and Expert Working Group.

The Community Design Group has been working in a co-design approach to develop and provide recommendations to ACC about how we might enable accessible and timely information to prevent pressure injuries in the Spinal Cord Injury population.

The Expert Working Group has concurrently been developing a consensus statement on prevention and treatment of pressure injuries for people with a SCI over the course of their life.

For more information about ACC's pressure injury prevention work email pressureinjuryprevention@acc.co.nz

For further resources and helpful tips please visit the following organisations:

- New Zealand Wound Care Society – nzwcs.org.nz
- New Zealand Spinal Trust – nzspinaltrust.org.nz/resources/pressureinjuryprevention/

From the community

Life After School and Leaving Home: Dylan's Story

Rachel McLeod, Project Manager, ConneXu

For most of us, leaving school is a time of change and mixed emotions. There's the excitement of perhaps leaving home, spreading your wings and gaining some independence. But there's also the pressure of having to decide what to do once school has finished – even though you find out later you'll probably change your mind about this a few times along the way.

Everyone's wants, needs and thought processes around these decisions are different. If you have a disability, the considerations are the same – what to do and whether you move out of home. However, finding the level and type of support to live the life you want can also be tricky. Especially if your disability requires high levels of support and your family have always provided this for you. →



This is Dylan. He finished school last year and, just like many other young men, had always dreamed of moving out of home and into a flat. In late November last year, with the support of ConneXu his dream became reality; he moved into a flat in Tauranga.

Dylan has had a great summer with his flatmate Will and ConneXu supporters and has settled into his flat well. There is a great morale in the house and Dylan has given everyone in the flat a nickname. For example, Tara (his ConneXu Service Manager) is 'Lion', because she wears her hair in a topknot, Mike (one of Dylan's supporters) is very tall, so Dylan calls him 'Ostrich' and Will is 'Whale', because it sounds like his name.

Dylan feels at home here, and even helped to pick out the flat's furnishings, texting pictures of things he would like included in the flat to Tara. Dylan loves horses, so there is a picture of one in the hallway and his bedroom has been painted his favourite colour – yellow. Because Dylan has Coloboma of the eye (a condition where part of the eye structure is missing), he has limited vision and yellow is one of the only colours he can see. Coloboma of the eye is a common symptom of CHARGE syndrome, a condition Dylan was diagnosed with when he was 2 months old, which is also characterised by other physical and learning disabilities.

As Dylan and Will each have their own needs, interests and goals they are working towards, their schedules look slightly different. Dylan attends a program run by Geneva 3 days a week where he is part of a small group of young people that does fun activities like karaoke, baking, drumming, going to a café or arts and crafts. He is currently making a police car that he's spent a lot of time on and is very proud of. Will on the other hand is doing a level 2 computer studies course at Toi Ohomai. However, Will and Dylan also enjoy time together. They might go to Dylan's grandma's house for a swim or enjoy a trip to McLaren's Falls or the Mount to hang out or explore.



Dylan in his yellow bedroom.



Dylan and his flatmate Will playing basketball.

The young men's ConneXu supporters are really aware of the lightest touch approach, which means that the flatmates have responsibility for the day-to-day running of the flat with backup and guidance if they need it.

So just like any flat, it is Dylan and Will's responsibility to ensure the house is clean and tidy, and the groceries are done. If a plumber has been called, they will greet them at the door, then communicate with them to get the problem fixed. This allows Dylan and Will to grow in independence and confidence, with the safety net of their ConneXu supporters in the house if they need them.

I had the pleasure of speaking with Chris, Dylan's Mum, to get the family's perspective on how things are going two months since Dylan moved into his flat.

'I have always felt that Dylan needed to be living somewhere independent of David and I. Not being morbid – but the reality is that we won't always be here, and we needed to have another plan in place. Plus, we both work, and that has become an issue with the ongoing and future care for Dylan,' said Chris.

'Our supporters are absolutely lovely. They are very much aware of Dylan's needs and will change the situation if he is getting agitated. They are very intuitive. And they are great at communicating with us.

'Having Dylan in his own flat is fantastic. As he is here in Tauranga, I love that we can pop in if we are passing and catch up. Plus, there is a huge – perhaps not relief – but the sense of ease we feel knowing Dylan is ok is wonderful,' says Chris.

This is where I heard Dylan's Dad, David, and sister, Holly, call out to me through the phone Chris was holding: 'We love it! He is happy and we are happy.'

At this all-important stage in Dylan's life, what more could a family want?



Dylan with his ConneXu supporters.

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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