



HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Report on complaints to HDC about Residential Disability Support Services

JULY 2024



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Thank you to Dr Brent Neilson, Dr Esther Woodbury, and Natasha Davidson for their work on this report.

Feedback

We welcome your feedback on this report. Please email any feedback to hdc@hdc.org.nz

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Foreword

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Deputy Health and Disability Commissioner



A recent review of policies, processes, and practices for managing complaints about a large disability support provider (the Review) commissioned by the Ministry of Disabled People|Whaikaha (Whaikaha) gave many people across the disability sector, including myself, reason for concern. The Review gave visibility to the inherent power imbalance that exists between disabled people receiving support in residential settings, and providers, as well as the power imbalance that can exist for family and whānau who speak up for their loved ones. It showed the crucial need for Whaikaha to rebuild the trust of the community they serve.

Following the publication of the Review findings, I decided to undertake a thematic analysis of all complaints to the Health and Disability Commissioner (HDC) and the Nationwide Health and Disability Advocacy Service about residential disability support services over the past five years. My objective was to consolidate the information obtained from the Review (which focused on a single provider) with an analysis of complaints about the broader residential disability sector. This Report on Complaints to HDC about Residential Disability Support Services offers a unique data set grounded in the experience of disabled people and their families and whānau who have raised concerns with HDC about the support provided in residential settings. The report draws together insights from their collective experiences, alongside the findings from HDC's assessment and investigation of these complaints.

I acknowledge that the majority of people working in residential support services are committed to upholding disabled people's rights, within a sector under significant pressure. However, when systems are under pressure it is important that safeguards are in place to uphold disabled people's rights, and that there are responsive pathways for people to raise concerns and make complaints. This thematic analysis has given me an opportunity to make recommendations that will further strengthen the supports provided to disabled people.

This is the first thematic analysis of residential disability support service complaints to HDC. In future reports, I am committed to ensuring that there is a stronger Māori voice reflected in HDC's disability data. Acknowledging that Māori communities are not always supported to be aware of their rights under the Code and do not always have a high degree of trust in complaints processes as they are designed currently, HDC is working on new ways of listening to, and working together with, tāngata whaikaha Māori and whānau hauā to reduce barriers to our complaints process.

Finally, this report is being released ahead of the forthcoming final report of the Royal Commission of Inquiry into Abuse in Care, which will shine a significant light on the historic and contemporary experiences of disabled people in residential settings. The Royal Commission's findings will no doubt have lasting reverberations for the contemporary and future provision of care, support, and services for disabled people – and HDC will be looking to support the recommendations of the Royal Commission's final report, as well as examining the learnings we can apply to our own work.

Executive summary

Aotearoa New Zealand's disability sector is under significant pressure. In recent years, concerns have been raised about staff shortages, service disruptions and closures, geographical inequities in access to support, the sustainability of disability funding, and the level of safeguards for disabled people within the system. For tāngata whaikaha|disabled people and their family and whānau, these pressures can result in inadequate support, experiences of exclusion, and a lack of respect for their inherent dignity and individual autonomy.

HDC's data is focused on people's concerns about the support they are receiving, and therefore this report is focused on issues of concern. We acknowledge the dedication and passion of many people who work in the disability sector, who are striving to provide quality, rights-focused support in an imperfect system.

HDC further acknowledges the multiple barriers disabled people|tāngata whaikaha and their family and whānau face in raising concerns and making complaints about the support they are receiving. We have also heard from tāngata whaikaha Māori groups that Māori may be less interested in formal complaint processes than in opportunities for collective conversations about experiences, and opportunities to contribute to system improvements. It is likely, therefore, that the issues presented in this report are not a true representation of the extent of concern held by disabled people and whānau and families, with many issues not escalated to formal complaints agencies such as HDC.

Notwithstanding this, HDC's data provides valuable insight into consumer experience and the issues people care about most, and it is one part of a broader monitoring landscape, with other agencies also holding valuable information about the quality of support provided. Insights can be gained from provider feedback and complaints mechanisms, funder monitoring, complaints and feedback systems, as well as through the activities of other independent agencies, such as the Ombudsman and Te Kāhui Tika Tangata|New Zealand Human Rights Commission.

We note that residential disability support services are funded by a range of agencies, and while it is likely the majority of complaints detailed in this report are funded by Whaikaha, they may also include services funded by agencies such as ACC and Health NZ, etc.

Context

The disability population will continue to grow as our overall population increases and ages, and so will the need for safe, secure, accessible, and affordable housing options that enable disabled people to live with dignity and with a level of support and independence suitable to their needs and situations. However, disabled people|tāngata whaikaha continue to face inequities across both health and housing, and quality of support and safety issues continue to arise in respect of residential services for disabled people.

We acknowledge the range of circumstances in which disabled people receive support services in a variety of residential and out-of-home settings. The residential disability support services referenced in this report ('residential disability support services') exclude aged residential care (except where they have been funded to provide care to younger disabled people), residential school settings, mental health inpatient units, care and protection orders from Oranga Tamariki, and supports provided to disabled people while in prison. Although this report focuses exclusively on a narrower range of residential disability support services, we are aware of concerns raised about funded disability support provided in other settings and HDC continues to work with a range of agencies in respect of our concerns in these areas.

Gaining a better understanding of the experiences of the disability community in the residential disability support settings identified in this report, particularly when things have gone wrong, can improve our understanding of what is important to disabled people|tāngata whaikaha and their family or whānau, and the ways providers can improve their services to better support disabled people to live well.

We have undertaken an analysis of five years of complaints to HDC about residential disability support services (363 complaints) and have identified several themes that highlight areas of concern. We have also considered how pressures on the sector and issues that are themselves exacerbated by institutional models of support (for example, one-size-fits-all approaches to disability support) affect the experience of disabled people | tāngata whaikaha and their family and whānau. These themes include the following:

- Failure to adhere to support plans.
- Inadequate standards of care, including:
 - household safety issues;
 - poor medication management;
 - poor identification and management of long- and short-term health conditions – including deteriorating health; and
 - poor oversight and supervision of staff.
- Use of restraint and force.
- Concerns about one-size-fits-all approaches to individual disabled people's needs.
- Lack of culturally safe and appropriate support services.
- Poor coordination with other services, including health services.
- Poor communication with disabled people, family and whānau, including:
 - a lack of respectful and culturally appropriate communication;
 - when there are diverging views between the will and preferences of disabled people and their family;
 - ensuring clarity about what level of support has been funded; and
 - changes and termination of support.
- Shortages of skilled staff to support specific needs of individuals.
- Poor responses to feedback and complaints, including fear of retaliatory behaviour from staff and management.
- The role family and whānau, support networks, and staff play in raising concerns on behalf of disabled people | tāngata whaikaha.

The following broader systemic issues contribute to these themes:

- Workforce shortages;
- Slow progress in respect of transforming the system in line with Enabling Good Lives (EGL) and geographical inequities in access to services across Aotearoa New Zealand;

- Lack of safeguards and quality frameworks; and
- Sustainable and appropriate funding of services and individual alternatives.

HDC also acknowledges the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Committee's concerns that New Zealand does not have a comprehensive strategy to deinstitutionalise the disability sector. We support the Committee's recommendations and guidelines toward continued deinstitutionalisation.

Informed by these themes, this report makes several recommendations to improve the quality of residential disability support and to assist in addressing some of the broader systemic issues identified as contributing to these issues. We also make a number of recommendations and comments to support the continued development of community-based alternatives to residential support in line with the UNCRPD.

Recommendations

HDC's role is to promote and protect the rights of people using health and disability services, including by resolving complaints about the infringement of those rights, holding service providers to account, and using complaint findings to improve the quality of services, at an individual provider level and across the health and disability system. Upholding people's rights extends beyond just the standard of care provided – it encompasses respect, dignity, communication, complaints processes, and being supported to make an informed choice and give informed consent.

HDC acknowledges that some complaints about disability support can span the jurisdiction of several different agencies (including Whaikaha, Health NZ, ACC, HealthCERT, Worksafe, the Ombudsman, HDC, the Coroner, Police etc). Continued collaboration and a whole-of-sector approach is needed to clarify the roles of each agency, streamline processes for referral, and simplify the complaints system for disabled people and their family or whānau. HDC remains focused on ensuring public safety issues are escalated in a timely way to those agencies who can take action, as well as sharing our complaints data in a way that highlights the experience of disabled people and supports quality improvement.



Recommendations to Whaikaha

1. HDC supports the recommendations made in the recent Whaikaha-commissioned review of policies, processes and practices for managing complaints about a large disability service provider, written by Rachael Schmidt-McCleave (the Schmidt-McCleave report). In particular:

- The continued work of Whaikaha and service providers in better facilitating and resolving complaints about disability services. HDC will also be considering the improvements we can make to our own processes in this respect;
- That Whaikaha make available to disabled people and their whānau information on what they can expect from disability service providers; and
- Acknowledging current resource constraints, the potential for increasing the role of the Nationwide Health and Disability Advocacy Service in supporting people who live in residential disability services.

While Whaikaha retains overall responsibility for ensuring that the recommendations of the Schmidt-McCleave report are met, HDC is maintaining a watching brief over progress being made.

In addition, HDC makes the following recommendations based on the findings of our analysis of the complaints we have received about residential disability support services (RDSSs) over the past five years.

2. HDC recommends that Whaikaha, in its role as steward of the broader disability sector, and in consultation with disabled people|tāngata whaikaha, whānau, and disability service providers and funders, develop and implement a consistent quality framework across all funded disability service provision. Such a framework would set out expectations of disability support and allow the quality of supports to be measured and monitored consistently across all funding agencies. Clear expectations also empower disabled people and their families to communicate their concerns when these expectations are not met. The following points could be considered in developing a quality framework:

- The proactive monitoring and reporting of the experience of disabled people and their family and whānau in services, including sector-wide opportunities for contractual levers to support this monitoring and reporting;
- That the recommendations made in the Schmidt-McCleave report may have wider utility across the sector, including ACC, Health New Zealand|Te Whatu Ora, and Oranga Tamariki-funded services; and
- Progression of Whaikaha's work on a consistent framework and guidance for complaints management.

This report is focused on the quality of support provided in residential support services, including issues that are exacerbated by institutional models of support (for example, one-size-fits-all approaches to disability support). HDC supports continued work to

provide community-based alternatives to residential support across the disability sector, in line with the UNCRPD. With this in mind, and taking into consideration the broader systems issues outlined above, we also make the following recommendations:

3. HDC notes Whaikaha's publication of the Disability Support Workforce Community Engagement report and supports a workforce planning programme remaining a priority.

4. HDC notes and supports work underway as part of the My Home My Choice programme and the Choice in Community Living programme available in some parts of the country. HDC encourages Whaikaha to consider making Choice in Community Living available nationwide.

5. HDC encourages Whaikaha in its stewardship role to support development of Māori-led disability services, both residential and community based.

6. HDC encourages Whaikaha to communicate with the disability community about progress to roll out EGL systems transformation nationally.

Comments about the Independent review of disability support services administered by Whaikaha

In May 2024, the Government announced an 'Independent review of disability support services administered by Whaikaha'. We acknowledge that this review does not focus solely on residential support. However, the review offers an important opportunity to improve outcomes for disabled people, including those in residential support services, and to further work to deinstitutionalise disability support. We have therefore made some comments on this review below.

In noting the May 2024 government announcement of an 'Independent review of disability support services administered by Whaikaha', HDC is disappointed that there are no tāngata whaikaha Māori or disability community leaders among the three-person panel. However, we encourage the review panel to:

- Ensure that tāngata whaikaha Māori and disability community leaders, family and whānau are closely involved in the review, in particular around the development of recommendations;

- Use the articles and principles of Te Tiriti o Waitangi, the UNCRPD, and EGL to create a framework for recommendations that will ensure a sustainable, high quality, and inclusive disability support system;
- Ensure that the review has a strong focus on guaranteeing the quality of disability supports, including any lessons learned from previous reviews and inquiries;
- Include a strong focus on disability workforce planning and the long-term sustainability of the workforce, including career pathways and supported on-the-job upskilling and training opportunities for RDSS staff; and
- Consider the Aged Care Funding and Services Models Review as a possible road map and further justification for the development of a similar review of disability sector funding. Such a review should address current inequities in funding of disability support based on diagnosis and origin of impairment.

Introduction

This report presents insights and themes identified through an analysis of complaints to the Health and Disability Commissioner (HDC) about residential services for disabled people | tāngata whaikaha over the five-year period ending 31 December 2023.

It has been more than 40 years since calls for deinstitutionalisation gathered momentum in Aotearoa New Zealand, and nearly 20 years since the closure of our last large-scale residential institution for disabled people | tāngata whaikaha. However, in 2022, in its periodic reporting on Aotearoa New Zealand, the United Nations Committee on the Rights of Persons with Disabilities expressed concern that significant numbers of disabled people | tāngata whaikaha in New Zealand still lived in smaller institutional settings, where they experienced violence, abuse, and neglect. The Committee also found that there was no comprehensive strategy to deinstitutionalise the disability sector further.[1]

The disability sector is under significant pressure. In recent years, concerns have been raised about staff shortages, service disruptions and closures, geographical inequities in access to support, the sustainability of disability funding, and the level of safeguards for disabled people within the system. A report commissioned by Whaikaha | Ministry of Disabled People (released in October 2023) outlined several findings and recommendations in response to concerns raised about the management of complaints by a disability service provider. HDC's analysis of complaints about all residential disability services largely supports the findings of the Whaikaha-commissioned report.

The prevalence of disability increases significantly with age, meaning that with an ageing population, increasing numbers of people are likely to experience chronic, disabling health conditions. As our population increases, so too does the disabled community, and those in need of safe, secure, accessible, and affordable

housing options that enable disabled people | tāngata whaikaha to live with dignity and with a level of support and independence suitable to their needs and situations.

The Enabling Good Lives (EGL) approach to disability support was developed in 2011 by the disability community, with a vision and principles, to underpin a new approach to disability support. EGL was piloted in two demonstration sites, before being prototyped in the MidCentral region (under the name Mana Whaikaha). The use of EGL increased the engagement of tāngata whaikaha Māori and Pacific peoples with the disability system by 60% in Mana Whaikaha, and 33% overall.[2]

In 2021 Cabinet decided to implement EGL nationally. However, national implementation of disability systems transformation is yet to be realised, and there is some uncertainty among the disability community about the status of EGL. This uncertainty stems partly from changes to the flexibility of disability support funding on 18 March 2024 and the subsequent announcement in May 2024 of an independent review into long-term sustainability of the disability support services administered by Whaikaha | Ministry of Disabled People.

HDC has a key role in upholding the rights of disabled people | tāngata whaikaha. Residential support settings come with inherent risks that must be managed — and it is crucial that monitoring agencies support disabled people | tāngata whaikaha and whānau, share information, and are alert to emerging trends to provide the necessary checks and balances and ensure the health, safety, and wellbeing of people who live in these settings.

HDC's role is to promote and protect the rights of people using health and disability services as set out in the Code of Health and Disability Services Consumers' Rights. HDC can highlight consumer rights issues, hold providers to account for the

1. United Nations Committee on the Rights of Persons with Disabilities (2022), 'Concluding observations on the combined second and third periodic reports of New Zealand'. See: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolNo=CRPD%2FC%2FNZL%2FCO%2F2-3&Lang=en. Accessed 20/06/2024.

2. Ministry of Social Development, Enabling Good Lives. See: <https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/disability-system-transformation/enabling-good-lives.html>. Accessed 20/06/2024.

responsibilities they carry, make recommendations for improvement, and monitor actions taken. However, we do not have direct oversight of, or powers in relation to, funding decisions, workforce planning, and service design and planning – primarily these are matters for Whaikaha. As such, HDC is focused on working with other agencies to amplify the voice of disabled people, address areas of systemic concern, and ensure that public safety issues are identified and addressed in a timely way.

Disabled people|tāngata whaikaha and their family and whānau experience systemic barriers that may prevent them from engaging with HDC, particularly in respect of their reliance on the support provided to them and fear of retaliation from the service provider – a concern that is discussed later in this report. Some disabled people may struggle, even with significant support, to raise concerns themselves and may also be without family and whānau or support networks to advocate on their behalf. Tāngata whaikaha Māori and Pacific peoples are also under-represented in complaints to HDC. Therefore, it is important to acknowledge that the complaints HDC receives about disability services likely represents the ‘tip of the iceberg’ and may not provide an overview of the experience of all communities.

Complaints data is grounded in the consumer and whānau/family voice. While the voices represented in this report constitute only a small proportion of the disabled community, we know that disabled people|tāngata whaikaha experience poorer mental and physical health and wellbeing outcomes as compared with non-disabled people, and that many areas of the disability community face compounding inequities, particularly tāngata whaikaha Māori. For instance, research done by IHC identified that Māori and Pacific peoples have higher rates of learning disability than the general population. The inequities experienced by Māori and Pacific peoples with learning disability result in lower life expectancies, being less likely to have qualifications and access to secure housing, being more likely to suffer from chronic health conditions, and having poorer access to health and disability services.[3] While 16% of all HDC complaints are made about services provided to Māori, only 10% of residential disability services

complaints are about support provided to Māori. Given what we know about the prevalence of disability and unmet need among Māori, it is likely that the complaints HDC receives from this community are under-representative of their actual concerns and issues.

We acknowledge that there are a range of circumstances in which disabled people receive support services in other residential and out-of-home settings that are not captured by this report, including in aged residential care, residential school settings, under care and protection orders from Oranga Tamariki, and while in prison. Although this report focuses exclusively on residential disability services, we are aware of concerns raised about funded disability support provided in other settings. For example, we have been told that a small but concerning number of young disabled people continue to be housed in aged residential care settings because of a lack of accessible and appropriate options for them in the community, or in disability services with people of similar ages. HDC continues to work with other agencies in respect of our concerns in these areas.

Gaining a better understanding of the experiences of the disabled community in residential support settings, particularly when things have gone wrong, can improve our understanding of what is important to disabled people|tāngata whaikaha and their whānau/family, and the ways providers can improve their services to better support disabled people to live well.

3. IHC: Despite stark warnings, intellectually disabled Kiwis neglected by Government for another 20 years. See: <https://www.ihc.org.nz/news/despite-stark-warnings-intellectually-disabled-kiwis-neglected-by-government-for-another-20-years>. Accessed 20/06/2024.

Complaints to the Health and Disability Commissioner

HDC is an independent Crown entity established under the Health and Disability Commissioner Act 1994 to promote and protect the rights of people using health and disability services. These rights are set out in the Code of Health and Disability Services Consumers' Rights (the Code). The Code places corresponding obligations on all providers of health and disability services, including organisational providers, such as RDSSs, and individual providers, such as the support staff who work at RDSSs.

HDC promotes and protects the rights of people using health and disability services by:

- Resolving complaints about the quality of support provided to people;
- Promoting the Code through publicity and education;
- Improving quality and safety within the sector; and
- Where appropriate, holding providers to account.

As such, HDC fulfils the critical role of independent watchdog for consumer rights within the sector.

Rights under the Code

- The right to be treated with respect
- The right to freedom from discrimination, coercion, harassment, and exploitation
- The right to dignity and independence
- The right to services of an appropriate standard
- The right to effective communication
- The right to be fully informed
- The right to make an informed choice and give informed consent
- The right to support
- Rights in respect of teaching or research
- The right to complain

Anyone may make a complaint to HDC about a health or disability service that has been provided to a disabled person|tangata whaikaha. It is not uncommon for HDC to receive complaints from third parties, such as whānau/family members, friends, staff, or other providers involved in support, particularly for people with communication barriers and those living in residential services. The Commissioner may also commence an investigation on her own initiative, without having received a complaint, if she considers it appropriate to do so.



HDC also funds an independent Nationwide Health and Disability Advocacy Service (the Advocacy Service). The Advocacy Service assists to mitigate the power imbalance between people and their health and disability service providers by assisting people to resolve concerns directly with their provider. Advocates can also assist people to raise complaints with HDC. Raising awareness of the Code is a central aspect of an advocate's role, and advocates have a particular focus on ensuring that people in residential settings are aware of their rights.

Complaints and resolution pathways

The Code gives people the right to complain and requires every provider to facilitate the fair, simple, speedy, and efficient resolution of complaints (Right 10).

HDC is focused on supporting early resolution of complaints where appropriate and has a wide discretion as to the action it can take on a complaint. On receiving a complaint, HDC undertakes a preliminary assessment and determines the pathway for resolution considering the relative significance of the issues raised, the resolution needs of the complainant, and the evidence available.

Following preliminary assessment, HDC can:

- Refer the complaint to the provider, often with the assistance of the Advocacy Service, for direct resolution between the parties;
- Refer the complaint to other agencies where the issues raised are more appropriately dealt with by that agency or when a public safety concern requires a timely response by that agency;
- Call a hui/mediation involving the parties in the complaint. While this complaint pathway is used infrequently, in recent years HDC has introduced a hui ā-whānau option, which brings a te ao Māori approach to complaints resolution;
- Take no further action on a complaint where the preliminary assessment indicates that a formal investigation is not warranted. This may be accompanied by educational comment or recommendations; or
- Conduct a formal investigation, which can result in the provider being found in breach of the Code, as well as recommendations; and

- Refer a provider to the Director of Proceedings (DP) where the Commissioner has determined that the Code has been breached, to consider whether legal action should be taken. This option is reserved for the most serious breaches of the Code.

Value of complaints for quality improvement

Every individual complaint to HDC represents an opportunity for learning. Both local and sector-wide changes can result from the assessment and/or investigation of what went wrong in a particular case, and an analysis of how such events can be prevented in future. HDC aims to take an educational approach to complaints and makes hundreds of recommendations on individual complaints each year. These recommendations have a high compliance rate – with providers complying with 96% of recommendations made by HDC.

Complaints are grounded in consumer voice and experience. While not all issues raised in the complaints analysed and presented here will have been factually and/or clinically substantiated subsequently, complaints provide unique insights into aspects of support such as compassion and dignity, feelings of mistrust, and psychological harm, which are not captured by other systems of healthcare monitoring. HDC's unique dataset therefore provides an additional perspective on the experiences of disabled people |tāngata whaikaha in residential services, and the issues they and their family and whānau care about most.

Considered together, complaints can become an even more powerful tool for widespread quality improvement. Understanding trends and patterns in the complaints received allows for the identification of common issues, systemic failings within an organisation, and possible solutions. In terms of RDSSs, an analysis of the issues commonly complained about can point to quality indicators that may require possible improvement or further investigation, as well as identifying important aspects of consumer experience and the issues that are important to disabled people |tāngata whaikaha and their family and whānau in terms of service quality.



The rights-based model of disability

The importance of disabled people/tāngata whaikaha having access to appropriate support to live in the community has been recognised for more than 50 years. The deinstitutionalisation of disabled people/tāngata whaikaha (particularly people with learning disability) began with a gradual shift from large hospital-like institutions in the 1970s and 1980s, to smaller residential services and group homes.

In parallel, over the last 20 years there has been momentum toward the recognition of human rights for disabled people/tāngata whaikaha. One of the key drivers was the development of the United Nations Convention on the Rights of People with Disabilities (UNCRPD), which Aotearoa New Zealand helped to develop and signed up to in 2008. More recently, the United Nations 2022 guidelines on deinstitutionalisation aim to guide countries in their efforts to support disabled people/tāngata whaikaha to live independently in the community, dismantle existing institutionalisation, and prevent further institutionalisation.[4]

The UNCRPD did not create new rights but clarified countries' obligations in ensuring that disabled people/tāngata whaikaha enjoy equal rights. In doing so, the UNCRPD is guided by the following principles:

- Respect for the inherent dignity and individual autonomy of persons with disabilities, including the freedom to make one's own choices;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women; and
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.[5]

The rights-based model of disability identifies disability as a natural part of human diversity that should be valued. It focuses on the inherent dignity of disabled people/tāngata whaikaha, placing the individual at the centre of decisions that affect them, and locates the main barriers to wellbeing and inclusion as being the result of societal factors, as opposed to medical or physical factors.[6]

4. United Nations Office of the High Commissioner, 2022, CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies. See: <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>. Accessed 20/06/2024.

5. Tika Tāngata — Rights of Disabled People. See: <https://tikatāngata.org.nz/human-rights-in-aotearoa/rights-of-disabled-people>. Accessed 20/06/2024.

6. Quinn, G and Degener, T, 'The Moral Authority for Change: Human Rights Values and the World Wide Process of Disability Reform', in Human Rights and Disability: The Current Use and Future Potential of Human Rights Instruments in the Context of Disability. Quinn, G and Degener, T (eds) (United Nations, 2002), pp 13–14.

Disability support services in Aotearoa New Zealand

‘Disability’ is an evolving and contested concept. The United Nations describes disability as resulting from the interaction between people with impairments (disabled people) and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

‘Impairment’ is a broad term intended to encompass long-term physical, neurological, psychological, or sensory difference in a person — including people with disabling chronic health conditions. HDC acknowledges that people have a wide variety of preferences when talking about disability. In this report, HDC uses the term ‘disabled people|tāngata whaikaha’.

New Zealand is committed to upholding the principles of the UNCRPD. The Articles contained in the UNCRPD encapsulate evolving approaches to support that have seen policies developed to encourage greater deinstitutionalisation, independence, and improved access to services for disabled people|tāngata whaikaha. In New Zealand, these approaches are put into practice through the principles guiding the Enabling Good Lives (EGL) approach.

Beginning in 2011, EGL has seen an approach to disability support in which disabled people|tāngata whaikaha and their whānau and families have increased control over their lives, are encouraged to imagine what a good life looks like for them, and where supports and services make that good life easier to achieve.[7] The EGL vision is that in the future, disabled children and adults and their families will have greater choice and control over their supports and lives and make more use of natural and universally available supports. The EGL principles are:

- Self-determination — disabled people are in control of their lives.
- Beginning early — invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

- Person-centred — disabled people have supports that are tailored to their individual needs and goals and take a whole-life approach rather than being split across programmes.
- Ordinary life outcomes — disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation — like others at similar stages of life.
- Mainstream first — disabled people are supported to access mainstream services before specialist disability services.
- Mana enhancing — the abilities and contributions of disabled people and their families are recognised and respected.
- Easy to use — disabled people have supports that are simple to use and flexible.
- Relationship building — supports build and strengthen relationships between disabled people, their whānau, and community.

Over the past 30 years, through moves to deinstitutionalise residential support, ratification of the UNCRPD, and more recently through the development of EGL and the creation of Whaikaha, New Zealand has committed to creating positive change for disabled people|tāngata whaikaha and their family and whānau. However, despite this shift away from institutionalised care, many disabled people|tāngata whaikaha still live in residential support settings, with more still on waiting lists. The UN Human Rights Council notes:

‘In many countries, the drive towards deinstitutionalization has led to a rise in the number of group homes ... [T]his development undermines community inclusion efforts and raises concerns about its compatibility with the Convention of the Rights of Persons with Disabilities. In group home settings power imbalances between staff and residents persist, choices and control are limited and residents are at a higher risk of experiencing violence, abuse and neglect.’[8]

7. Objectives — Enabling Good Lives. See: <https://www.enablinggoodlives.co.nz/about-egl/egl-approach/objectives/>. Accessed 25/06/2024.

8. United Nations Office of the High Commissioner, 2023, A/HRC/55/34: Good practices of support systems enabling community inclusion of persons with disabilities. See: <https://www.ohchr.org/en/documents/thematic-reports/ahrc5534-good-practices-support-systems-enabling-community-inclusion>. Accessed 20/06/2024.

HDC acknowledges Whaikaha's development of the 'Choice in Community Living' and 'My Home, My Choice' programmes to focus on evolving the residential system so that disabled people who require this level of support have more choice and control over their lives in line with the Enabling Good Lives principles. However, while work in this area is progressing, currently it has not been realised fully, and there is geographical variation across the country in respect of access to the 'Choice in Community Living' programme.

Not all disabled people receive, or are eligible for, funded disability support. In general, Needs Assessment Service Co-ordination (NASC) services determine both people's eligibility for disability support and the amount of disability support they may be eligible for. As of February 2023, approximately 46,000 people received some form of disability support from Whaikaha. Of those 46,000 people, approximately 7,700 were in residential services,[9] with most residents having a learning disability, and some having no family involved in their lives.

Whaikaha-funded disability support services may be available to people who have a long-term physical, learning, or sensory disability, and people with a diagnosis of autism. A range of other agencies also fund disability support services. For example, ACC may fund services for people who have become disabled through an accident or injury, Oranga Tamariki provides disability support to children|tamariki and adolescents|rangatahi in their care, and aged residential care services may provide support to disabled people over the age of 65 years. However, Whaikaha retains an overall stewardship role over the disability sector. The range in funders means that there can be inequities based on the source of the person's disability support funding.

Whaikaha contracts community residential support services to provide services to enable disabled people|tāngata whaikaha to 'live in a home-like setting within their community while receiving support for up to 24 hours a day'.[10]

Services are provided in a range of settings such as small or large residences, groups homes, and flatting situations. To be eligible for community residential support services, a NASC must have assessed the individual and determined that their needs are best met by this level of service provision. For the purpose of this report, RDSSs refers to services incorporating community residential support services in both large group and smaller shared living arrangements.

The Ngā Paerewa Health and Disability Services Standard (the Standard) outlines the minimum requirements for a range of services, including residential disability services. The Standard includes requirements around upholding consumer rights, support and care, providing a safe environment, infection prevention, and the use of restraint and seclusion. HealthCERT plays a role in monitoring compliance with the Standard, including by undertaking audits of residential services that house five or more people.

Whaikaha provides an overarching service specification for the community residential services they fund (the CRSS service specification). These specifications outline guidance around aspects of residential disability services, including:

- Personal planning;
- Supervision, assistance, and support;
- Access to the community;
- Communication;
- Involvement of the person and their family and whānau and others;
- Staffing;
- Health, medicine, and first aid;
- Supported decision-making; and
- Complaints resolution.
-

Whaikaha purchases community residential support services for disabled people|tāngata whaikaha who need this level of support, with the expectation that they can enjoy a good quality of life, live in a place that feels like home, and have their rights to personal dignity, independence, and privacy upheld.

9. Whaikaha|Ministry of Disabled People, 2023, Briefing to the Incoming Minister February 2023. See: https://www.whaikaha.govt.nz/assets/About-us/Corporate-Publications/BIMs/BIM-Minister-for-Disability-Issues_2023.pdf. Accessed 25/06/2024.

10. Whaikaha|Ministry of Disabled People. See: <https://www.whaikaha.govt.nz/support-and-services/housing-and-transport/living-at-home-and-in-a-community-residence/community-residential-support-services>. Accessed 25/06/2024.



The data used in this report

Around 25% of consumers whose care and support is complained about to HDC identify as having a disability. This is similar to the proportion of the population that identifies as having a disability. However, most of these complaints are about care provided by health services. Just 4% of complaints to HDC each year are about disability support providers, and only 1% concern residential disability support providers.

It is important to note that while the number of people living in residential disability settings is small, it is a group whose welfare is at significant risk in respect of their health, wellbeing, care, and support. Furthermore, while complaints to HDC about RDSSs are relatively low, HDC is aware that people in residential services and those with learning disability face multiple barriers to engaging with HDC and may not be aware of their rights under the Code. HDC tends to receive a higher number of complaints from staff in the disability sector than is seen for other service areas. This highlights the barriers to making complaints for disabled people and, in some cases, could be indicative of an organisational culture where staff do not feel safe and supported to raise their concerns with their employer, or do not feel assured that their concerns will be addressed.

The data analysed in this report was extracted from the complaints databases of both HDC and the Advocacy Service. Between 1 July 2018 and 31 December 2023, 363 complaints were made

about RDSSs (the complaint data). A thematic analysis of issues raised by complainants in complaints to HDC and the Advocacy Service about RDSSs was carried out, and revealed several recurring themes that were then grouped into five thematic categories:

- Wellbeing and self-determination
- Care and support issues
- Staffing issues
- Access and service co-ordination
- Communication

Illustrative quotes from complainants and staff members have been anonymised, and in some cases edited, to ensure anonymity while maintaining the voice and intention of the person.

It should be noted that complaints to HDC about services provided to disabled people/tāngata whaikaha can raise complex and contested issues. For example, in a small number of complaints there may be a difference between the views of family and whānau, who have a deep interest in the disabled person's safety and wellbeing (and may potentially be their legal guardian), and the views of the disabled person, who has the right to self-determination. At times, the examples within this report may reflect these complexities.

Themes identified in complaints about RDSSs

1. Promoting wellbeing and self-determination

Introduction

The promotion of wellbeing and self-determination is central to the UNCRPD and EGL, which guide disability support service provision in New Zealand. Complaints to HDC can provide insight into how disabled people and their family and whānau feel they are supported in services to exercise self-determination and express their aspirations, strengths, capacities, cultural identity, and vision for their future.

The CRSS service specification^[11] provides requirements for residential disability services around personal planning, access to the community and cultural support, supported decision-making, and other guidance promoting the wellbeing and self-determination of service users.

In addition, all RDSSs are required to comply with the Code, which states that all people using disability services have the right to services that meet their needs, uphold their dignity and mana, maintain their independence, and provide them with the information and support they need to make an informed choice and give informed consent.

Three themes best illustrate the common concerns expressed by complainants in respect to the promotion of wellbeing and self-determination – a failure to adhere to established individual support plans, a lack of cultural safety and support for cultural identity, and a one-size-fits-all approach to care and support.

Failure to adhere to established support plans

Complaints to HDC highlight people's concerns around support plans not being adhered to within RDSSs, as well as a failure to communicate effectively or consult on changes or limitations in support plan implementation. The consequences of such failures can be significant and in a few of the most serious cases result in death (as demonstrated in the following case study).

Provision of suitable food for man at risk of choking

A complaint was made to HDC about support provided by an RDSS to a man with cerebral palsy and a learning disability. The man's support plans identified him as being at risk of choking. The man's risk of choking was also noted prominently on the house menu plan.

On the day of the event, two support staff were rostered for work, but one support worker left early, with no cover arranged. The man's dinner was not cut for him as was required by his support plan. The man left the dinner table while the sole support worker was in the adjoining kitchen and, minutes later, the support worker found the man unresponsive in another part of the house, having choked on his meal. The support worker performed CPR and the man was transported to hospital by paramedics, but, sadly, the man died two days later having suffered a fatal brain injury.

The Deputy Commissioner concluded that in failing to provide a consistent and unambiguous support plan and have staff adhere to it, and in not ensuring that appropriate staffing levels were maintained, the provider failed to provide services to the man with reasonable care and skill, and in a manner consistent with his needs, in breach of Right 4(1) and Right 4(3) of the Code.

11. Whaikaha|Ministry of Disabled People. See: <https://www.whaikaha.govt.nz/assets/Contract-and-Service-Specification-documents/Community-Residential-Support-Services.pdf>. Accessed 25/06/2024.

Support/care/personal plans are an important tool used by disabled people|tāngata whaikaha in exercising self-determination. Providers are required to develop and document a personal support plan for each resident in their service, ensuring that the planning process is person-centred and agreed upon in partnership with the disabled person|tangata whaikaha and/or their family, whānau, guardian, or advocate. The creation and maintenance of support plans should be a flexible, responsive, and ongoing process, and support plans should evolve as a disabled person's needs and aspirations evolve. However, there can be challenges for providers in implementing support plans, where they must consider the goals, abilities, and needs of multiple people residing within a shared living environment, particularly in the context of constrained resources and staffing capacity and capability issues.

Complaints to HDC about RDSSs reflect concerns that disabled people do not always feel they are supported in achieving their goals. Tensions can arise between disabled people, their family or whānau, and the provider, when family feel that the disabled person|tangata whaikaha is not being supported in a manner that promotes their wellbeing and independence.

'[The provider] set 8 personal goals in [the family member's] Personal Plan ... I have received monthly reports around these personal goals ... In all of these months they have failed to meet her goals ... There has been no improvement ... They said she would commence swimming sessions ... but to date this has not happened.'

We seek better outcomes for [our family member] who is reliant upon [the provider] to deliver on set goals. [Our family member's] quality of living is not being met. Why?'

Disabled people|tāngata whaikaha living in RDSSs report to HDC that they can, at times, feel as though they have little control over their daily life, whether that be their choice of meal, control over their personal finances, participation in activities, or how they spend their time and who they spend it with. Concerns have also been expressed about a lack of support to achieve personal independence goals. Many of these concerns have been exacerbated by the closure of services following the COVID-19 pandemic and a lack of staff to provide goal-focused support.

'All trips and outings were stopped as they were considered too expensive ... COVID-19 made things even more difficult but even when everything opened up again our son was not allowed to go to choir practice and as a result lost his place in the choir. Our daughter found another choir for our son within walking distance of where he lived. The manager said that we had no right to do this without her consent.'

Self-determination and person-centred support are key principles within the EGL approach. Personalised support plans aim to provide disabled people|tāngata whaikaha with greater voice in how their support, care, and personal goals can be achieved. For family and whānau of disabled people|tāngata whaikaha, personal plans and other forms of documentation can act as a means of ensuring progress and can act as a window into their loved one's long-term care and support.

Planning, routine, and knowing what to expect can be central to the wellbeing of disabled people|tāngata whaikaha. When support plans are not followed, and when delays or deviations from agreed plans are not communicated and consulted upon, these changes can cause significant anxiety and distress for disabled people and their families.

Lack of cultural safety and support for cultural identity

Right 1(3) of the Code requires that services take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori. Where relevant, a person's cultural needs should be considered to be as important as their other support needs.

New Zealand society is growing increasingly diverse, and so too is the disabled community. Frameworks and strategies designed to increase wellbeing and self-determination assert the need to recognise this diversity and ensure that disabled people are supported and provided opportunities to express their cultural identity and to be supported with cultural awareness and safety. Service specifications for residential support services also require that staff have awareness of the cultural needs of people with different ethnicities, including Māori, and Pacific and Asian peoples, and that providers have linkages to Māori social and community services.

Complaints can highlight a lack of knowledge or understanding about important cultural practices, for example limited choices of food on offer and failure to observe cultural dietary requirements/restrictions. Whānau Māori have also raised concerns with HDC around a failure to provide culturally led, mana-enhancing practices, and a lack of models of support that reflect te ao Māori and that are whānau-centric.

‘Staff didn’t understand the intricacies of my care and directions I gave them. They would walk away whilst I was speaking to them. They didn’t do enough turns even when I had pressure sores. One carer caused a wound that has not healed for a year ... [T]heir attitude was inconsiderate, unhelpful and didn’t respect my mana.’

As the New Zealand Disability Strategy acknowledges:

‘Most Māori disabled people identify as Māori first. The importance of their cultural identity, which encompasses language, whānau, cultural principles, practices, and linkages to the land through genealogy, is paramount to how they live their day to day lives in both Te Ao Māori and Te Ao Pakeha.’

While cultural considerations are noted in personal plans, complaints to HDC express concerns that RDSSs may not be doing enough to establish meaningful and ongoing connections with local hapū and iwi, and other ethnic and cultural organisations to support disabled people|tāngata whaikaha to establish and/or maintain and express their cultural identity.

One-size-fits-all approach to support

Disabled people often express concerns about the use of a one-size-fits-all approach within RDSSs that is in contrast to EGL and the ongoing process of deinstitutionalisation.

Disabled people|tāngata whaikaha describe a lack of choice and input into daily activities, and the management of what little discretionary income they may have. While HDC acknowledges the challenges providers can, at times, face in meeting the individual, varied needs and preferences of multiple residents all living under the one roof, disabled people|tāngata whaikaha have a right to independence and must be supported to live everyday lives.

Complaints illustrate the distress that can be experienced by disabled people|tāngata whaikaha when they lack choice and personal autonomy over their daily life.

‘The [House Team Leader] said to me she was making strict new rules, that I can’t make coffee in the house ... and when my support person was having a house meeting, I’m not part of it. I should be involved. They’re talking behind my back ... [T]here’s new people I don’t know, and they let new staff in my house without my permission. They don’t knock on the door they come in my flat and snoop around ...’

Complaints such as this indicate the lack of self-determination that some disabled people|tāngata whaikaha can have over their home environment, personal boundaries, decision-making, and privacy when they live in residential settings. Disabled people|tāngata whaikaha and their family and whānau expressed the importance of clear communication, consultation, and joint planning of any changes that may impact the life of the disabled person. EGL sets out the importance of disabled people being in control of their lives and being supported to live everyday lives in everyday settings. Involving the individual and their whānau — as well as the disability community as a broader group — in decisions that impact them, no matter how minor, is crucial to maintaining self-determination.

2. Care and support

Introduction

Under Right 4 of the Code, people have the right to an appropriate standard of care that is well coordinated, meets their needs, complies with relevant standards, optimises their quality of life, and minimises potential harm to them.

Disabled people|tāngata whaikaha often have multiple, interconnected and compounding care and support needs encompassing their physical, social, cultural, and economic wellbeing. People with learning disability[12] experience an increased risk of chronic disease and are more likely to live with mental illness. However, despite high rates of enrolment in primary health care, people with learning disability experience a variety of poor health outcomes and are over-represented in emergency department presentations and potentially avoidable hospitalisations.[13] Within RDSSs, particularly for those with high or complex support requirements, daily support and care needs can require 24-hour-a-day management. The CRSS service specification provides guidance around the support of people living in RDSSs, including but not limited to, support in carrying out activities of daily living and personal care; ensuring access to external healthcare providers, including a GP, dentist, and specialists; ensuring and overseeing the administration of medications; and making sure people have the opportunity to maintain optimum health.

In the context of residential disability support, inadequate supports can be the result of a number of factors, including, for instance, staffing capacity, the skills/training of staff, a lack of adherence to support plans, a failure to follow policies/procedures, including inadequate medication management, a lack of timely access to external social and health services, and people not receiving their required hours of support or not receiving one-to-one support.

Analysis of HDC complaints data in respect of complaints about support provided by RDSSs identified five themes that encapsulate the core concerns expressed by complainants –

inadequate standard of support and care, deterioration in physical and mental wellbeing, failure to adhere to funded level of support, unsafe medication management and practices, and use of restraint and force.

Inadequate standard of support and care

A central concern for disabled people|tāngata whaikaha and their family and whānau is that they receive support and care that promotes their physical and mental health and ensures their safety and wellbeing. However, complaints to HDC indicate that the level of support provided by RDSSs does not always meet the expectations of disabled people|tāngata whaikaha and whānau or adhere to service specifications.

'This past year has been a very sorry, often disappointing, and almost fatal experience for [the disabled resident] and for our family. We spent over two years exploring residential options ... hoping to find somewhere that would make her feel welcome, support her in her daily cares in a safe and positive manner, and help her extend her abilities through meaningful activities and interaction. Our experience has shown that some of the staff lack motivation and regard of basic medical and health cares. Even worse, is that they are responsible for vulnerable, dependent residents, who are easily bullied into silence and must suffer their caregiver's dereliction of duty ... [T]here is no excuse for the poor quality of care in such a placement.'

Given the additional risks that people with learning disability may face, including barriers to self-advocacy and communication challenges, lapses in their support and care can result in significant physical and psychological harm to them. Complaints from family and whānau about their loved one's support raise concerns around:

- The level and standard of support provided, including multiple lapses in personal and hygiene cares and the quality and nutritional value of the food provided;

12. In this report we have used the term 'learning disability', as a community-preferred term. We acknowledge that the term 'intellectual disability' is used in legislation, as well as by other organisations and individuals.

13. IHC: Despite stark warnings, intellectually disabled Kiwis neglected by Government for another 20 years, 2023. See: <https://www.ihc.org.nz/news/despite-stark-warnings-intellectually-disabled-kiwis-neglected-by-government-for-another-20-years>. Accessed 25/06/2024.

- Risk assessment and management, including mitigating the risk of on-site hazards, managing multiple complex support needs, ensuring that people are receiving the level of oversight and support they require, and the standard of housing;
- Safe management of medications, including staff not following medication administration practices and inadequate policies/procedures and staff oversight/training to guide safe medication management;
- Inadequate oversight and supervision of both residents and support staff;
- Inadequate management of long-term health conditions; and
- Inadequate escalation of care when clinically indicated.

For both disabled people/tāngata whaikaha and their families and whānau, a lack of transparency over the support provided can exacerbate concerns around support and wellbeing and can damage their relationship with the provider. Open and consistent communication between the provider and family and whānau, including regular reporting of any incidents or concerns, can help alleviate concerns and strengthen the relationship between family and provider. Lapses in support can also lead to more serious issues, particularly for those with complex needs.

It is distressing again to see that our son's welfare has not been looked after. Again, late on Saturday night he was able to walk out of the house under the supervision of staff. [After being advised that our family member had left the residence] I immediately drove ... to the scene of [our family member] being manhandled by two police officers struggling to force him to the ground ... When I spoke to [staff] back at the house I observed that the hall door alarm was not in place to alert staff of [the resident] getting up ...

Once again [we] cannot trust that your staff can look after the care and wellbeing of our son ... I cannot convey the stress and anxiety that this is causing us. We have not had a decent night's sleep worrying that he may end up in a Police cell or get beaten up ...'

Inadequate support and care can be particularly distressing for family and whānau when they believe that it is causing their loved one's health or wellbeing to deteriorate. Family and whānau often raise concerns that lapses in personal cares, a lack of continuity of support and care (eg, changes in carers), adverse events or incidents, or difficult interpersonal relationships with other residents and staff lead to a significant deterioration in their loved one's health and wellbeing.

Woman suffers burns

HDC received a complaint about the support provided by an RDSS to a woman with cerebral palsy who was nonverbal. She used continence products that required regular monitoring.

Early in the morning a support worker replaced the woman's continence product for a size XXL, rather than her usual size because there were no products left in her size. This was not documented, but the support worker did communicate this verbally to the incoming morning shift. Because staff were waiting for a new product to arrive, the woman's continence product was not checked until about 6.45pm. At this point it was found that her trousers and wheelchair were very wet and there were burn blisters on both her thighs. Staff also failed to undertake formal pain assessments following the discovery of the burns, did not adequately administer paracetamol, and did not seek timely medical review of the burns.

Following the discovery of the burns, the woman's mother and welfare guardian was contacted once to let her know that the woman had been found with blisters on her thighs. Over the next two days, staff did not contact the woman's mother to update her on the woman's condition. When the woman's mother visited, she viewed the burns and requested an ambulance transfer to hospital for the woman.

The Deputy Commissioner found the RDSS in breach of Right 4(1) and Right 3 of the Code for failing to provide services with reasonable care and skill and in a manner that respected the woman's dignity. The Deputy Commissioner found the manager in breach of Right 4(1) of the Code for failing to seek clinical advice from a registered nurse and for providing insufficient guidance to staff when the burns were reported to her.

There is obviously an increased risk of spread of infection and communicable diseases in residential group settings, and the prevalence of chronic illness and comorbidities among people who live in residential support settings can put them at heightened risk for ill health. Complaints to HDC can highlight people's concerns about a lack of medical oversight of disabled people | tāngata whaikaha in residential settings and a failure to escalate care in a timely manner when clinically indicated.

Inadequate assessment and escalation of care and a lack of medical oversight can be particularly concerning in residential settings where people may not be able to easily communicate the symptoms they are experiencing and their evolving health needs. It is therefore particularly important that there are systems in place and that staff receive the training they require to identify changes in people's health status accurately and escalate care where needed.

Failure to adhere to funded level of support

Complaints about support and care of disabled people | tāngata whaikaha in RDSSs often relate to the level of care and support provided. A common issue seen in complaints to HDC is people not receiving the level of support they have been funded for and assessed as requiring. An insufficient level of support could place people at significant risk of harm, and/or reduced quality of life, particularly if they have complex support requirements.

'[Our family member] came under the care of [the provider] when she was still in a residential care home. She was then moved to supported independent living ... and from then her care was changed from 24 hours to only three times a day despite being approved for funding for 24/7 care. Since being in independent living, she feels the carers that visit her have not been treating her appropriately.'

'I have repeatedly requested [the provider] meet its obligations in providing [our family member] with the support he has been funded for. This support should be 24 hours, 7 days a week, including a daily sleepover shift. This has yet to happen, and despite a fair amount of notice [the provider] has deliberately fallen short ...'

RDSSs are funded in a manner that allows them to coordinate funding to support 3–5 residents in a group-home setting. Whilst individuals receive certain individual support, they also receive coordinated support that is used flexibly so that support can be provided to all residents in the congregate setting. At times, these complaints can be contributed to by misunderstandings on the part of whānau around the nature of this funded support. This points to poor communication with family by providers about what they can expect in terms of the level of support provided and can contribute to a breakdown in relationships and a loss of trust in the provider.

Support provided by a residential provider to a young woman with complex needs

HDC received a complaint about the support provided by an RDSS to a woman with a complex medical history. She required close monitoring in the event of illness as her medical history increased her risk of complications. When the woman was accepted into the RDSS, her parents provided the service with considerable information and guidance about her needs.

The woman fell ill and was taken by the provider to visit her GP. The GP advised staff to bring her back to the medical centre if her symptoms worsened or her condition did not improve over the next 48 hours. Three days after the GP visit, the woman was still unwell. The mother asked the provider whether her daughter could be taken to see her GP again, but the provider said that it was too late in the evening and that a home visit by the GP was too expensive. Later that evening, the mother decided to take her daughter to hospital, where she was admitted to the Critical Care Unit with a severe kidney and lung infection.

The Deputy Commissioner concluded that the provider had failed to monitor the woman's food and fluid intake in order to alert staff to any need for an escalation in her care, had failed to create a short-term support plan or update her existing personal plan, and failed to notify the woman's family of her deteriorating condition in a timely manner. The provider was therefore found in breach of Right 4(1) of the Code for failing to provide services of with reasonable care and skill

Unsafe medication management and practices

Where disabled people/tāngata whaikaha require it, ensuring timely and safe dispensing and administering of medication is vital to their effective support and care. However, disabled people/tāngata whaikaha and family and whānau often complain to HDC that medication has been missed or not administered on time, that medications within the residence have not been stored securely, or that inadequate documentation practices have led to medication errors.

'I felt I had to bring [our family member] home during COVID-19 as I was not able to trust that the staff were able to care for him around careful administration of his epilepsy medication. Several doses had been missed and he had been having an unusually high number of seizures ...

Last year there were several incidents where medication was not given properly. Tablets or even whole doses missed. It became apparent that the medication chart was old and had had many changes, so I was asked to go to the GP and get this updated – which I did. Early this year when a drug issue happened again, I looked through the medicine folder and found the old medication sheet was in the folder. I asked where the updated one was, and no one knew where it was, and everyone said they had never seen it. I had given it to a staff member, and I had sighted it alongside the old form on a number of other occasions. It has totally disappeared ...'

Disabled people in RDSSs often require support workers to supply or support them with medication to manage long-term conditions, chronic illness, and pain. Therefore, ensuring that there are systems in place, including staff training/oversight, to support the safe dispensing and administration of medication is vital to disabled people in RDSSs receiving an appropriate standard of care.

Use of restraint and force

Safety and management plans are dependent on the support needs of the individual, including supporting positive engagement and communication. Staff are expected to be trained in recognised approaches to conflict management and de-escalation. In addition to this training, individual risk management plans or support plans should provide staff with the information they need to support early identification of triggers, successful de-escalation strategies, and non-physical intervention methods to keep people safe.

Staff are also required to report and record all incidents to ensure that these are monitored and reviewed appropriately. Regular meetings also provide staff with opportunities to raise and discuss issues that may result in requests for additional review or support from the NASC or other health professionals. Such meetings, together with continued review of support plans and consultation with tāngata whaikaha/disabled people and their family and whānau, are an important means of monitoring residents' evolving support needs.

Managing individual risk in group settings can be complex. While detailed support and safety plans and a focus on training and upskilling of staff can support the maintenance of a safe living and work environment, several potential triggers (such as people's sensory needs or difficult interpersonal relationships) in such settings can lead to distress. Complaints to HDC can highlight concern from tāngata whaikaha/disabled people and their family and whānau around the use of both physical and chemical restraint, particularly where restraint leads to physical injury.

A failure to notify family and whānau adequately of restraint use or of conflict between residents can cause significant damage to the relationship between family and provider.

'There have been many instances of [our family member] being physically restrained by staff ... [T]here have been reports of [a staff member] physically restraining residents in a violent manner, overpowering them during incidents ... This is extremely concerning, particularly as [the provider is] aware of these incidents but appear[s] to show an alarming lack of concern of the physical harm that may result, and the scarring psychological impact on those being restrained.'

Many of the concerns expressed in complaints about support relate to the appropriate management of risk, as well as ensuring that people receive personal care in such a way that upholds their dignity and mana. These complaints can also highlight the importance of regular and transparent communication with family, as well as any support plans being developed in an on-going partnership with disabled people and their family to take account of evolving risk and support needs.

Guidance around physical interventions lacking from an individual support plan

A complaint was made to HDC about the support provided by an RDSS to a young man with learning disability who is non-verbal and has several physical health conditions. Two support staff were rostered to work at the residence at the time, neither of whom were overly familiar with the young man.

On the day of the events the young man was unsettled and had tried to climb the property's boundary fence. Later, while preparing the man's meal, a support worker raised his voice at the man, and forcibly dragged him away from the kitchen several times, as he felt that the area was not safe for him at that time. One of the support workers who observed this behaviour later realised that the young man had been trying to indicate that he required his lunch to be puréed, but neither support worker had been provided with this information at handover. No incident report was made over the physical intervention, but the support worker who observed these behaviours later lodged a complaint about the incident directly with the provider.

An investigation by HDC found that there were no approved personal restraints in place for the young man. None of the young man's various support documents included authorisation or specific instructions or guidance on when and how to manage physical interventions.

The Deputy Commissioner found that the RDSS's failure to ensure that information regarding approved physical interventions was contained in the consumer's individual support plan breached the man's right to have support provided to him with reasonable care and skill (Right 4(1)). The Deputy Commissioner also found that by failing to inform the young man's guardian in a timely manner of a complaint relating to the standard of care he received, the provider failed to provide care in line with professional standards (Right 4(2)).

3. Staffing

Introduction

Staff shortages and associated rostering and scheduling issues — particularly providers' ability to ensure an appropriate level of skilled, experienced, and qualified staff — are common challenges in the provision of residential support in New Zealand. Providers have come under growing pressure in recent years in respect of workforce shortages and funding sustainability.

The CRSS service specification provides guidance around aspects of staffing, including that every person is supported to choose a staff member to be their primary support worker; that the provider will supervise, assist, and support the service user; and that they will recruit and orient staff to ensure that they understand the particular needs of the people they will support, including ensuring that the provider employs sufficiently experienced and competent staff to provide good quality services.

With reference to the CRSS service specification, providers schedule their own policies specifying requirements for staffing and rostering that are developed based on the identified needs of the various individuals, the level of support needed (as assessed by NASC), specifically funded hours of support, and the appropriate skill mix of staff.

Staffing concerns are one of the most common issues raised in complaints to HDC about RDSSs, including persistent issues with staff rostering, relief cover, resident/staff ratios, and skills/training of staff.

HDC acknowledges the workforce challenges faced by RDSSs. While this has been exacerbated in recent times by the impacts of the COVID-19 pandemic, a lack of people entering the disability workforce has been a challenge over many years. The disability workforce can be trained relatively rapidly, and long-term workforce planning is needed if the sector is to address workforce shortages both now and in the future.

Staff skill and training

The skills, training, experience, and professionalism of staff is often raised in complaints to HDC, particularly in respect of staff capacity to meet the disabled person's specific support needs. These concerns can often relate to the support of people with complex support plans, for example people requiring wound or catheter care, a hoist for personal cares, and those who experience significant communication challenges or who require support to manage important medications. Having the right skills mix and oversight of staff to meet the often-complex needs of residents in RDSSs is a fundamental aspect of providing safe, quality support.

Consistency of support staff can be particularly important to disabled people |tāngata whaikaha. For people with learning disability and who are neurodivergent, unexpected change and disruptions to daily living can cause significant distress. Such changes in staff, particularly where staff are unknown to residents, can also result in people not receiving sufficient behaviour support. This insufficient support is particularly evident where staff providing support are not aware of potential triggers and mitigation strategies.

'It seems apparent to us [that the provider is] removing key staff who know and care about the residents, for someone new who doesn't know or understand the residents needs and requirements to keep them safe and happy, just to save some money ... We believe [the provider] cannot continue delivering high quality services when cutting experienced and knowledgeable staff.'

Similarly, where disabled people |tāngata whaikaha require support with medication, ensuring that appropriately trained staff are available for the administering and dispensing of that medication is crucial for safe and effective support.

'All residents at the facility require medication and [I'm] concerned that the workplace is unsafe due to some workers not qualified to give medication ... Concerns have been raised with management, but nothing is done. [We're] told if you don't like it, leave. This is an unsafe environment for staff and clients. It is only a matter of time before someone is hurt or given the wrong medication ...'

Ensuring the safety and wellbeing of all residents requires the appropriate training and upskilling of staff, and an appropriate skill-mix of staff.

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However, concerns are often raised with HDC that unforeseen staff absences can lead to significant disruption, and health and safety concerns for residents. Staffing can be so stretched that relatively minor rostering disruptions can impact the support and immediate safety of residents.

Inadequate staffing levels

Adequate staffing levels are required to ensure the safety of all residents and support their participation in the community.

'[Our family member] lives with cerebral palsy, is non-verbal and requires full support for all her cares. As a whānau we have been trying to work proactively with [the provider] around a range of issues, including the level and capacity of the staff in her home, the level and consistency of clinical and service oversight, the level and capacity of dedicated staff to support [our family member] to access her community, capability of staff to assist with communication devices, and of staff to assist her to utilise her power chair and standing frame ...'

The staffing ratios used by providers is based upon the assessed support needs and funding allocation undertaken by NASC. The provider is expected to use this funding to provide support at a level appropriate to the disabled person's needs. When approved and funded by NASC, disabled people |tāngata whaikaha can receive 1:1 support. However, often there is no straightforward ratio calculation to support safe staffing levels, particularly as support needs can change depending on daily activities or plans.

'I am concerned at the difficulty there has been providing me with 24 hour support recently. While I understand that it can be difficult to cover for sudden and unexpected absences, that is something your service should have planned for when agreeing to provide me with 24 hour care. I appreciate the extra time and dedication of remaining staff who have to provide cover beyond their rostered hours, but I worry that this might affect their health and so make the problem even more serious.'

Staffing levels sufficient to meet the support needs of disabled people |tāngata whaikaha is crucial for promoting their health and wellbeing. Complaints to HDC can highlight the harm that can occur to residents where safe staffing levels are not supported. In addition, inadequate staffing can interfere with promoting disabled people's self-determination within RDSSs, by restricting their choice over activities and ability to participate in the community.

4. Access and service coordination

Introduction

Under Right 4(5) of the Code, providers involved in a person's support must cooperate to ensure quality and continuity of services for that person.

Disabled people/tāngata whaikaha face multiple barriers to accessing health care and social support. Therefore, it is important that RDSSs support people to access support for their health and other needs. Changes in access to support should be communicated effectively and consulted upon in order to support equity of access, minimise disruption, and ensure continuity of support.

The CRSS service specification provides guidance around access to health and social services, including that disabled people/tāngata whaikaha must have access to a GP, dental and specialist care, and other external services. The CRSS service specification also provides guidance around residents' exiting of service and movement of residence.

Complaints to HDC indicate that, at times, disabled people/tāngata whaikaha in residential services are not able to access health services in a timely manner. Family and whānau also raise concerns that when people are admitted to hospital there can be a lack of co-ordination between RDSSs, specialist services, and the family or whānau.

Access issues are also reflected in a lack of support for disabled people to access community supports, particularly where there has been a sudden or poorly communicated discontinuation of community-based services.

Delays and inadequate coordination with external services

Delayed access to external services and poor coordination between services is seen in complaints to HDC about RDSSs. Often these complaints relate to delays in accessing external healthcare providers, for example a disabled person's GP or specialist. People residing in RDSSs can have high health needs but face multiple barriers in accessing health services, and are often reliant on staff within RDSSs to assist them to access the care they need. RDSSs must ensure that their staff are equipped to

support disabled people to identify when care is required and facilitate access to that care when needed or requested.

'[Our family member] asked to go to the GP regarding his extremely bad eczema ... He was aware he needed antibiotics. The caregiver said he could only go when his medications were due to be renewed. Under no circumstances have we ever said we would not pay for medical attention when required.'

Disabled people/tāngata whaikaha and their family or whānau also raise concerns around inadequate coordination of care between RDSSs and external health services. This can cause significant harm where a disabled person's support needs evolve beyond the capability of the RDSS to manage, but this is not communicated adequately to the NASC and other external agencies who may be able to support the person. More commonly, however, poor communication between RDSSs and external healthcare providers means that the disabled person's health needs are not supported adequately by staff, for example, by missing follow-up appointments, or medication and discharge instructions not being adhered to.

'Due to the poor communication at the hand over ... [the disabled person] missed an important medical appointment for the dermatologist. She has had to go back on the waiting list. This has led to her leg condition not being addressed in a timely manner and now requires the District Nurse to visit to dress her legs, as there is no proper diagnosis.'

Also important for the appropriate care and support of disabled people is effective communication between the RDSS and external health and social service providers. As disabled people/tāngata whaikaha in residential services may experience communication challenges, staff can play a role in advocating for the person in the health system and helping them to communicate their medical history and their social and cultural needs.

Transitions of support can be particularly prone to error, and documentation and systems must support important information about the person's health and social needs being transferred between providers.

'We were extremely surprised and concerned when [the resident] was received at our facility [and] not one piece of paper came with her. Not one single piece of information regarding her medical history, daily notes, doctor's information, specialist appointments, assessments, bank information, dietary requirements, medical protocols, allergies, NOTHING. We didn't even know if [the resident] had eaten prior to coming or what time she was administered her last medication ... Several times we had requested the documentation and information and none of what we had requested was unusual and these should have automatically come with [the resident] when she exited [the previous provider] and entered our facility.'

Together with preventative measures and early detection of health needs, effective access and coordination with external services can prevent deteriorating mental and physical health and promote the disabled person's self-determination. Studies show that adults with a learning disability can endure prolonged suffering from health conditions that are treatable. RDSSs therefore have an important role to play in ensuring that disabled people receive equitable access to the health care they require and have their right to an appropriate standard of care upheld.

Changes and termination of support

HDC receives relatively few complaints about a lack of access to RDSSs, although we are aware of the challenges the disabled community can face in accessing support. However, our complaints data does show concerns about the way in which decisions are made to exit people from services when the RDSS believes they cannot meet the support needs of the person or protect the health and safety of other residents.

From time to time, people's support needs will evolve, and a higher level of support may be required. However, often people raise concerns about a lack of consultation, effective communication, or shared decision-making with the disabled person and their family or whānau about these changes.

'[The provider] decided to move [our family member] from a property he has lived in for 20 years without the family's consent. They have made decisions and taken steps to move [our family member] without ensuring he was properly represented, nor did they allow the family to have

the information required to properly advocate for him. He is not able to understand ...'

These types of changes are very significant for the disabled person and their family or whānau – the residential service is the disabled person's home, and the requirement to move to another property or service can cause enormous distress. They are not merely losing support, but also the relationships and social networks they have developed. Familiar people and settings can be particularly important for disabled people | tāngata whaikaha in RDSSs to allow them to feel safe and promote their independence and wellbeing. Inadequate consultation and ineffective communication of these changes adds to this distress and is extremely challenging for everyone involved. Poor planning, consultation, and communication can also have a negative impact on the wellbeing of the disabled person and their family where there is a lack of alternative accommodation available and difficulties in accessing other providers. In these cases, often the family feels that they have been placed in a very difficult situation by the provider with little warning or assistance.

'Last year things came to a head. We were very worried about our young man's mental health and then found out [that the provider] wanted to exit him from their service and there was no one else to take him, so we had to step in ... Now we find out there is no placements available for him here and there is long waiting lists.'

I was under the impression during all of this time that they would know how to manage disabled peoples' behaviour. To me, the houses were set up to care for people with a range of disabilities, with two houses and "handpicked" staff ... I thought that they would be familiar with challenging behaviours ... I was told that they would never "chuck her out" and that [the provider] would "work something out" ... [T]he decision to exit [our family member] last year was a shock to me and the disability professionals that were present, as there was no indication from [the provider] that this was their goal. I had the impression that exiting someone from a residential placement was rare.'

When a disabled person is unexpectedly exited from a support service, transparent, early and effective engagement and consultation about any required changes in support are vitally important to supporting continuity and quality of support.

5. Communication

Introduction

A lack of communication is one of the most common themes identified in complaints about RDSSs. Almost all complaints raise communication issues to some extent. Under Right 5 of the Code, people have the right to open, honest, and effective communication in a form and manner that allows them to understand the information provided, and Right 8 gives people the right to support. Under Right 10 of the Code, people have the right to complain about the services provided, and providers must also facilitate the fair, simple, speedy, and efficient resolution of complaints.

The CRSS service specification provides guidance around aspects of residential disability services, including that the provider will engage in effective and timely communication to build strong and trusting relationships with disabled people/tāngata whaikaha and their family and whānau, proactively facilitate and value family and whānau in their role of supporting the disabled people/tāngata whaikaha to the extent that they want this, and ensure that there is a process to resolve complaints or air any grievances between parties.

Communication with disabled people/tāngata whaikaha

Complaints received by HDC about RDSSs can relate to the management of interpersonal disputes between residents, and between residents and particular staff members. These complaints can reflect both a breakdown in relationships between the disabled person and particular staff members, and inadequate management by staff of complex needs in shared living arrangements.

For disabled people/tāngata whaikaha, effective communication between themselves, their whānau, and their support workers and provider, is essential to having a say in their support, maintaining relationships, and improving their health and wellbeing. However, poor communication can leave people feeling as though they do not have a voice or control in their daily living and support.

'The service is not understanding my rights and not listening to my rights in what I want to do for the last year ... I want them to listen to me and my rights. They haven't listened so I want to go further with my complaint.'

'I have made complaints to the service over the last few years about not being given information in a way that I understand. I once lost temper with a needs assessment coordinator as I wasn't aware that she was coming to visit me as my service failed to let me know when they knew.'

For disabled people/tāngata whaikaha living in RDSSs, their relationships with staff can be central to supporting their wellbeing and feelings of safety and control. Any unprofessional conduct (such as disrespectful, threatening, or abusive behaviour) by staff or breakdown in relationships can cause significant anxiety and distress. While these complaints are small in number, the fact that they occur at all is concerning, and obviously it is unacceptable for people to be subject to trauma and harm in the place where they live, and by the people who are meant to provide them with support. Oversight and transparency over the support provided to people in RDSSs and the conduct of staff is vital in protecting the welfare of a vulnerable population.

Communication with whānau

Family and whānau often play a critical role in the lives of disabled people and their wellbeing and support. Families can play an important role in supporting the disabled person's self-determination and control by assisting to amplify their voice so that their preferences, aspirations, and goals can be understood and adhered to. Therefore, often family and whānau can be left feeling very frustrated when their knowledge of the disabled person is not respected or considered by a provider, when they are not consulted on key decisions, or where they are not kept adequately informed of incidents or changes in health or support needs.

'[Our family member] was moved from the house where he has been well established and comfortable for some time, to another house without any consultation with us or his welfare guardian ... He is not one to complain but we know he is not happy where he is ... The fact that they made this decision without any consultation is totally not acceptable ... We have spoken on the phone and through email with absolutely no result. We feel that we are just being fobbed off and they hope we might just go away.'

'[Our family member] was admitted to hospital for a week. I am his next of kin and no one contacted me to let me know. I have since found out he has also been moved from his accommodation ... I have gone and found [our family member] at his house and he told me how he ended up in hospital. He said he was told by his support person she had contacted me. To reiterate – I have not been contact[ed] – still. [Our family member] was in hospital for a week. Had someone let me know I could have visited him, taken him things for comfort and been available for him emotionally ...'

Early, effective, and transparent communication by RDSS staff with disabled people and their families, particularly in respect of incidents or changes in routines and schedules, is important in ensuring that a partnership approach is taken and assists to manage concerns as they arise while strengthening and protecting relationships.

Complaints management

Often people escalate their concerns to HDC after being dissatisfied with the provider's response to their complaint. Disabled people and their families report having their concerns minimised or dismissed or providers failing to make requested changes following a complaint. Concerns about provider complaints management processes relate to both informal expressions of concern made to support workers and management, and to complaints made through the provider's formal complaints process.

'A complaint/concern form was filled out by three care recipients ... regarding a staff member who is bullying them ... This form was handed into their care organisation. Nothing has been done about this to date. The care recipients exercised their right to complain by filling out this form. They did not receive speedy or efficient resolution to their complaint, they have not been informed of the progress of their complaint and there has been no acknowledgement of their complaint in writing.'

Community support worker takes non-consensual photos and videos of clients

A community support worker, who was employed to provide support to a group of disabled people (tāngata whaikaha), took non-consensual photos and videos of several consumers. These were stored on her phone and later accessed by her husband.

The Deputy Commissioner considered that the act of taking these photos and videos was inappropriate and did not demonstrate respect for the consumers. The Deputy Commissioner rejected the support worker's submission that she took the recordings as evidence of 'violent and erratic behaviour' as most of the recordings showed the consumers looking calm or in a defenceless position (eg, sleeping). The support worker had no regard for the consumers' privacy in the most vulnerable of circumstances and did not respect the trust placed in her by the disabled consumers, their families or the disability service.

The Deputy Commissioner concluded that by taking non-consensual photographs and video recordings of the consumers, storing them on her personal mobile device, and failing to keep them secure, the support worker failed to treat multiple consumers of disability support services with respect or dignity, in breach of Right 1(1) and Right 3 of the Code.



Power imbalances are inherent in the provision of health and disability services. Nowhere within the sector is this power imbalance more evident than in the support of disabled people/tāngata whaikaha by residential providers. Disabled people residing in these services are particularly reliant on the support provided and can face multiple communication barriers. In addition, the residence is their home, and the fear of being exited from the service or damaging relationships with staff by making a complaint can be a significant barrier to raising concerns. In light of this, disabled people/tāngata whaikaha and their family and whānau often raise concerns with HDC about the possible repercussions that complaining may have on service availability and/or quality.

'[Our family member] cannot speak and I have not advised him I am doing this as he is in danger of retaliation from staff and clients who live at the house ... We have tried to raise our concerns with [the provider] and to date they have failed to address our concerns ...

It has been brought to my attention by concerned staff working at [the residence] that [staff] have indeed reverted to old institutional and abusive practices. Good staff are too frightened to raise their concerns higher up the ladder given historic bullying within the area and the threat of retaliation by managers.'

The recent Whaikaha-commissioned review of services provided by one of New Zealand's largest disability service providers found that disabled people/tāngata whaikaha and their family or whānau feared retaliation for raising issues, that their complaints were stifled, and that they experienced terse and threatening interactions and communication from the provider. This is not rights-compliant support. People have the right to raise concerns and to have their concerns addressed in a meaningful, compassionate way.

The right to complain is a fundamental aspect of the Code. Done well, complaints resolution plays a central role in the safety of consumers, maintenance of trust in the health and disability system, and the restoration of relationships and mana, and ensures consumer input into quality improvement. A complaints management process must first and foremost be people centred. It must focus on the resolution needs of the complainant and place the needs of people above the needs of the system. Creating a culture that welcomes complaints and where complainants are treated with respect and provided with a constructive outcome is an important aspect of quality service provision.

Conclusions

Services and supports for disabled people | tāngata whaikaha face many challenges, and the sector is under significant pressure. Disabled people | tāngata whaikaha continue to face several inequities across both health and housing, and quality of support and safety issues continue to arise in respect of residential services for disabled people.

We acknowledge the important work that has been undertaken to examine the abuse in care experienced by disabled people | tāngata whaikaha in residential and institutional settings, which will be fully explored in the forthcoming final report of the Royal Commission of Inquiry into Abuse in Care. We also acknowledge the important insights from the Whaikaha-commissioned review of policies, processes, and practices for managing complaints about a disability service provider. It is our hope that the recommendations we make below will provide a timely contribution to Aotearoa New Zealand's continued work to improve services and deinstitutionalise and transform the disability sector in line with the UNCRPD and the principles of EGL.

HDC has a key role to play in upholding the rights of disabled people | tāngata whaikaha. Residential settings come with inherent risks that must be managed. Transparency and oversight over the support provided in these settings is crucial to maintaining the welfare and safety of people using these services, and monitoring agencies, including Whaikaha, need to ensure that appropriate safeguards are in place. HDC is an important mechanism for providers to be held to account for failing to uphold the rights of disabled people | tāngata whaikaha. Accountability, where required, protects people's rights and improves the quality of support provided.

Through the making and monitoring of recommendations, HDC also holds the system to account to ensure that learning and change occur. Over the past five years, the most common themes in our recommendations to individual RDSSs about complaints we receive were in relation to:

- *Preventative measures:* Support planning, communication, supported decision-making, supporting consumer safety, supporting wellbeing and positive engagement and communication, identifying and managing risks to consumers and staff.
- *Responsive measures:* Responding to neglect and abuse, incident reporting, and identifying and escalating issues as they arise.
- *Restorative measures:* Facilitating an explanation and/or apology from the provider to the disabled person and their family or whānau.

Disability-related complaints are reviewed regularly to identify emerging trends and concerning issues that require further action. HDC shares information with other agencies about risks to immediate safety and wellbeing to ensure that timely action is taken. We also share intelligence regularly to encourage a common understanding of the experience of disabled people | tāngata whaikaha in the health and disability system, and to facilitate collaborative solutions.

HDC acknowledges the voices that are under-represented in our complaints data, particularly those of tāngata whaikaha Māori and Pacific peoples. HDC is focused on improving the responsiveness of our organisation to the needs of the disability community, including through:

- Prioritising consultation with disability | tāngata whaikaha communities as part of HDC's Act and Code Review. The consultation has already produced a range of recommendations to support disabled people | tāngata whaikaha engagement with HDC, alongside proposed recommendations to amend the Act and Code.
- Focusing on engaging with tāngata whaikaha Māori, in collaboration with HDC's Director, Māori.
- Exploring the use of hui ā-whānau and hohou te rongo (tikanga Māori dispute resolution) options for complaint resolution, where appropriate.
- Developing an internal disability strategy to enhance HDC's focus on the promotion and protection of the rights of disabled people | tāngata whaikaha and their family and whānau.

- Continuing to make improvements to our management of complaints about support provided to disabled people, including increasing the capability of staff in respect of disability, prioritising those complaints where people are reliant on the support provided, and focusing resource on serious and urgent complaints, including by taking a timely approach to escalating emerging risk to other oversight bodies.
- Increasing opportunities to share complaint trend information and associated improvements and recommendations across the disability sector and highlighting recurrent and systemic issues with providers and funders, such as with this report.

HDC also acknowledges that we have heard that our own complaints processes need to continue to evolve towards becoming more culturally appropriate, accessible, timely, and responsive, and to provide greater opportunities for restorative approaches. While we are focused on improving our processes in these respects, including a focus on early resolution where possible, progress can, at times, be hampered by on-going significant increases in complaint volume within a resource-constrained environment.

We acknowledge that progress has been slow towards transformation of the disability sector in line with the principles of EGL. The establishment of Whaikaha was a positive step, but considerable improvements must be made if Aotearoa New Zealand is to truly realise the UNCRPD, and the EGL approach to supporting disabled people | tāngata whaikaha. To this end, HDC supports the UNCRPD recommendations and guidelines toward continued deinstitutionalisation.

Recommendations

HDC's role is to promote and protect the rights of people using health and disability services, including by resolving complaints about the infringement of those rights, holding service providers to account, and using complaint findings to improve the quality of services, at an individual provider level and across the health and disability system. Upholding people's rights extends beyond just the standard of care provided – it encompasses respect, dignity, communication, complaints processes, and being supported to make an informed choice and give informed consent.

HDC acknowledges that some complaints about disability support can span the jurisdiction of several different agencies (including Whaikaha, Health NZ, ACC, HealthCERT, Worksafe, the Ombudsman, HDC, the Coroner, Police etc). Continued collaboration and a whole-of-sector approach is needed to clarify the roles of each agency, streamline processes for referral, and simplify the complaints system for disabled people and their family or whānau. HDC remains focused on ensuring public safety issues are escalated in a timely way to those agencies that can take action, as well as sharing our complaints data in a way that highlights the experience of disabled people and supports quality improvement.

Recommendations to Whaikaha

1. HDC supports the recommendations made in the recent Whaikaha-commissioned review of policies, processes and practices for managing complaints about a large disability service provider, written by Rachael Schmidt-McCleave (the Schmidt-McCleave report). In particular:

- The continued work of Whaikaha and service providers in better facilitating and resolving complaints about disability services. HDC will also be considering what improvements we can make to our own processes in this respect;
- That Whaikaha make available to disabled people and their whānau information on what they can expect from disability service providers; and
- Acknowledging current resource constraints, the potential for increasing the role of the Nationwide Health and Disability Advocacy Service in supporting people who live in residential disability services.

While Whaikaha retains overall responsibility for ensuring that the recommendations of the Schmidt-McCleave report are met, HDC is maintaining a watching brief over progress being made.

In addition, HDC makes the following recommendations based on the findings of our analysis of the complaints we have received about residential disability support services (RDSSs) over the past five years.

2. HDC recommends that Whaikaha, in its role as steward of the broader disability sector, and in consultation with disabled people|tāngata whaikaha, whānau, and disability service providers and funders, develop and implement a consistent quality framework across all funded disability service provision. Such a framework would set out expectations of disability support and allow the quality of supports to be measured and monitored consistently across all funding agencies. Clear expectations also empower disabled people and their families to communicate their concerns when these expectations are not met. The following points could be considered in developing a quality framework:

- The proactive monitoring and reporting of the experience of disabled people and their family and whānau in services, including sector-wide opportunities for contractual levers to support this monitoring and reporting;
- That the recommendations made in the Schmidt-McCleave report may have wider utility across the sector, including ACC, Health New Zealand|Te Whatu Ora, and Oranga Tamariki-funded services; and
- Progression of Whaikaha's work on a consistent framework and guidance for complaints management.

This report is focused on the quality of support provided in residential support services, including issues that are exacerbated by institutional models of support (for example, one-size-fits-all approaches to disability support). HDC supports continued work to provide community-based alternatives to residential support across the disability sector, in line with the UNCRPD. With this in mind, and taking into consideration the broader systems issues outlined above, we also make the following recommendations:

3. HDC notes Whaikaha's publication of the Disability Support Workforce Community Engagement report and supports a workforce planning programme remaining a priority.

4. HDC notes and supports work underway as part of the My Home My Choice programme and the Choice in Community Living programme available in some parts of the country. HDC encourages Whaikaha to consider making Choice in Community Living available nationwide.

5. HDC encourages Whaikaha in its stewardship role to support development of Māori-led disability services, both residential and community based.

6. HDC encourages Whaikaha to communicate with the disability community about progress to roll out EGL systems transformation nationally.

Comments about the Independent review of disability support services administered by Whaikaha

In May 2024, the Government announced an 'Independent review of disability support services administered by Whaikaha'. We acknowledge that this review does not focus solely on residential support. However, the review offers an important opportunity to improve outcomes for disabled people, including those in residential support services, and to further work to deinstitutionalise disability support. We have therefore made some comments on this review below.

In noting the May 2024 government announcement of an 'Independent review of disability support services administered by Whaikaha', HDC is disappointed that there are no tāngata whaikaha Māori or disability community leaders among the three-person panel. However, we encourage the review panel to:

- Ensure that tāngata whaikaha Māori and disability community leaders, family and whānau are closely involved in the review, in particular around the development of recommendations;

- Use the articles and principles of Te Tiriti o Waitangi, the UNCRPD, and EGL to create a framework for recommendations that will ensure a sustainable, high quality, and inclusive disability support system;
- Ensure that the review has a strong focus on guaranteeing the quality of disability supports, including any lessons learned from previous reviews and inquiries;
- Include a strong focus on disability workforce planning and the long-term sustainability of the workforce, including career pathways and supported on-the-job upskilling and training opportunities for RDSS staff; and
- Consider the Aged Care Funding and Services Models Review as a possible road map and further justification for the development of a similar review of disability sector funding. Such a review should address current inequities in funding of disability support based on diagnosis and origin of impairment.



HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA