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Newsletter April 2025

Hope this email finds you all well. The school holidays are starting, and Easter is nearly here. Hope you all have the opportunity for a small (or big!) break over the long weekend though I know how hard this can be to organise and fund, particularly since all the changes the use of disability funding. Here's my updates for the first quarter of 2025:

Disability Support Services Consultation

Most of you will be aware that the Ministry of Social Development Disability Support Services conducted a consultation into disability supports in New Zealand as part of their drive to 'stabilise' the system.

This consultation was in follow-up to the 2024 Review of Disability Support Services – there's more information about that Review here

<https://www.whaikaha.govt.nz/news/independent-review>

In implementing the recommendations from this Review, the commissioning (buying) of disability services was transferred over to the Ministry of Social Development Disability Support Services.

MSD DSS then began a consultation phase with the disability sector from 10th February to 24th March 2025 to gain feedback on possible changes to stabilise the disability system. Here's a link to more information

<https://www.disabilitysupport.govt.nz/consultation> There were in person consultation meetings held in cities and towns throughout New Zealand, as well as online meetings – disabled people, their families and organisations were also invited to participate in a survey and/or send a submission. Complex Care Group ran two online meetings for our members, the feedback from which formed our submission to MSD DSS.

Complex Care Group is following progress of this consultation closely and will keep you informed.

Rokket App

Rokket is a new tool for people living with disabilities, their family members and carers. With *Rokket*, you can give clarity, structure and rhythm to any day. Made by a couple with disabled family members, it lets people with their family and carers – plan what to do, when and where. You can set up regular routines, reminders with alarms, and so on. Get the app at <https://rokket.app> or search for 'Rokket' in any app store (GooglePlay, App Store, Microsoft Store, Mac App Store).

Membership of Complex Care Group provides you with a FREE 6-month advanced level of *Rokket* with the below activation code: **CCG-TEA7**

Survivor Experience Service (survivors of Abuse in Care)

Survivor Experience Service is aware that people in state and faith-based care are still experiencing abuse. We are there for people who were abused in state, faith-based or other forms of care. We also support people who are whanau of survivors, or employees who have been affected by and / or witnessed systemic abuse in care as part of their mahi either historically or presently.

If people have been abused in care, they can share their experiences to continue their healing journey and be acknowledged and validated. We can hear experiences from the past right up to present day. They can also get support to

request, receive and understand their care records. We act as a portal between survivors, NGOs, community and advocacy groups, Iwi, and government agencies to provide wide-ranging insights for the incoming redress system.

International studies show that as a population, Deaf and disabled people experience abuse at far higher rates and for more prolonged periods than non-disabled people. It is estimated between 11 and 34% (22,000 and 72,000) of people in NZ state-run Health and Disability care settings may have been abused.

This implies there is a significant number of Deaf and disabled survivors who remain hidden for a variety of reasons. Reaching Deaf and disabled survivors to ensure they are aware of the support provided by our service is a priority, and why we have established targeted Engagement Leads to reach these communities.

Alexandra Carr is the Deaf and Disability Engagement Lead for Survivor Experiences. Alexandra is actively engaging with providers and the Deaf and disabled community to raise awareness of, and gain trust and confidence in, our service. People can phone us on 0800 456 090 (NZ). Our phone lines are open 8:30am – 4:30pm Monday – Friday. Email us contact@survivorexperiences.govt.nz Text us on 8328

You can also use the New Zealand Relay Service - www.nzrelay.co.nz or reach Alexandra directly on messenger using video phone to call in Sign Language, or text her on 022 1099 485. We look forward to hearing from you!

Cerebral Palsy Resource 0-5yrs

The Cerebral Palsy Society have created a resource booklet called ‘Cerebral Palsy – Hōkai Nukurangi: The Early Years Kete’. This booklet provides information about health resources for parents of newly diagnosed children with cerebral palsy under the age of 5yrs. The booklet is available online or as a pdf and in Te Reo [The Early Years \(0-5\) - Cerebral Palsy Society](#)

Rare Disorders New Zealand

This great organisation advocates for the rare disorders community and run petitions to government. They also send out an informative newsletter. More information about Rare Disorders NZ is available here

<https://raredisorders.org.nz/>

Child to Parent Violence and Abuse

An initiative of VisAble

Child to Parent Violence and Abuse (CPVA) is more common than we think. It can occur in any family and there are many reasons why it may happen.

Parents/caregivers have reported feeling ashamed that this is happening to them.

There have been no prevalence studies in Aotearoa New Zealand which means that it remains invisible in policy and service provision.

We (VisAble) think that this needs to change and we have recently completed a survey to better understand CPVA in New Zealand. The report resulting from this survey is due for publication in the next month or so and will help us advocate for more inclusive and effective policies and services.

An information booklet for families and caregivers is also available here

<https://www.complexcaregroup.org.nz/wp-content/uploads/2024/11/VisAble-Parents-Caregivers-Booklet.pdf> If you would like to know more about Child to Parent Violence and Abuse, and possible supports, please email lee.tempest@visible.co.nz

Guide to Autism in Childhood

Altogether Autism and Your Way Kia Roha have created a free online Guide to Autism in Childhood resource. Designed as a practical tool to educate and empower, we hope the passion put into this project—and the insights and strategies shared in these pages—will inspire others. Please share the link below widely to create a circle of understanding around our Autistic tamariki. Every child

deserves to be understood, and celebrated. Booklet is available here <https://parent2parent.org.nz/resource-hub/about-autism-a-guide-to-autism-in-childhood/>

Continence NZ

Continence NZ have a new website <https://www.continence.org.nz/> This organisation provides education, information, advocacy and support for people living with incontinence, caregivers, health professionals and the general public. They have useful guides and product information on their website.

Findings from the Disabled People's Organisations Coalition Monitoring of Disability Rights

DPO Coalition by email: us-dpo@groups.io

Media Release 31st March 2025: A different way of sharing power Findings from Disabled People's Organisations Coalition Monitoring of Disability Rights

The Disabled People's Organisations (DPO) Coalition has released findings from the Disabled Person-Led Monitoring research project. This project monitors how well the New Zealand government implements the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The current report focuses on the establishment and intent of Whaikaha – Ministry of Disabled People and is the first of five reports monitoring disabled people's experiences of supports and services. Conducted by the Donald Beasley Institute on behalf of the DPO Coalition, the research, which is based on interviews with disability sector leaders and disabled people, whānau, aiga, and close supporters, highlights both progress and concerns about the Ministry's structure, operations, and alignment with the needs of the disability community. The data was collected between late 2022 and early 2024, before the reduction of function and operations of Whaikaha - Ministry of Disabled People, and the findings provide critical insights for shaping a Ministry that genuinely represents the rights, needs, and aspirations of disabled people in Aotearoa New Zealand.

“[The government officials] don’t have all the answers clearly, that’s why things have to change so [there is] a different way of sharing power.” (Disability Sector Leader 13-01).

Key findings include:

Respect for Foundational Principles: While the establishment of Whaikaha was grounded in Te Tiriti o Waitangi, the UNCRPD, and Enabling Good Lives (EGL) principles, participants expressed concern that these were not always respected in practice. There was a call for stronger partnerships between tākata whaikaha Māori, disabled people, and the Crown.

Operations and Functions: Participants emphasised the importance of well-resourced Disability Supports and Services (DSS) to achieve equity for disabled people, including addressing the disparities between disability funding from DSS and ACC.

Frustrations and Cautious Optimism: Participants felt frustrated with the lack of accessible information about Whaikaha’s functions. They were also concerned about the impact that changes in government have on the Ministry’s direction and about the exclusion of certain disability groups, such as people with psychosocial disabilities, chronic health conditions and older disabled people, that prevented them from benefitting from the new Ministry.

Participants recommended Whaikaha:

- Upholds Te Tiriti o Waitangi, the UNCRPD, EGL principles, and the social and human rights models of disability, and promotes a government-wide commitment to the human rights of disabled people.
- Strengthens partnerships with disability communities, prioritising leadership from tākata whaikaha and whānau hauā.
- Serves as a "one-stop-shop" for accessible information and support for disabled people and their whānau.

The report is available in official languages and accessible formats (Te Reo Māori, NZSL, Easy Read, Braille, Large Print, and audio) from the Donald Beasley Institute’s website at <https://www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/>

Contacts: Alexia Black (Chair Balance, DPO Coalition Member): 022 395 9761

Umi Asaka (Researcher - the Donald Beasley Institute):

uasaka@donaldbeasley.org.nz

Carers Alliance – We Care Petition

The Carers Alliance are running a petition called We Care:

More than a million New Zealanders care for family members and whānau who are ill, frail, injured, or have a health condition or disability. *But family carers can feel invisible, taken for granted. They aren't getting the support they need to keep going.* That's why the Carers Alliance of 50+ national not for profits is calling for a home in government for family carers, and for action to protect their mental, physical, and financial wellbeing.

Help us by adding your voice to ours! Take one action, or do them all. The action we take together for family carers will make a real difference.

Sign the petition here [Petition of NZ Carers Alliance: Recognise and protect New Zealand's family, whānau and āiga carers](#)

Complex Care Group Community Zooms

I continue to run these Complex Care Group Community Zoom meetings on a Tuesday (early evening) about once every six weeks. The next one will be between Easter and the end of April – I'll promote it by email and on our social media sites. These meetings are an opportunity to share your concerns and enjoy companionship with parents in similar circumstances.

Family-Whanau Network

I continue to represent Complex Care Group on the Family-Whanau Network. At these network meetings topical disability sector issues are discussed and our concerns have a channel through to Whaikaha Ministry of Disabled People and to

Ministry of Social Development Disability Support Services. The Family-Whanau Network has long advocated for the voice of those with severe high and complex disability needs (often via their family) to be heard at Ministry level. Please let me know if there are particular issues you would like raised.

Wishing all our members a peaceful Easter. Feel free to contact me anytime.

Kind regards,

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