Welcome to our final newsletter for 2016. The year seems to go by so quickly, but I’m sure we are all looking forward to the warmer weather and the Christmas break.

The DSS team’s 2016/17 work programme requires us to deliver on a number of strategies, including some development work. It is important that this has input from the sector, so I encourage you to attend the various forums and workshops we will be hosting to help us set the direction of travel. Our important strategic work over the next 12 months includes strategies for community rehabilitation, respite, child development, residential and supported living.

We are also liaising with our colleagues in the Ministries of Education and Social Development on system transformation across the disability sector. We have learned much from our New Model and Enabling Good Lives (EGL) demonstrations. Now is the time to put what we’ve learnt into use. We will be able to tell you more about the next steps for system transformation in the new year.

I hope you enjoy this edition of the newsletter, and wish you all well for a happy and enjoyable summer break.

PS: Our special edition newsletter will be coming out on International Day of Persons with Disabilities – 3 December. It will celebrate innovative practice within the sector that makes a significant difference in the lives of people with a disability!
Christchurch

**Joanna Martino, EGL lead, Ministry of Health**

**As the end of the school year rapidly approaches, EGL participants and their families are busy activating their EGL personal budgets and working with their schools and independent facilitators on their plans for 2017.**

LifeLinks, our local NASC, is also working hard, completing participants’ supported self-assessments and coordinating personal budgets.

We see an increasing number of participants exercising choice and control over their budgets now that there is a variety of flexible providers for them to choose from. Some participants have even split their personal budgets between providers, to get the best support for different aspects of their life.

Our team of independent facilitators recently held a networking meeting with host and flexible disability providers to clarify issues, ask questions of each other and share experiences. Local providers continue to hold monthly lunchbox sessions together.

Our local schools network liaises closely with EGL officials and independent facilitators. We are planning a get-together during Term 1 of 2017 for 2017 school leavers and their families, where they can meet the independent facilitators and ask questions about the EGL journey.

The EGL independent facilitators continue to report great news about the plans and achievements of EGL participants in Christchurch. Our participants are living independently, going on to university, joining clubs and gyms and generally making real choices about what they do, where they live and the nature of the support they receive.

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Waikato

**Chris Potts, director, EGL Waikato demonstration**

**Enabling Good Lives Waikato is continuing to see high interest from people wanting to participate in the demonstration, which ends in June 2017.**

There are 195 people taking part; some are managing their own budgets and others are using host agencies. Over the last six months, there has been a significant increase in the number of families with younger children taking part.

At the start of November, we celebrated the first 100 participants receiving their budgets and living their good lives.

The tūhono (connector) role is key to the success of the EGL approach. The role includes:

- establishing respectful, enduring relationships
- turning ideas to action – creating opportunities and linking people and opportunities
• helping people to think about what their good life looks like, and what they need to make it a reality
• helping people to understand their budget and develop appropriate systems to self-manage, or connecting them with others who can host their individual budgets and manage supports
• building the knowledge and skills of disabled people and their families and whānau so they can understand their choices and take up opportunities for more control over their lives.

We have published the first evaluation of the demonstration on the Enabling Good Lives website, www.enablinggoodlives.co.nz. The report is very positive. The second evaluation is currently under way: one-third of participants have agreed to take part in the interviewing process.

Here are some examples of what our people have achieved.

• Two young men wanted to go flatting together; they combined their EGL budgets to give them control over their supports. They say having control of what supports they choose, who delivers them and when support happens is making a huge difference in their lives. The tūhono role has been important to these young men in terms of building their confidence, linking them to services, managing their pooled funding and working through issues and plans.

• Recently, a tūhono had a review meeting with a participant who said that he is successful and happy and no longer needs so much support. He told his tūhono he wanted to give some support hours back: ‘I want to see the opportunity I’ve had to be there for someone else.’

• A provider referred a person who had been supported by the same disability service for most of his life to the EGL demonstration. The provider felt the person would benefit from new opportunities and a fresh approach. The person was not sure about EGL at first, he said he didn’t trust services. A tūhono built a relationship with the person over time, and worked closely with his service provider to build a transition plan. The person chose to have his EGL budget hosted by a new provider. As he described it, the benefit of EGL was ‘it’s all about me now’. He is making the most of being able to control who supports him, and when. He recently contacted his tūhono to tell him, ‘I need to change my support staff; they aren’t listening, and they’re going over my head’. The tūhono reaffirmed the person in his role as the one in charge, and the person went on to sort out the issues successfully with his service provider.

DSS news

Kia ora: What a difference you have made!

The Ministry of Health’s Equipment and Modification Services funds free or subsidised equipment and modifications to people with disabilities.

This funding supports people to move in and around their home safely, and to access their community.

We would like to share an amazing story of the impact this assistance has had.

Our funding provided one particular man with a ramp that allowed him to safely get into and out of his home in his wheelchair. His family told us: ‘With the ramp came the freedom. Little things which some take for granted are such a blessing for our brother, his caregivers and his whānau’.

DSS news

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This man was always part of the decision-making process prior to the ramp going in, and was there to keep an eye on the installation. Before it was installed, his siblings had had to lift him out of the house to give him the opportunity to look at the gardens and his surroundings. Now, he often ventures out of his whare: going shopping, lunching out and, more importantly, maintaining his cultural connection to his marae and to tikanga (for example, by attending tangihanga).

In his own words:

‘Ngā mihi nui. Words cannot express how grateful I am with these wonderful blessings. I am very happy with the equipment and I am so pleased my sisters are safe and can continue to care for me in my own home. Again thank you very, very much.’

More of this story can be found in our special edition newsletter.

**Sector updates**

**MyCare helps people find a support worker**

MyCare ([www.mycare.co.nz](http://www.mycare.co.nz)) provides people with online assistance to find support workers close to their home. It matches people seeking support with support workers in their local community.

Almost 2000 support workers across New Zealand have registered with MyCare. They offer services ranging from personal care and companionship to transport and assistance with social activities such as sport.

MyCare is funded for people eligible for Disability Support Services.

Through MyCare, people with a disability can advertise a job, view profiles of support workers in their area and make private contact with anyone who they think may be suitable to arrange an interview. People may be referred to MyCare by their NASC agency, but are welcome to use the service without a referral.

Trust and safety are important to people looking for support workers. MyCare has a process to verify users’ identities and asks all workers to complete a Ministry of Justice criminal convictions check. Worker profiles give helpful information about workers’ experience, training and personal interests. Workers whose names appear at the top of the list will have completed the processes for trust and safety checks, and will be good at responding to messages from people seeking work.

People can get help to register on MyCare by calling 0800 677 700, or by visiting the site. Carers NZ can provide workers with support for using the site: call Katrina Fletcher on 0800 777 797.
Care Matters: Wellbeing and Learning for Carers

Care Matters is a national service delivered by Standards and Monitoring Services and Parent to Parent. It provides resources developed by carers for carers.

Care Matters provides training workshops and online information for small groups of carers. Carers can access these resources themselves, or through their local NASC organisation.

Since September 2015, approximately 500 carers have attended face-to-face Care Matters workshops. The workshops support carers to look after themselves by increasing their knowledge and skills. The workshop topics cover communication, managing challenging behaviour, managing support workers in your home, managing conflict, working with professionals, developing personal plans and managing stress.

In addition, Care Matters is developing two great written resources: How to stay on top of it all and Guidelines for selecting a support worker. These will be available online soon.

Carers who have attended the workshops report that they feel more connected, are able to communicate effectively and manage conflict situations. They also report feeling particularly grateful for the opportunity to talk to experienced facilitators with a great depth of knowledge of caring for people with a disability. Participants have found workshop material and online information both practical and useful. They are reporting increased confidence and assertiveness in their care work.

Rebecca Walton, Care Matters development manager, says: ‘Carers are also wanting to explore and understand more about how they can increase choice and flexibility in using their disability supports services. Care Matters continues to develop its service and resources that meet the needs of carers.’

For future workshop information, visit www.carematters.org.nz or call 0508 236 236.

Te Pou’s online grants portal

Feala Afoa, development manager, Ministry of Health

Te Pou recently launched its new online portal for administering disability workforce development grants.

Eligible organisations can register and submit grant applications online by following easy automated steps, which also allow them to save their applications and view their status. Previously, all grants were administered using a manual process.

For more information, visit www.tepou.co.nz/disability-workforce/online-grants-portal/176
The New Zealand Disability Support Network Workforce Survey 2015

Feala Afoa, development manager, Ministry of Health

The New Zealand Disability Support Network, in partnership with Te Pou, has recently released a report on the New Zealand Disability Support Network Workforce Survey 2015.

This report will enable better disability sector workforce planning and development.

To view the full report, visit:


Provider forums

Barbara Crawford, manager strategy and contracts, Ministry of Health

The Ministry of Health hosted five provider forums in the first two weeks of November, in Dunedin, Christchurch, Wellington, Hamilton and Auckland.

The purpose of the forums was to give providers an update on some of the work of the Ministry over the past year and for providers to have input into some of our strategy development work. In response to feedback from DSS’s survey of providers in early 2016, we changed the format of these forums, to allow more time for consultation with the sector.

The workshops sought providers’ input to the refresh of Whāia Te Ao Mārama (the Māori Disability Action Plan), and also to the development of the five service strategies (described further below). Group manager Toni Atkinson also gave an update on the future of disability support services, and a presentation of the results of the survey of people with disabilities living in residential services.

Feedback from providers and Ministry staff attending the forums was overwhelmingly positive. Disability Support Services is now using many ideas presented by providers to inform its work.
ImagineBetter conference

ImagineBetter is holding its annual conference in Auckland on 16 and 17 February 2017.

Titled ‘Will You Friend Me? Social Capital and the Value of Relationships’, the two-day event will bring together community leaders, disabled people, families and professionals to discuss the important role that friendships play in people’s ability to maintain a happy and meaningful life.

Run in partnership with CCS Disability Action, the conference will feature presentations from international experts Dr Al Condeluci (United States) and Janet Klees (Canada).

Dr Al Condeluci is widely regarded as a leading authority in social capital (the value and power of friendships), community engagement and macro change. His work as an advocate and catalyst for community building over the last 45 years has earned him immense respect in the disability sector. Al will discuss the importance of friendships in maintaining happiness, and how important happiness is to maintaining overall health.

Janet Klees has been involved in the lives of people with disabilities, their families and support systems for more than 30 years. She is best known for her work with the Deohaeko Support Network, which encourages independent living for disabled people. Janet is now sharing her knowledge with a wider group of families in her new role as executive director at the Durham Association for Family Respite Services. She has become a leading expert in the importance of relationships, roles and places in creating meaning, fulfilment and belonging.

Find out more and register at www.imaginebetter.co.nz

DSS project updates

Feedback from people living in residential disability services

Feala Afoa, development manager, Ministry of Health

In October 2016, Malatest International completed a report on feedback from people living in Ministry-funded community residential disability services.

To obtain the feedback, Malatest International adapted the international Schalock quality of life survey tool for the New Zealand environment, and asked questions about three broad areas: independence, social participation and wellbeing.

Malatest International employed people with disabilities and trained them to conduct 332 face-to-face interviews of people living in residential services in Auckland, Palmerston North and Wellington.
The report noted the following overall points.

• Overall, satisfaction was relatively high, rated as 84/100 with most respondents liking the residence or home where they lived.

• Staff was an important factor in terms of whether service users liked their homes. Staff who engaged with residents and got to know them were highly valued.

• The majority of respondents reported positively about their quality of life.

• Service users with consistently higher quality of life scores were more likely to be younger (under 40 years old) and to have an intellectual/learning disability rather than a physical disability.

• The main reason respondents with physical disabilities reported being less satisfied about their level of social inclusion was a difficulty in accessing the community.

• Quality of life scores did not vary significantly between respondents from different gender and ethnic groups.


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Te Ao Marama

Barbara Crawford, manager strategy and contracts, Ministry of Health

On 8 September, Te Ao Marama met with Minister Peseta Sam Lotu-liga to update him on the imminent process of refreshing Whāia Te Ao Mārama (the Māori Disability Action Plan), which has since commenced.

The meeting covered a variety of topics, and provided a good opportunity for the group to discuss the work it has done to support DSS over the past year. This work identified key priorities for the annual Whāia Te Ao Mārama implementation plan, including linking performance indicators to the plan. The Minister was very interested in key issues affecting Māori disabled, and has asked for advice on relevant indicators that could assist in measuring improvement of outcomes.

Left to right: Peseta Sam Lotu-liga, Andrea Lamont, Lee Rutene, Trish Davis, David Tamatea, Dr Tristram Ingham.
Faiva Ora – National Pasifika Disability Plan 2016 to 2021

Feala Afoa, development manager, Ministry of Health

In September 2016, DSS approved implementation of the new Faiva Ora – National Pasifika Disability Plan 2016 to 2021.

The Ministry of Health has developed this plan, and will implement it, in partnership with Pasifika disabled people, Pasifika communities, disability support services, Pacific health providers, district health boards and government agencies.

The plan will focus on the following priorities.

1. Improving outcomes for Pasifika disabled children and youth and their families.
2. Enabling Pasifika communities to better engage with and support individuals with disabilities and their families to participate in their communities.
3. Ensuring that disability services and supports meet the needs of Pasifika disabled people and their families.
4. Working in partnership with stakeholders to address challenges experienced by Pasifika disabled people and their families.

Faiva Ora Leadership Group meeting

Feala Afoa, development manager, Ministry of Health

On 7 October, the Faiva Ora Leadership Group met to discuss and provide advice on the new DSS Respite Strategy and DSS Rehabilitation Strategy.

At this meeting, Feala Afoa from the Ministry presented the Faiva Ora – National Pasifika Disability Plan 2016 to 2021 and summarised the achievements of the previous plan (covering 2014 to 2016). Jade Farrar, a member of the EGL National Leadership Group, provided an update on EGL, and Le Va provided an update on its 2016/2017 activities.
Streamlined contracting

Barbara Crawford, manager strategy and contracting, Ministry of Health

Over the past year, DSS and providers have worked together to move over 530 service contracts onto the new cross-government Streamlined Contracting Framework using the new outcome agreement template, which includes Results-Based Accountability outcomes measures.

This is a great achievement, and DSS acknowledges the significant contribution of the disability sector, including providers, people with disabilities and their families/whānau, to this important change.

Disability Support Services will continue to work with providers, disabled people and the wider disability sector to move contracts to the outcome agreement template as they come up for review.

Child Development Services improvement project

Gordon Sinclair, development manager, Ministry of Health

The Ministry of Health is working on a project to improve services for children and their families/whānau throughout New Zealand by creating a national structure for Child Development Services to measure outcomes for each child.

The Ministry hosted a Results Based Accountability workshop in Wellington in November to update the Child Development Service Specification and begin a move to outcomes-based contracting.

The project lead, Gordon Sinclair, will meet with key stakeholders through November and December to present and discuss the recommendations of the project.

Respite Strategy

Deborah Mills, development manager, Ministry of Health

Disability Support Services is developing a Respite Strategy to improve the way we purchase respite for carers across the country.

Respite is a planned, temporary break for families/whānau or carers from caring for a person with disability. A break can be for a few hours, a day or longer, and may take place in or out of the family home. Timely access to respite can reduce stress for carers and help sustain the family unit.

Respite can also give disabled people a break from their normal routine. It can offer them new experiences, help develop their independence, facilitate visits to different places and encourage a broader range of friendships.

Disability Support Services’ strategic direction focuses on greater choice and control, and on improving outcomes for disabled people. Trends in New Zealand and overseas indicate the need to move to more flexible options in care, which allow carers to take a break.
The Respite Strategy aims to provide families, whānau and disabled people with:

- greater control and flexibility over their respite options and the way they are funded or purchased
- access to respite at a time and in a way that suits their needs.

The Strategy addresses:

- respite funded through current carer support, in-home support, host family respite, individualised funding respite, and facility-based respite
- respite for disabled children, young people and adults and their families and carers
- increasing the capability of needs assessors and coordinators to support families/whānau to access respite in a form that suits them
- development of a range of respite options in line with what families/whānau want.

We will offer people a range of opportunities to participate in the Respite Strategy development. We are very keen to hear from disabled people, their families/whānau and providers about their needs and preferences.

Please take part in our survey on respite services, currently available on the Ministry’s website: www.health.govt.nz/respitestrategy

To find out more, please contact us by emailing respitestrategy@moh.govt.nz

Other service strategies

Barbara Crawford, manager strategy and contracts, Ministry of Health

Disability Support Services will develop three other service strategies over the next 12 months: supported living, community residential services (including consideration of how to better meet the needs of disabled people whose behaviour challenges these services) and community rehabilitation.

As we in DSS move to transform the disability system through such strategies, we need to consider the component parts of the system and ensure that we work together with the sector to continue to improve outcomes for people using services, while making the best use of the funding available. We will base all our strategy development on the principles of EGL.

Our general approach to developing these strategies is as follows:

- consumer consortium feedback obtained at the October 2016 meeting
- analysing feedback from the workshops at the five provider forums hosted in November 2016
- hosting workshops for each service strategy involving representatives of providers, service users, disabled people’s organisations and carers
- developing a draft strategy
- seeking online feedback from stakeholders in regard to each strategy
- finalising the strategies
- working with the sector to implement the strategies.

When we have developed all of the strategies, we will develop an overarching procurement strategy to integrate them.
Behaviour support services

The contract for specialist behaviour support services (BSS) provided by Explore has been in operation for one year.

Our DSS research tells us that 96 percent of people are satisfied, very satisfied or extremely satisfied with the service.

The BSS sets goals for service users in partnership with people themselves. It measures achievement against these goals regularly throughout the period of service, and again at discharge. An average of 78 percent of users are achieving their goals. This, combined with the levels of satisfaction we found, indicates that the contract is performing well.

Waiting times are consistently reducing as we continue to invest in behaviour support. Unfortunately, however, it is proving difficult to keep up with increasing demand to guarantee more timely access.

In looking at the effectiveness of BSS, we have identified three focus questions concerning providers’ ability to assist people achieve their goals.

1. How do we support families if they are not able to implement or sustain a behaviour support plan?
2. How do we work with residential providers when an agreed behaviour support plan is not implemented or is not able to be sustained?
3. How can we measure the impact of BSS on a person’s support allocation?

These areas will be the focus for the next phase of development for behaviour support.

The BSS has two pathways for referral: early intervention (EI) and general services. We are looking at ways to improve identification of the need for EI, and make it available quickly for more people. Early intervention detects behaviours before they become entrenched, and reduces the need for intensive support later on.

We need to be able to demonstrate the longer-term effectiveness of the BSS; we are currently exploring this.

DSS Publications

New Zealand Autism Spectrum Disorder Guideline


This Guideline outlines how we can best support people with autism spectrum disorder (ASD) and their families. It also provides a framework for improving services to people with ASD, based on robust and reliable information. It acknowledges the whole of a person’s life – covering topics from early intervention and diagnosis to community living for adults.
The Guideline is the world’s first living ASD Guideline: the Ministry of Health regularly updates it when new, significant research emerges. Every year since 2009, the Ministry has identified a topic for update and critically reviewed the new evidence. A small advisory panel then considers this review, and develops new recommendations if necessary. The 2016 edition of the Guideline incorporates the panel’s updated recommendations and rationale for each of the seven topics updated since 2009.

This regular review means that the Guideline is particularly responsive to the needs of the people it has been written for, and truly meaningful to those who use it.

Contributors to the Guideline include individuals with ASD; parents of children with ASD; medical, educational and community providers; government agencies; and New Zealand and overseas researchers. It represents a ground-breaking collaborative effort.

The 2016 edition of the Guideline represents the Ministries of Health and Education’s commitment to providing meaningful, contemporary resources to support people with ASD and their families.

Our people

Kimberley Sanerivi, team administrator, Family and Community Support Team

I have been working as the team administrator for the Family and Community Support Team since May 2016.

I am based in the Auckland office, and support my team as well as other DSS Auckland-based staff.

This is my first role within government and within the disability sector. I came to the Ministry with a background in health, having completed the first three years of my medical degree and a postgraduate diploma in public health, majoring in Pacific health. I have taken on this role while I take an extended break from my university studies.

My role is heavily administrative and organisational. I am grateful for the opportunities it gives me to discover the macro-level workings of the disability sector while supporting my team. My mother works within the disability sector, so perhaps I am finally following in her footsteps!

I was involved on the front line during my medical studies. Working at the government level has given me a greater understanding and appreciation of the wider health and disability sector. I find it a privilege to be surrounded by so many experts within DSS, and I look forward to meeting more of my colleagues over the coming months.
**Madeleine Sands, contract relationship manager**

In September an opportunity arose for me to use my many years of experience in the disability sector and make a change from my role as team leader of the Child Development Team for Auckland District Health Board.

I have long worked within health and disability, initially as a physiotherapist working with people with neurological needs (stroke rehabilitation) and then with paediatrics.

My current role as contract relationship manager within Environmental Support Services in DSS is challenging and rewarding. The challenges are in terms of making services work for clients and their families, and the rewards in terms of seeing those clients maximise their potential.

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**Deborah Mills, development manager**

I joined DSS in August 2016, and am leading the work on the Respite Strategy.

It’s been a fabulous two months. It’s been great to meet providers, disabled people and their families as I learn about the sector and about our opportunities to improve respite. For most of my career, I have been in audit and quality improvement roles; I enjoy work that results in a positive change for individuals and communities. It was the opportunity to improve quality of life for people with disabilities and their families that drew me to this role.

I spent the previous three years in the National Cervical Screening Programme (also within the Ministry of Health) and, before that, the Ministry of Business, Innovation and Employment and the Office of the Auditor-General. I started my career in the health sector, and have worked as a scientist in medical laboratories in New Zealand and in the United Kingdom.

I am based in Wellington. Outside of work, I am a mum to two daughters, and I run, climb Wellington’s hills and practise yoga to keep fit. I did Oxfam Trailwalker this year in April. Walking 100 km in torrential rain and mud to raise funds for Oxfam was perhaps not the best idea I had ever had, but it was a fantastic experience – one that required badly singing 80s hits to keep team spirits up during the night, and unexpected treacherous mud slides at 3 am!
Toni Gray, contract relationship manager

I am delighted to return to DSS after a six-month stint away.

Last year I worked in DSS’s Strategy and Contracts Team in a fixed-term role supporting the strategic business plan development and reporting functions.

I enjoyed working within DSS so much I was determined to return at the next available opportunity. Fortunately that opportunity presented itself in the form of another fixed-term role, as contract relationship manager for 12 months. I am currently covering the vision services portfolio.

My background is primarily as coach and operations manager of Wellington Riding for the Disabled Association (RDA), where I gained an appreciation for children and their families living with disability. I found it truly inspiring how remarkably determined, dedicated and positive these families are, and the joy they experience from little achievements and small daily things. I felt blessed to be around people who seemed so grateful and never took anything for granted.

I ended up at RDA through my passion for horse riding, which I do competitively. I’m also a qualified coach, having instructed beginner riders and teams for national Pony Club championships. My spare time is spent riding, coaching and helping out on our family sheep farm on the beautiful Pauatahanui Inlet.

Since I started in late August I have been learning a lot about vision impairment in New Zealand, and I look forward to working with our providers of these services.

Sonya Hintz, contract relationship manager, Community Living Team

My role covers services from Auckland right up to the top of the North Island, across a range of service types (residential, supported living, rehabilitation and young people with disabilities (YPD).

I have worked in the disability sector for over 15 years, 10 of which as a Service Provider Manager (in the UK). Over the last couple of years I was fortunate in that I could take a career break to have and look after my tamariki. During this time I joined the voluntary sector to provide early childhood education (‘parents as first educators’) to my children and those in our Playcentre whanau. I have taken part in the Education Review Office inspections and many fundraising activities.

My tamariki are growing up fast, they are now 1 and 4. After a while I started to hear that all familiar inner voice – heard and felt by many women and men – a personal need beyond parenting. As a result of that inner voice I am enjoying the challenges of working in a Government department to improve outcomes for people with disability.

I look forward to working with you in the future.
ASD Portfolio

Gordon Sinclair, development manager, Family and Community Team, is now responsible for ASD development work.

Disability Support Services has begun initial work with the Ministry of Education to identify key priorities for our joint work programme.

Contact Disability Support Services

Email: disability@moh.govt.nz    Phone: 0800 DSD MOH (0800 373 664)
Web: www.health.govt.nz/disability

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