Welcome to the final edition of our newsletter for 2017. The year has once again gone past very quickly!

The team in DSS are very excited about the progress of the system transformation work and want to thank everyone who has taken the time to be involved in helping design a better disability support system for the future.

One of the consequences of this work is that we have not invested in our usual programme of strategic development and service improvements. Instead we have focused on the changing landscape and planning for improvements ready for MidCentral and a future transformational roll out.

Having said that, we continue to develop services in key areas such as implementing activities identified in the respite strategy, and our Māori and Pasifika disability action plans. Work has also continued on the new residential pricing model and of course we have been working with our wider Ministry colleagues on implementing the pay equity settlement.

There is plenty to update you on in this newsletter and we look forward to your feedback on our work.

I would like to take this opportunity to wish you all a great Christmas and New Year and a safe and happy holiday period.
Christchurch

Hannah Perry, EGL Lead, Ministry of Health

*Kia ora koutou, ko Hannah Perry toku ingoa and I am privileged to join the Ministry of Health as Enabling Good Lives (EGL) Christchurch lead.*

I am based in Christchurch and am part of the system transformation team. I’ve been part of the EGL Christchurch team since 2013, in a variety of roles, initially as a navigator, then as co-manager for Families and Community Development, and for the past year as Practice Supervisor.

I believe in the principles of EGL. I believe that we should invest early in whānau, connect families and build networks so that disabled people have a stronger voice. I know from experience that there is a wealth of opportunities in our own neighbourhoods and that the local community is strengthened and made richer by the inclusion of all people.

Young people and their families are using their EGL personal budgets flexibly to achieve goals identified in their Good Life Plans. Examples include a young woman who has bought a stationary bike so she can get fit and improve her wellbeing at home in a supportive and calm environment. A young man has also purchased an iPad which is physically easier for him to use, and means he can take more responsibility for his own life; paying bills and managing his budget as he develops skills towards moving out of home.

I am very proud of the outcomes achieved for some of the EGL participants and their families over the last four years. I know we can make things even better for young people, their whānau, and the services and communities that support them. I am eager to meet with as many individuals and groups as possible over the next few months, and to listen carefully to the different perspectives of how the EGL approach in Christchurch can be improved, made more simple, flexible and easy to use.

Waikato

Kate Cosgriff, Director, Enabling Good Lives Waikato

*Enabling Good Lives (EGL) Waikato is continuing to thrive. The demonstration has been extended until June 2019 with 60 additional people able to join each year.*

At the end of October there were 270 active participants in the demonstration. There are 83 disabled people, families and whānau waiting to join EGL Waikato.

Just over half of current participants live in Hamilton and the remaining 48 percent live all around the greater Waikato region, including participants from every small town and rural area. Thirty-three percent of participants are Māori and 22 percent are aged under 10 years.

Some disabled people, family members and providers who are involved in EGL Waikato are contributing to the national system transformation work.
The Waikato Leadership Group and staff team are also very pleased that the Phase 3 evaluation is in the detailed planning stage. The evaluation team is aiming to talk directly with 60 disabled people, families and whānau about their experiences in EGL Waikato and their achievements. This third evaluation will also help the team focus their energy on changes and improvements that need to happen.

The EGL Waikato Māori Action Group recently reviewed their 2015–2017 plan. The goals and tasks in this plan have been achieved and there are high numbers of disabled Māori and whānau that have participated in EGL Waikato.

The Action Group has set goals for the next two years. The overarching goal remains that disabled Māori and their whānau have full access to EGL in order to plan for and have the lives they want. A hui for Māori participants and whānau is being planned for later this year.

It has been a busy period of presenting on EGL Waikato, including presentations to the Waikato/Bay of Plenty Regional ACC team, the Ministry of Social Development’s Service Delivery and Policy Teams in Wellington, the Regional Wheelchair and Seating Assessment Services, the Waikato DHD Community Occupational Therapists and staff at Community Living. Over 200 people attended these various presentations, with significant interest and questions.

A particular highlight was meeting with the ACC team, where all present were very excited by the level of synergy between EGL and where ACC are heading.

**DSS system transformation**

**Sacha O’Dea, Programme Lead, Ministry of Health**

The new design for the disability support system is now being developed after the high-level design was presented to Cabinet earlier this year. We are continuing to co-design with the sector and are committed to ensuring the voice of the disabled person is heard.

There were 13 people on the co-design group which developed the high-level plan. But for this next phase, more than 20 working groups have been set up and there are up to 15 people in each. At least a third of each working group is made up of disabled people, no more than a third are from government agencies and the rest is made up of members of the disability sector.

The groups will be holding up to five workshops or meetings. Some of the working groups that have started include:

- funding mechanism for building capability of disabled people and families
- disability information – front end to the new system
- funding
- EGL roles
- system responsiveness – creating a learning system
- safeguarding.

Working groups on the interfaces with government agencies will start meeting this month. Some working groups will start meeting later this year or early next year; for example, market shaping, regulation and brand/identity.
We are also creating virtual testing groups with unlimited membership so anyone can provide feedback.

There are three formal groups providing feedback on the detailed design. They include the:

- co-design group – is it consistent with the intent of the high-level design?
- regional leadership group – will it work in MidCentral?
- national Enabling Good Lives leadership group – Is it consistent with the EGL vision and principles?

In addition, there is a governance group that oversees all of the EGL work.

The transformed system will result in some fundamental shifts including putting decision-making in the hands of disabled people and families/whānau, there will be more individualised support, more flexibility to achieve outcomes, and a greater role for disabled people and whānau in governance and leadership.

The prototype will be made available to people in MidCentral on 1 July 2018, and for the first year it will be a ‘try, learn and refine’ approach.

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**DSS news**

**Co-design approach attracts international interest**

*Linda Skates, Communication Advisor, Ministry of Health*

*Interest in New Zealand’s approach to the co-design of the new disability support system with the disability sector, led to the opportunity to present at the International Initiative for Disability Leadership (IIDL).*

The IIDL meets once a year, this time in Ottawa Canada, where they showcase examples of international innovation.

Toni Atkinson, the Ministry of Health’s Group Manager Disability Support Services, attended as a member of the IIDL sponsoring countries’ governance group. Also invited were the Ministry’s Sacha O’Dea, System Transformation Lead, and Gerri Pomeroy, the incoming president of the Disabled Persons’ Assembly and a member of the Enabling Good Lives leadership group.

Gerri, Sacha and Toni were part of the co-design group which, earlier this year, developed the high-level design to transform New Zealand’s disability support system. Sacha and Gerri presented on co-design to a number of interested groups in Canada. Speaking to the Deputy Ministers Taskforce on Disability and Inclusiveness, Gerri told the group she ‘found the co-design process both fantastic and challenging’.

‘It was mentally tough, the conversations were frequently crunchy and, for myself, it took a while to trust that everyone in the group genuinely wanted transformational change.'
'The people in the co-design group were flexible, generous, honest and human. They brought different experiences, expertise, perspectives and networks to the conversations.'

Sacha and Gerri then presented to the IIDL at the Office for Disability Issues and to an interested group from DG Policy/DG Social Partnerships Groups, Employment and Social Development Canada. There was also an exchange of ideas and an opportunity to hear about developments in other countries, with an update presented on Australia’s National Disability Insurance Scheme (NDIS).

The IIDL group then travelled to Montreal to McGill University for discussions on social inclusion and engagement. This included conversations about universal design culminating in a tour of Place Vauquelin. This is an accessible park that the city of Montreal is very proud of, showcasing a great example of universal design.

Squeezed into a busy schedule, Toni, Sacha and Gerri attended presentations from groups including the Disability Women’s Network of Canada, which is focused on growing leadership of disabled women and girls, and AMI – a not-for-profit media company with an open described and closed captioned channel for people with sight and hearing impairments.

Toni said one of the highlights for her was a presentation on emerging technologies for people who are non-verbal and unable to communicate. A bio-medical engineer from McGill University, Dr Stefanie Blain-Moraes, described how they created bio-music by monitoring the heart rate, skin temperature and other physical indicators of people with conditions such as Locked-In Syndrome. The father of one boy noticed how the music changed as he interacted with his son. This work has been shown to change the way that family and carers interact with those who are unable to respond, as the bio-music reminded others of their ‘personhood’.

Sacha found it particularly memorable talking about co-design to the taskforce. She commented that it allowed her to understand more about the experiences in rolling out the NDIS in Australia, and thinking about how this could be applied to New Zealand.

Sacha observed that while not all the processes are perfect, ground-breaking work is happening with system transformation and the team is making more genuine attempts to co-design with the disability sector.
Spotlight on quality

Christina Curd, Senior Advisor Quality, Disability Support Services

Welcome to our spotlight on quality, where we provide a snapshot of data and insights about DSS-funded services to support continuous quality improvement.

We thought we would start off with a snapshot of the critical incidents reported to the Ministry of Health by DSS providers.

Number of incidents reported

We continue to receive a steady stream of critical incident reports, with increases in numbers usually correlating to when we remind providers to send us their reports (as seen in the jump in numbers from April to May).

Graph 1: Reported critical incidents for 2016/17, by month

DSS sees reporting critical incidents as an opportunity for service providers to learn and improve their delivery of services. Because of this, over-reporting is better than under-reporting. If in doubt, report it – this is in line with the recommendations of the Putting People First review.

Reporting critical incidents immediately is an important part of ensuring the safety of disabled people. DSS requires its providers to report all critical incidents to the Ministry within 24 hours of the incident occurring.

The Ministry wants to make sure that providers are doing three things with these incidents.

• Appropriately managing the incident to make sure that the people involved are safe.
• Analysing the incident to identify root causes and then implementing improvements to prevent this incident from occurring again.
• Analysing the incident trends to identify opportunities for quality improvement.

The information collected from reported incidents can prevent similar, or more serious incidents from happening in the future. If incidents are not reported, lessons cannot be learned.

Types of incidents reported

Abuse and assault remains a concern within the disability support system. We all need to ensure there is a reduction in abuse and assault of people – of those with a disability and those working in the disability support system. Let’s work together to instil a culture of zero tolerance of abuse and assault in disability services.

The Quality Team and Contract Relationship Managers continue to work with providers to reduce the amount of abuse/assault incidents occurring in their services. We have been excited to hear that some providers are taking up the challenge and implementing organisational wide changes and improvements.
The prevention and management of abuse guide for services, provides good insight and practical advice to support providers in the prevention of abuse. It is available on the Ministry website at www.health.govt.nz/publication/prevention-and-management-abuse-guide-services-funded-disability-support-services

If you have any questions or thoughts, please contact the DSS quality team at dsscomplaints@moh.govt.nz

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**Transforming respite**

Deborah Mills, Development Manager, Ministry of Health

**With the release of the disability respite strategy in July 2017, we are now working to implement changes to make it easier for carers of disabled people to take a break from their caring responsibilities.**

An implementation plan was approved in August 2017. This plan sets up four work streams.

- **Flexible respite budgets** – involves planning how to administer the funding and communicate the changes with disabled people and their families/whānau.
- **New resources** – developing Easy Read information on how to use a flexible respite budget, and how to find respite options to suit each family situation.
- **New options** – includes sharing information with current and potential new providers on the respite market in each region and any service gaps. This work stream will also involve a co-design process in each region to identify opportunities to collaborate on facility-based respite solutions.
- **Evaluation** – creating an evaluation framework to measure improvements in access to respite and to improve its quality.

To discuss any aspect of the strategy, please contact us on respitestrategy@moh.govt.nz

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**Whāia Te Ao Mārama is ready for release**

Jason Moses, Senior Advisor Māori, Ministry of Health

**Following consultation with more than 200 Māori from around the country, Whāia Te Ao Mārama 2017–2022: The Māori Disability Action Plan, is nearly ready to be published.**

It will be published on the Ministry of Health’s website in Te Reo Māori, Easy Read and English (with visual descriptions) once it becomes final later this month.

The vision of Whāia Te Ao Mārama is that tāngata whaikaha (Māori with disabilities) pursue a good life with support. The 2017–2022 action plan includes six goals to help achieve this vision, and 12 actions for the Ministry of Health to contribute towards achieving these goals. Once finalised and published, the Ministry will develop an implementation plan that outlines how the Ministry will deliver its actions, how progress will be measured, and how progress will be monitored. One of the
actions the Ministry is keen to commit to is to actively involve tāngata whaikaha in the design and implementation of the transformation of the disability support system.

The 2017–2022 action plan recognises that everyone must work together to achieve the vision. It also outlines what the Ministry is committing to do and provides examples of actions tāngata whaikaha, whānau, disability providers, iwi and other organisations can take. We encourage everyone to take a look at those examples and think about what else can be done to help achieve the six goals.

Sector updates

The TalkLink Trust: A shining light

Most of us do not have to think about the implications of suddenly being unable to communicate. We take the ability to talk to one another, to share information, make decisions, question, protest, comment and even argue, for granted.

After all communication is a fundamental human right. It is one of the things that makes us uniquely human.

At TalkLink we do not take communication for granted, because every day we see people who find communication challenging. We also see the difference that communication tools and strategies can make to the individual and all the people they interact with on a daily basis. The team at the TalkLink Trust are passionate about communication.

One of the innovations TalkLink is working on at the current time is raising awareness about Voice Banking, which gives people who are losing the ability to speak the option to continue to speak with their own voice, rather than the generic computerised American, British or Australian voices currently on the market. In addition, TalkLink is exploring the options around developing Kiwi accent voices and with an ultimate goal of creating a Te Reo Māori voice. For more information visit [www.talklink.org.nz](http://www.talklink.org.nz) or email support@talklink.org.nz

We were thrilled and humbled when Motor Neurone Disease (MND) New Zealand called to say that TalkLink had been chosen as the recipient of the David Oliver Beacon Award for 2017.

This award was established to recognise publicly how much the MND community benefits from people and services who care and support them. The theme this year was ‘A Shining Light’.

The values against which the award was assessed were:

- a philosophy of advocacy for person and family/whānau care
- exceptional communication and collaboration
- advocacy
- cultural safety
exemplary practice promoting independence and management
compassion
leadership
evidence-based decision making in improving quality of life.

Beth Watson, president of MND New Zealand said: ‘We trust that TalkLink sees this as an affirmation indeed of the excellent, proactive and timely work that it does all over New Zealand for people with MND. Thank you so much for your work.’

Thank you Beth, it is gratifying to see that providing communication options can make such a difference in people’s lives. For the team at TalkLink, some of the most rewarding, challenging and emotional work we do, is when we walk alongside people with MND. We are absolutely privileged to share their journey.

The David Oliver Beacon Award is a new award, presented annually to health practitioners. It is open to individuals, groups and services that provide a positive contribution, improvement or innovation in MND support or care. There are many examples of individuals and organisations who work diligently to support people with MND. The theme for the 2018 award will be announced on the MND New Zealand Facebook page and in the MND News newsletter in March. Nominations will be open for about 3 months and close on 21 June. For more information visit the MND website https://mnda.org.nz and consider making a nomination for next year’s award.

Flexible, partnership-oriented approach welcomed by families

Late last year, Auckland-based support provider Spectrum Care was contacted by a number of Wellington-based families in relation to accessing disability support services in the region.

Spectrum has since been able to explore other support opportunities, such as flexible respite and vocational support with existing and new families.

‘Our presence in the Wellington region offered the opportunity for a partnership-based approach in providing a range of valuable new support options to people with disabilities and their families,’ said Spectrum’s Chief Executive, Sean Stowers, at the launch.

Building these deeper relationships between support provider and people/families has been an important focus for the organisation. Spectrum has also recently commissioned work to enhance its understanding of the customer experience and journey.

Through more meaningful interactions, Spectrum has helped build higher levels of alignment between the support options offered and people’s wants and needs, as well as aligning more closely with the Transforming Respite strategy launched earlier this year.

Spectrum has also launched a variety of flexible, fee-for-service support options which allow families to engage in new ways, including school holiday and after-school programmes, weekend-day respite options in collaboration with New Zealand’s Special School network and a suite of new ‘Taking a break’ respite support opportunities.
Family feedback has been strongly positive, particularly in relation to this partnership-oriented approach.

As interest in living a more independent life increases, and the sector moves towards offering families and people with disabilities more control over the supports they receive, Spectrum has endeavoured to take an increasingly partnership-oriented role in the co-design of these support options.

Contact: Spectrum Care Trust at
W: www.spectrumcare.org.nz
E: info@spectrumcare.org.nz
T: (09) 634 3790 / 0508 NAVIG8 (628448)

Seeking feedback on technology support for disabled people

Contact: Kathryn Hall, Development Manager, Ministry of Health

We are seeking feedback for a research study into the value that assistive technologies offer disabled people.

Assistive technology can be any product that helps a person take part in everyday activities. This includes mainstream technology that is modified or technology that is designed specifically for people with cognitive and/or physical impairments. Examples of assistive technology include software such as smartphone apps that help with communication, or a power wheelchair that helps with getting around.

The Disabled People’s Organisations and ACC (along with the Ministry of Health, Ministry of Education and Ministry of Social Development) are doing a study to learn from disabled people how assistive technology makes a difference to their lives; which technologies are being used, and what disabled people think of current government funding.

Please provide your feedback to us. To take part in the survey go to:

If you would prefer to do the survey over the phone or by postal hard copy (including an Easy Read version) please contact: Andrew Whitsed on 0800 825 5867 or email at andrew@umr.co.nz

The survey is running until mid-December.

Jason Moses – Senior Advisor Māori

Rau rangatira mā, tēna koutou katoa. Ko Putauaki te maunga, ko Rangitaiki te awa, Ko Tūteao te marae, Ko Ngā Maihi te hapū, Ko Ngāti Awa te iwi.

My name is Jason Moses and I am the new Senior Advisor Māori.

I have joined DSS after having spent the best part of 18 years in the public sector in various policy, service design and advisory roles. My education and passion is for Māori and Pacific development, so I look forward to being able to help tāngata whaikaha (Māori with disabilities) pursue a good life with support.

My key responsibility is to drive the implementation of Whāia Te Ao Mārama 2017-2022: The Māori Disability Action Plan. Bringing Whāia Te Ao Mārama to life requires the contributions of many, including the Ministry of Health, tāngata whaikaha, disability providers, community groups and iwi. If you have any ideas on how we can improve the lives of tāngata whaikaha, or any good news stories about how you or your organisation are implementing the actions of Whaia te ao Marama, please feel free to contact me.

Ma tau rourou, ma taku rourou, ka ora ai te iwi (with our joint contributions, we will make progress).

jason_moses@moh.govt.nz

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 the email list of this newsletter, or if you no longer wish to receive this newsletter, please email disability@moh.govt.nz