Happy New Year to everyone! I hope you are enjoying a better summer than Wellington is. We have settled into our new offices at 133 Molesworth Street (the old building having been refurbished) and are enjoying the new flexible way of working. It is really nice to have all of the Wellington Ministry of Health team together on one site.

We are planning a big year of activity, which includes finalising the strategy work we have undertaken and using the feedback from the strategy workshops and other reviews over the past year (including the DIAS/NASC review and Enabling Good Lives (EGL) evaluations) to plan for further improvements to the disability support system. We hope to be able to provide more detail on this work in the next newsletter.

In the meantime, thank you to everyone in the sector who is working with us on our current work plan and on future system improvements. It is heartening to hear the good stories coming from the sector about how the increased choice and flexibility we have introduced to disability supports is making a difference to peoples’ lives. We acknowledge we still have some way to go.

I look forward to working with you over the coming year.
Christchurch

Joanna Martino, EGL Lead, Ministry of Health

With the end of one school year and the beginning of another, there has been much activity in EGL Christchurch.

Last year, we supported young people leaving school and their families to dream big and work with their independent facilitators as allies in their journeys. Teachers continued to prepare these young people for life after school, and our local NASC, LifeLinks, supported the completion of supported self-assessments and allocation of EGL personal budgets.

Young people and their families have engaged with Manawanui (individualised funding support provider) and, increasingly, Flexible Disability Support providers to arrange hosting and support, enabling them to achieve their desired life outcomes within their budgets.

The great stories emerging from our young people reflect their ability to exercise greater choice and control over their funding, as well as the flexibility that providers are embracing. Our independent facilitators keep us all on track through their championing of the EGL principles.

Young people participating in EGL Christchurch are turning work experience into paid work, attending assemblies and enrolling in mainstream training and tertiary education. They are using their budgets to engage with providers, or creating for themselves a lifestyle they’ve always envisaged. One example is four young men who will start flatting together in April. Their families have engaged the support of a Flexible Disability Support provider to help them achieve this goal, and LifeLinks and the Ministry of Social Development are working together to turn the dream into reality. The collaboration between the families and their dedication to the young men is EGL in action; these participants and their families and others continue to inspire us all.

This year, EGL participants will have an opportunity to attend a ‘Meet the Facilitators’ event in February. This is a chance for them to ask questions about EGL and independent facilitation and to connect with other families and school leavers. In addition, local providers are arranging a transition expo called ‘Next Steps’, to be held in the first school holiday, where young people and their families can connect with local providers and other agencies that may support them in their lives after school.

If you have any queries, please contact Joanna Martino on (03) 974 2308 or joanna_martino@moh.govt.nz
By June this year, the Waikato EGL demonstration will have supported over 236 people. Interest continues to be high; 17 people contacted us in January alone wanting to participate.

The reason for their interest is the feedback they are hearing from both providers and current participants. As people have watched the positive impact EGL has had on other people’s lives, it has helped them build up their confidence to give it a go themselves. The demonstration has already reached its maximum participant target numbers.

The key components of the EGL Waikato Demonstration continue to be as follows.

• Co-design: Disabled people, families, service providers and officials are committed to co-designing their work programmes as the demonstration has progressed.

• Tūhono/connector engagement: Those working in tūhono/connector roles assist participants to think about where they’re at, make connections in the community, make their own plans, understand their own budgets and choose their own sources of information and support to work towards their vision of a good life.

• Building community connections: The team helps disabled people and their families and whānau to build or extend their connections with the community.

• Supported self-assessment (SSA) and planning: These processes help participants and their families and whānau and tūhono/connectors to understand what resources are required to support individual participants to plan for and live the lives they want. Participants can complete an SSA themselves or receive support from their tūhono/connector to do so.

• Pooled personal budgets: The demonstration links a person-centred funding allocation to an individual participant’s plan and SSA, and that person controls how this is spent to create a good life for themselves. Participants can either self-manage their personal budget or engage with a host to help them do so. The Ministries of Health, Education and Social Development provide the pooled funding package for this system; it has enabled people to develop unique and creative ways to meet their support needs.

The diversity of our participants compares favourably with regional demographics:

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Regional demographic</th>
<th>Demonstration demographic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pacific</td>
<td>2.9%</td>
<td>5%</td>
</tr>
<tr>
<td>Māori</td>
<td>22.9%</td>
<td>34%</td>
</tr>
<tr>
<td>Asian</td>
<td>6.9%</td>
<td>6%</td>
</tr>
</tbody>
</table>

In Waikato, a higher proportion of participants live in the more deprived sections of the population than they do nationally. This is evident in many of the situations tūhono/connectors are dealing with: they see that poverty, substandard housing, lack of heating and lack of food are compounding disability issues.

An evaluation team has completed a second evaluation of the demonstration and will release a report this month. The evaluation team, which included disabled evaluators, met with
32 participants to listen to their stories and record measurable outcomes that can be attributed to the demonstration.

Enabling Good Lives Waikato has recently published a short documentary about participant Kylee Black, giving her a platform upon which to share the great difference that EGL has had in her life. In the documentary, Kylee explains the life-changing effect choice and control over her supports has had for her. You can see the video on the EGL website: www.enablinggoodlives.co.nz

Enabling Good Lives Waikato forums are continuing this year. Last year’s final forum focused on the benefits of planning. A tūhono/connector led a group discussion in which participants described their experiences with formal and more casual planning, and the benefits of both approaches. The group reaffirmed the importance of the forums as a way of connecting to peer support and fostering hope and encouragement. If you are interested in finding out more about any forums, please contact Loren Corbett on 029 201 4780 or loren.corbett001@msd.govt.nz

A recent comment from a participant’s mother, Robyn O’Neill, to her daughter Erin’s tūhono/connector sums up the difference the EGL approach is continuing to make.

‘It’s refreshing to know that we have the opportunity and scope to do the best for Erin. It’s great being able to pick and choose our own people and do our own thing. We are able to make plans flexibly, we know what we can afford to pay and we can get people who are appropriately experienced and pay what they are worth. We need to know that there is some connection between us and the rest of the world and that is what you are.’

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**DSS news**

**DIAS/NASC review**

*Chris Petch, Contract Relationship Manager, Ministry of Health*

The Sapere Research Group has completed its independent review of the existing disability information advisory service (DIAS) and needs assessment service coordination (NASC) functions on behalf of the Ministry of Health and has submitted its final report, *A Proposed Design and Framework*.

This report will inform the work the Ministry will be undertaking to transform the disability system. It identifies ways in which we can improve the interface between disabled people and support services to better support people to have a good life.

The report will be available shortly on the Ministry’s website: www.health.govt.nz

The Ministry would like to thank all stakeholders who participated in this review.
Sector updates

Oceania Seating Symposium

Seating To Go, a specialist wheelchair and seating assessment, repair and training service, has been asked to host the inaugural Oceania Seating Symposium in conjunction with the International Seating Symposium.

The invitation was accepted by Seating To Go as part of their 20 year anniversary celebration in 2017 and to demonstrate their ongoing commitment to leading best practice in New Zealand. Deb attended the European Seating Symposium (ESS) in Dublin this year and found it extremely beneficial.

During the last quarter, the Symposium has gained traction and international interest. The committee includes Rachael MacDonald (Associate Professor Department of Health and Medical Science, Swinburne University in Melbourne) and Bonnie Sawatzky (Associate Professor Department of Orthopaedics, University of British Columbia), a committee member of the International Seating Symposium, Liz Wackrow (Mobility Solutions NZ) and the New Zealand Chair is Deb Wilson (SeatingToGo NZ).

The symposium will be a combination of keynote, plenary, instructional workshops, paper and poster session. It will be held at the Energy Event Centre in Rotorua from 20–22 November 2017. For more information visit http://www.oceaniaseatingsymposium.com/

Recent disability events

Disability Consumer Consortium

Cheryll Graham, Senior Advisor, Ministry of Health

The Disability Consumer Consortium met in October 2016, and held discussions on:

- the Ministry of Health’s structure and strategic goals, and DSS’s place in that structure and role in achieving the goals
- feedback on developing DSS strategies
- the Ministry’s guidelines on preventing abuse, which assist providers and others to safeguard disabled people against abuse, with a core focus on residential services
- the New Zealand Sign Language Board Action Plan, the aims of which include ensuring that information provided to parents of deaf children is timely, relevant and independent
- refreshing the Whāia Te Ao Mārama: The Māori Disability Action Plan
- ways of reducing potential barriers to accessing health screening services (eg, breast screening) for disabled people
• the DIAS/NASC review
• development of a national model of support and core functions for delivering low vision rehabilitation services
• Malatest International’s report on a survey of people with disabilities living in Ministry-funded community residential services.

The next consortium meeting will be held in March 2017.

For further information, contact Cheryll Graham on (04) 816 2358 or cheryll_graham@moh.govt.nz or see our website: www.health.govt.nz/our-work/disability-services/sector-and-consumer-partnerships/consumer-consortium

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**Disability Sector Strategic Reference Group**

**Barbara Crawford, Manager, Strategy and Contracts, Ministry of Health**

The Disability Sector Strategic Reference Group met on 9 December 2016 and discussed:

• projects and strategies that DSS is currently working on, including Faiva Ora – National Pasifika Disability Plan, Behaviour Support Services, DIAS and NASC (Group Manager DSS Toni Atkinson gave brief updates)
• *Purchasing Guidelines for the New Model for Supporting Disabled People*
• DSS strategy development
• feedback received from five hui on the refresh of *Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017*
• the New Zealand Disability Strategy (Megan McCoy from the Office for Disability Issues gave an update)
• Malatest International’s report on a survey of people with disabilities living in Ministry-funded community residential services.

The group will meet again in May 2017.

For further information, contact Barbara Crawford on (04) 816 4384 or barbara_crawford@moh.govt.nz
DSS project updates

Choice in Community Living

Craig Scott, Senior Disability Advisor, Ministry of Health

Choice in Community Living (CiCL) is a DSS-funded service that supports people who would normally be supported in a residential service to instead live independently in a home of their choice in the community.

Choice in Community Living demonstrations continue to run in Auckland and the Waikato. The service is now also being demonstrated in the Hutt and Otago/Southland regions. In each of these new regions, five CiCL providers will deliver services. The presence of Local Area Coordinators in these two new regions may enhance eligible people’s opportunities to live independently in their community with the support of their chosen CiCL provider.

Eligibility for CiCL is determined by a disabled person’s NASC. People living in the two new regions who may be interested in CiCL for themselves or a family member should contact Life Unlimited in the Hutt (www.lifeunlimited.net.nz) or AccessAbility in Otago/Southland (www.accessability.org.nz).

For further information, contact Craig Scott on (04) 816 3654 or craig_scott@moh.govt.nz

Refresh of Whāia Te Ao Mārama

Barbara Crawford, Manager Strategy and Contracts, Ministry of Health

The refresh of Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017 is under way. As part of the process, the Ministry of Health contracted Ngati Kāpo to run five hui with Māori disabled people and their whānau across the country during November 2016.

In addition, at the DSS provider forums in November 2016, workshops were held to obtain the input of DSS providers in this regard.

The Ministry is currently developing the updated plan and will distribute a final draft to hui and workshop attendees for further consultation in March 2017. We look forward to receiving feedback before finalising Whāia Te Ao Mārama 2017 to 2022.

Thank you to all those who participated and provided input and feedback to this process.

For further information, contact Barbara Crawford on (04) 816 4384 or barbara_crawford@moh.govt.nz
Te Ao Mārama meeting

Barbara Crawford, Manager Strategy and Contracts, Ministry of Health

Te Ao Mārama, the Māori Disability Leadership Group, met in December 2016 to provide DSS with advice and input into the service strategies DSS is currently developing. At this meeting, it also reviewed all the feedback received from the five hui and the DSS provider forums on the refresh of Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017, and provided its advice.

Te Ao Mārama will meet again in March 2017.

For further information, contact Barbara Crawford on (04) 816 4384 or barbara_crawford@moh.govt.nz

Respite strategy – survey feedback

Deborah Mills, Development Manager, Ministry of Health

Disability Support Services ran online surveys in October and November 2016 to inform development of its respite strategy. These surveys have provided us with a rich source of information.

We received 1,268 responses to a survey for disabled people and their families and a further 50 responses to a survey for providers. We were pleased to have achieved good representation across all parts of the country, age groups, ethnicities and disability types. Survey respondents were candid and provided significant insight into the struggles they face in their everyday lives, including in terms of accessing respite.

The key findings of the survey were as follows.

• 62 percent of respondents were satisfied or very satisfied with their current respite options.
• 51 percent of respondents were satisfied with the amount of respite they had been allocated.
• People’s ability to use their full respite allocation ranged from 31 percent to 66 percent, depending on the type of respite they had been allocated. The main reason cited for not using respite allocations was inability to find a suitable carer.
• 48 percent of respondents said they would like to access facility-based respite if it was available; 40 percent did not want facility-based respite. The remaining 12 percent already used facility-based respite. Families using facility-based respite reported higher levels of satisfaction with respite services overall, compared with those who were not using facility-based respite.
• Families cited benefits of respite that included having a break to take the pressure off, protecting carers’ mental health, enhancing the wellbeing of the family, sustaining the family in the caring role and providing new experiences for the disabled person.
• Families indicated that they wanted access to flexible respite funding (to buy a range of respite options that meet their needs) and help to access respite options.
• Non-contracted, community-based providers are currently running successful activity-based programmes using carer support and individualised funding.

Thank you to everyone who supported our surveys and helped others to access them. The feedback has been very valuable in our draft of the respite strategy.

For further information, contact Deborah Mills on (04) 816 3956 or deborah_mills@moh.govt.nz

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### Other service strategies

**Barbara Crawford, Manager Strategy and Contracts, Ministry of Health**

Disability Support Services hosted two workshops in December 2016 to obtain the advice and input of disabled people, disabled people’s organisations, families and disability support service providers into developing a strategy for the future of residential support services. One workshop focused on general residential services, and the other focused on better meeting the needs of disabled people with challenging behaviour who live in residential services. We are currently putting together a draft strategy and will circulate it for sector feedback in several months’ time.

Work is also occurring on the development of service strategies for purchasing community disability therapy services (currently known as community rehabilitation) and supported living. We will host sector workshops for both of these service strategies during February and March respectively.

The Ministry greatly appreciates the willingness of the disability sector to engage in these important discussions, which will shape the future of service delivery to disabled people.

For further information, contact Barbara Crawford on (04) 816 4384 or barbara_crawford@moh.govt.nz

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### Contact Disability Support Services

Email: disability@moh.govt.nz  
Phone: **0800 DSD MOH (0800 373 664)**  

To be added to the email list of this newsletter, or if you no longer wish to receive these newsletters, please contact disability@moh.govt.nz