

MINISTRY OF SOCIAL DEVELOPMENT

Disability Support Services Community Consultation Report

Further improvements to Disability Support Services

September 2026

Prepared by Global Research Ltd



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Executive summary

Background

In 2026, the Ministry of Social Development (MSD) undertook a community consultation to inform its operational strategy to strengthen Disability Support Services (DSS) for the future.

This consultation is the third since an independent review in 2024 found there was a lack of fairness and transparency around what support disabled people can access and that spending was becoming unsustainable. Prior consultations asked people about their experiences of accessing supports and about the assessment, allocation, and funding processes. The present consultation built on this feedback and sought to understand what further improvements should be made to disability support services that the community had said mattered most to them.

The consultation

Further improvements to DSS	Community engagement took place for almost eight weeks, ending 31 July 2026, with people asked to give feedback on broad outcomes, transition support, feedback and complaints processes, carer respite support, flexibility of supports, and information and advice.
850+ participants	Over 850 people contributed, including 432 attendees of 33 workshops (both in-person that were held around the country and online), 379 online survey respondents, and 55 submitters.
Disabled people, family and whānau, carers, stakeholders	Survey respondents included whānau/family of a disabled person (50%), disabled people (49%), carers (34%), combinations of these, and stakeholders. Workshop attendees and people/groups who made submissions were likewise affiliated with the disabled community in a range of ways.

This consultation was undertaken while several policy and operational changes were being implemented following previous engagement with the disability community, as such, not all people who use Disability Support Services may have experienced these changes. We acknowledge that the experiences and suggestions are made in this context. Disability Support Services will consider all feedback as part of their ongoing work to strengthen the disability support system.

Overall statement

People want to be able to maintain choice in supports – including when, how, who from, and of what nature – they want support that is personalised, person-centered, professionally delivered and proactive, and they want to access support via coordinated systems that are responsive, nimble, and that offer respectful and trusted interactions.

Findings by topic

Topic One: Outcomes that matter

What we heard People consistently expressed that their needs are far greater than staying safe and daily living: they want to see greater emphasis on quality of life as a point of focus for whoever it is that is providing services or supports for disabled people. To achieve this, people frequently called for the individualised provision of support that allows wellbeing to flourish – however that looks different for each person.

Survey findings Of the five wider benefits autonomy and connection stood out as of greatest importance, though, just over half of survey respondents disagreed or didn't know that the outcomes and wider benefits reflect the needs of all people.

Topic Two: A proactive approach

What we heard People recognise that support needs fluctuate and they want to see such periods anticipated and additional supports easy to access. One solution was to increase the amount of flexibility in service provision: that is, more options, more responsive systems that cater to change at short notice, and more trust that the disabled person and/or whānau know what they need. People want to see *reactive* systems replaced with *proactive* ones. They also want access to facilitated support when unexpected needs arise outside of standard review cycles, ensuring support is responsive and timely.

Survey findings Flexibility to allow for changes in support was the most popular change people want to see for a more proactive system

Topic Three: Feedback and complaints

What we heard People reported a degree of scepticism that feedback or complaints would be worth making, however, people indicated an increased likelihood of engaging with a feedback/complaints system if it were easy to find and use, and if fears about feedback resulting in negative consequences were allayed (such as via the use of independent advocates or confidentiality measures). People support clear communication about decisions and the opportunity for meaningful dialogue underpinned by trusted, personal relationships that enable them to feel heard and safe to raise concerns.

Survey findings Reliability and choice/control were what matter most when receiving support from a DSS provider (over three-quarters selected these). Being listened to and taken seriously was most often considered most important in respect of being safe from abuse/neglect. There was a lack of knowledge around how to make or escalate complaints, and over two-thirds agreed that a short survey would be a good mechanism for DSS to monitor service delivery.

Topic Four: Carer respite and breaks

What we heard Disabled people wanted to see more respite options, more options catering to higher needs, and respite that is easy to access. It was important that respite options be person-centered (i.e. appropriate and relevant to the disabled person and/or household), and it was important that options be available at short notice, that processes be simple and light on administration, and that respite for carers be free from stigma. People frequently made points that respite options should cater to what suits households best and not be limited by strict definitions.

Survey findings No quantitative survey questions were asked, all three questions allowed respondents to answer in their own words, and these are included in the commentary in the 'What we heard' section, above.

Topic Five: More choice and control

What we heard Disabled people were in agreement that autonomy and choice in services and supports is crucial. Having options and being able to exercise choice were viewed as fundamental to support that is person-centered, holistic, and responsive to changes in need. People want less bureaucracy and burden to receive the supports they require, and they want it to be clear what options are available.

Survey findings Over half of survey respondents agreed that having more options available would mean more flexibility, choice, and control in accessing services. Second to this, a majority agreed that funding a broader range of smaller providers would give more flexibility, choice, and control. Flexibility and choice is predicated on access.

Topic Six: Information and advice

What we heard People want a centralised source of information that offers a range of accessible formats and that paints a complete picture of what supports are available, and how to access them. Comments outlined the need for clear, simplified, up-to-date, and accurate information, as well as easy ways for people to find information relevant to them. People would value having someone they trust to help them navigate information, understand available options, and assess what is most relevant to their individual needs and circumstances, reducing the effort required to find and evaluate information from all sources.

Survey findings People get information about disability supports from a range of places; primarily NASC/EGL, social networks, and community groups (for people with similar disability to themselves). The biggest challenge faced in getting information about DSS was that it is hard to find; people primarily want to know about what services are available; and people want information to be clear and simple and easy to find.

Cross-cutting themes

Across the engagement some themes arose repeatedly, irrespective of which questions had been asked or which topic or theme was being addressed. Such themes are often revealing as points of interest and, as they are not necessarily captured in one dedicated place within the analysis framework, they are presented here.

Support that is personalised and flexible

We heard very clearly from disabled people that, owing to the individual and specific nature of people's circumstances, supports are needed that are personalised, tailored, and targeted. This was perhaps the most commonly raised point across this engagement. In the context of funding, this meant greater flexibility in funding models so that disabled people may get what is required to lead a fulfilling and meaningful life – according to personal needs and situations of each person. This necessarily requires a high-trust model whereby people are able to use funding in ways they see fit. In the context of supports, this meant more options and choices that enable responsiveness and spontaneity in the moment.

Navigable systems that require low energy expenditure

People talked about navigation coaches or single points of contact for accessing support and made direct statements about the difficulty of navigating systems; these point to systemic complexities that act as a barrier to accessing support. For some, applying for or managing certain supports was a burden and the time it takes to do this on top of uncertainty about outcomes prevented them from even taking steps to apply for or access supports; for others, it was having to go to a number of different places (physical locations, online, or attempts to reach people by phone) to get information or support options or outcomes.

It was suggested that greater coordination (or consolidation) of services could improve experiences for people accessing support. The fragmented nature of service information, access and provision was noted across many topics as a barrier.

The role of NASC and assessments

Overall, people expressed the need for NASCs to build capacity, trust, and create a positive, consistent, and constructive environment for assessments. Success with NASC was said to require people to answer in a particular way, heavily self-advocate, and independently find out what is available. They want fairness, consistent application of criteria and transparency.

While people like the idea of a personalised support plan as the final output, orienting or connecting people to what support is out there, and what suits their needs, is an important part of the process. Concern was expressed about needing to 'prove' needs as they occur, further prompting people to regard assessment as a tool that can only be activated after a significant need has come up, rather than one that can help people plan for the future.

Proactive support

Across many topics, people raised the idea that the provision of *proactive* support is preferable to *reactive* support. However, there is a fine line to walk between supports that are proactive and a system that intrudes on privacy or in which a person feels micro-managed. A system that is proactive is one in which supports are anticipated and offered (as opposed to fought for) in a reasonable timeframe, is one in which NASC coordinators apply consistent criteria across both regions and disabilities, and – potentially – is one in which there is potential for financial savings where early intervention and support may prevent larger needs and costs down the line.

A well-trained, professional and stable workforce

Related to the above, we heard from people that a well-trained, stable support worker workforce would reduce stress and fear for disabled people and whānau about who is caring for them/ their loved ones. A well-trained workforce was said to help people access support without fear of conditions being exacerbated by oversights in care and to assist with continuity of care and professionalism in support situations.

Meanwhile, stability was needed in a workforce that was characterised as relatively transient. This requires commissioning agencies and employers to consider how to ensure the disability sector to be viewed as a career option with long-term prospects.

Recognition of the role and needs of carers

Carers and whānau see themselves as a key part of the disability support system – a part that DSS relies on – but they do not feel recognised or supported as such. Moreover, the work required to access supports and funding for the person they care for is described across many parts of the engagement as burdensome, time consuming, and stressful.

Whānau carers, though aware that respite options may be available, can find the work of arranging this supersedes any benefits gained. They want to see the development of natural supports within communities, such as coffee groups, on top of other aspects such as easier, stigma-free access to respite, and, respite that, although it may not fit typical definitions of such, becomes available (this may include meal provision, cleaning, or flexibility in respite payments so that breaks may be taken as per personal preference).

More support, more services, more options

An overarching theme throughout the engagement was that people simply require more supports. This was sometimes expressed as calls for more money or more funding, particularly for respite, so that support could be purchased or statements to the effect that there is a lack of supports or service provider options in general. People sometimes added that a lack of service prevents disabled people from having a meaningful choice in the supports they use. They expressed the need for genuine support options that are sustainable for them, their family, whānau, and carers.

Introduction

Background and scope

This report presents full results of consultation run by the Ministry of Social Development (MSD) on future changes to the services that Disability Support Service (DSS) provides. From 8 June to 31 July 2026, DSS asked the disability community how to further improve a number of key service areas. People and stakeholders could respond to an online survey (including in accessible formats), email a submission (in writing, in video, or in audio format), or contribute via an online or in-person workshop.

A first round of consultation at the end of 2024 received responses from over 1,500 people. That process and a subsequent consultation with 1,800 people in 2025 informed policy work; the options consulted on in this engagement focus on key service areas the disability community has said matter most. This includes more flexible supports, better planning for life changes, outcomes that matter, better information and advice, making it easier to give feedback, and better respite options for carers.

This consultation will inform operational improvements to services and commissioning of supports and recommendations to the Government about how to further strengthen and improve the DSS system.

Public engagement

The 'Have your say on further improvements to Disability Support Services (DSS)' consultation accepted feedback via online survey, public workshop (in-person and online), and submissions (including audio, video, and text files). Over eight weeks, DSS received feedback and submission from over 850 people.



379

Survey responses



55

Submissions



432

Workshop attendees

Online survey

An online survey of 37 questions was open for eight weeks. It was structured by the following topics, each of which contained multiple questions, and all of which were optional.

Topic 1: Shaping the outcomes that matter for disabled people

Topic 2: A more proactive approach to support

Topic 3: Better feedback and complaints processes

Topic 4: Better support for carer respite and breaks

Topic 5: How we offer more choice and control in our services

Topic 6: Improving our information and advice

The online survey was accessible in the following formats:

- > Theme and contrast selector (a customisable light theme)

- > Large text format (bigger text)
- > Activate Easyread (simplified interface)
- > Activate read aloud (the application reads the questions)
- > New Zealand Sign Language (display SL video for each question)
- > Activate Voice assistance (answer questions by voice).

Percentage of survey respondents that answered each topic:

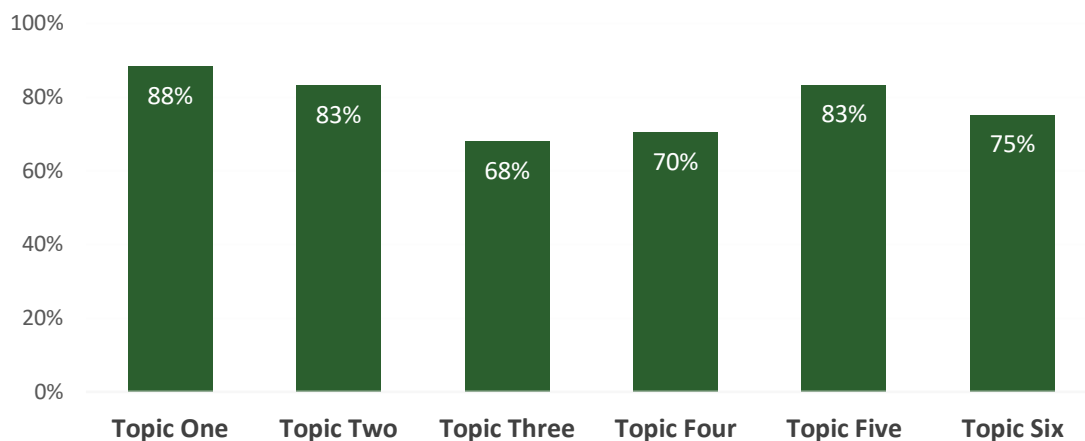


Chart 1: Percentage of survey respondents that answered each topic (n=379)

Popularity of survey topics

- > Online survey respondents were most likely to answer questions on Topic One: *Shaping the outcomes that matter most for disabled people*; 88% of respondents answered questions on this topic.
- > Topics Two and Five were also answered by more than four-fifths of respondents (83% each) indicating high interest in *A more proactive approach to support* and *How we offer more choice and control in our services*.
- > The topic that the least respondents answered was Topic Three: *Better feedback and complaints processes*, even so, more than two-thirds of respondents (68%) answered questions on this topic.

Workshops

Online and in-person workshops were hosted by DSS and stakeholder groups with assistance from DSS and/or independent facilitators. During workshops, detailed notes were taken at each table, or by the online host, to record what attendees were saying. Workshop notes were analysed alongside other data as described in the methods section of this report.

A total of 33 workshops totalling 432 attendees were hosted. Of these, seven regional in-person workshops were held in Central Auckland, South Auckland, Hamilton, Palmerston North, Wellington, Christchurch, and Dunedin

DSS assisted with workshops for the following stakeholder groups: DPO, Ngāti Hine, Hohepa, EGL Taranaki, Spectrum Care, HCHA, Vaka Tautua, and NZDSN.

Workshops were structured by the following topics:

Topic A: Outcomes that matter for disabled people

What would you be able to do, or what experiences would you be able to have, at different times in your life, if support were working well, and how do you know when it is working well?

Topic B: Flexibility of supports

What does flexibility look like for you? And how might we better reflect this in the services we deliver?

Topic C: Carers

Thinking about the services that DSS provides to carers and whānau, what is missing, or what else could we provide that could support you and your whānau?

Topic D: Information and advice, feedback and complaints

How can we improve the way information flows both ways so it works better for you – both when you're seeking advice or support, and when you want to give feedback or make a complaint?

Submissions

The 55 individual and stakeholder submissions received came in multiple formats. This included emails with or without attached documents, video submissions, audio files, written submissions handed to DSS staff at workshops, and infographic files.

Written submissions were structured in a variety of ways; some followed the online survey structure, while others shared views on one or more topics of interest to any degree of detail chosen. Audio/ video submissions received were transcribed and treated as a text submission and analysed alongside all other data as described below.

Analysis and reporting overview

Analysis process

This report presents results from stakeholders who contributed to this consultation in one of three ways:

- Completed the online survey;
- Submitted written/video/infographic feedback via email; or
- Attended an online or in-person workshop.

Free-text responses from the online survey, together with transcribed workshop feedback and submissions were imported into NVivo analysis software. NVivo software assists with managing and sorting large volumes of text; it is not an AI programme. Analysts read and code (sort) each comment, opinion, piece of workshop feedback into themes and topics so that all answers and comments are presented within the same framework.

Quantitative analysis

Quantitative analysis was carried out on closed-option questions from the online survey.

Frequency analysis was conducted on answers to multi-choice questions, which denoted the percentage of respondents who selected each option for each of the closed-option questions in the survey.

This data has been presented in charts and interpretation sits beneath each chart. Quantitative results are presented in relevant sections throughout the report as per the structure of the online survey which comprised the bulk of the data.

Qualitative analysis

All free-text responses from the online survey (including any accessible format in which the survey was completed), workshop feedback, and submissions of all types were analysed together. Comments were coded to the themes and topics used in the survey, with workshop and submission data woven throughout the topics that were most relevant.

Responses that were received via submissions, emails, voice, or video recordings have been coded and discussed within the most relevant topic.

Many responses and submissions contained multiple points relevant to multiple topics; these comments were coded to multiple places. The analysis was assisted by NVivo qualitative analysis software. AI was not used in analysis or in the production of this report.

About this report

Structure

This report is structured sections based on the six topics used in the online survey.

Topic 1: Shaping the outcomes that matter for disabled people

Topic 2: A more proactive approach to support

Topic 3: Better feedback and complaints processes

Topic 4: Better support for carer respite and breaks

Topic 5: How we offer more choice and control in our services

Topic 6: Improving information and advice

Demographic information (*survey respondents only*)

Each section commences with a summary which first shows what text that introduced the survey question/ relevant workshop discussion point(s). The second box includes:

- **Overall summary:** A topic summary statement;
- **Survey respondent preferences:** A summary of closed-option survey responses (*survey data only*);
- **What people said:** A summary of commentary under topic headings for each question (*all data*); and
- **What we heard:** These that were evident within each topic and actionable points.

Synthesising points

Throughout the discussion of written comments, headings show the topic and subtopics with numbers in brackets showing the weight of commentary. The results are presented in order of most-to-least mentioned sub-topics for each section, and numbers in brackets indicate approximate comment numbers.

To illustrate the sentiment and tone of the feedback, quotes have been included throughout the report. These are presented italicised and indented from the margin. Note that grammar and spelling mistakes have been amended in some cases where this did not alter meaning.

The number of people who made similar comments has been consistently represented through the scale shown below. This assists with readability while enabling proportionality between topics to be assessed.

Key for comment numbers	
3 comments	A few
4 – 7 comments	A small number
8 – 14 comments	Several
15 – 24 comments	A moderate number
25 – 49 comments	A considerable number
50 – 74 comments	A substantial number
75 – 99 comments	Sizeable
0 – 149 comments	Large amount/ number
150 + comments	Very large amount/ number

This report uses the term ‘people’ to refer to those that contributed to the consultation. Particular groups are referred to as survey respondents, workshop attendees, or submitters where differentiation is relevant

Acronyms and te reo terms used

Kaitūhono, tūhono, connector: those who work alongside disabled people and whānau in supporting aspirations using the Enabling Good Lives approach

Tāngata hunga hauā, tāngata hauā, hunga hauā: People with disabilities/ disabled people

Tāngata turi: Māori people who are deaf

Tāngata whaikaha Māori: Strengths-based, mana-enhancing approach for disabled Māori or Māori with lived experience of disability

ACC: Accident Compensation Corporation

DSS: Disability Support Services

DPO: Disabled People's Organisation

EGL: Enabling Good Lives

HCHA: Home and Community Health Association

IF: Individualised funding

MSD: Ministry of Social Development

MOE: Ministry of Education

MOH: Ministry of Health

NASC: Needs Assessment Service Coordination

NZDSN: New Zealand Disability Support Network

ORS: Ongoing Resource Scheme

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WINZ: Work and Income New Zealand, Work & Income

Engagement and reporting limitations

Though every effort was made to engage groups and encourage participation, and though good numbers did engage with this consultation, a number of aspects will have prevented some people from participating. Consequently, we cannot claim that the findings of this report are representative of the disabled community as a whole.

The questions used in the online survey differed slightly to the discussion points used for online and in-person workshops; in addition to this, as with many public engagements, people do not always directly answer the question that is asked of them. This has resulted in some repetition across questions. Analysts coded all comments from submissions and workshops to the most relevant section of the coding framework, and all survey responses were coded into topics related to the question that was asked. Due to repetition within responses and the use of different questioning frameworks across the engagement, when reading this report, it will not be useful to dwell on the number of people who made certain points under each topic heading; rather, the extent of arguments made, and the relative proportions in which topics arose.

Full consultation results

Topic 1: Shaping the outcomes that matter for disabled people

DSS prompts used in engagement

Introduction to survey questions 1 – 5

DSS propose two outcomes that we are responsible for:

- **Daily Living:** providing the essential supports required for everyday life (for example, personal cares, residential care).
- **Safety:** in the supports we provide, disabled people are safe from physical or psychological harm and free from abuse or neglect.

Alongside these we propose five wider benefits that we contribute to. Other government agencies also make a contribution.

- **Autonomy:** enabling people to grow, maintain, or regain autonomy in everyday life.
- **Connection:** enabling meaningful personal, social, and community networks.
- **Contribution:** supporting people to contribute meaningfully to communities.
- **Growth:** supporting people to grow the skills and knowledge needed in life
- **Experience:** people can feel positive about the direction of their everyday life.

Relevant workshop discussion point

Topic A: Outcomes that matter for disabled people: What would you be able to do, or what experiences would you be able to have, at different times in your life, if support were working well, and how do you know when it is working well?

Key findings on outcomes that matter

Overall summary

The two outcomes proposed by DSS as key responsibilities (daily living and safety) – though supported – were deemed the minimum that DSS should aim to achieve. Disabled people, alongside carers, whānau and the wider community, consistently called for greater attention to the five wider benefits characterised as the responsibility of DSS *and* other agencies. This perhaps speaks to a lack of targeted messaging (and therefore a lack of widespread understanding) of exactly what the role of DSS is in the context of providing support.

In addition, the prevalence of commentary on the importance of incorporating all of the wider benefits into service provision, revealed the existence of generalised unease about exactly who it is that is responsible for the ultimate wellbeing of disabled people. In the context of ‘shaping the outcomes that matter for disabled people’, it matters to disabled people who contributed to this engagement that there be accountability in service provision.

Survey respondent preferences

- > Autonomy was most often identified as the most important wider benefit by survey respondents. This was closely followed by Connection.
- > Almost half of survey respondents agreed that the DSS outcomes and wider benefits reflect people's needs, though most of this support was tepid and almost one in five (18%) strongly disagreed that this was the case. In explanation, most stated that the outcomes may not cater to varying needs.

What people said

Other outcomes or wider benefits to include

- > When asked about other outcomes or wider benefits that DSS should be achieving or contributing to, the most frequently made point was that DSS should take steps to increase options for disabled people to participate, connect with people, and be included in community life. In practical terms this meant being able to purchase support.
- > People also frequently commented on DSS's relationship with disabled people and provision of support as an aspect that should be built on, particularly the ease of accessing support.

Measuring progress towards the outcomes and wider benefits, what tells DSS that things are improving?

- > The two key measures of progress identified within comments were related to the individual personal wellbeing, and the provision of support to disabled people that is reliable, accessible, and timely. These two factors were often related to each other, where people's overall wellbeing was said to be contingent on accessing tailored support with relative ease.
- > People also generally encouraged measuring progress by asking disabled people, their families, and carers how things are going.

Other thoughts about what DSS aims to achieve for disabled people

- > When asked for additional thoughts about *Shaping the outcomes that matter for disabled people*, people talked about deficits in suitable support and in equal numbers urged that flexibility be prioritised (both in goals for disabled people and in the supports they receive).
- > There was demand for greater understanding that disabled people/whānau know their own needs, which in practical terms would translate to being allowed greater flexibility in how support funds are spent.

What we heard

Concern about the definitions and application of the outcomes and wider benefits and what that will ultimately mean for disabled people

What this would mean for assessing outcomes and wider benefits

- > People want clarity around the purpose for defining outcomes and wider benefits, how this will be used, and what changes people are likely to expect as a result.
- > There is concern about wider benefits being overlooked and this suggests DSS should identify and show people how their contribution extends beyond the two key outcomes identified. This could include a mechanism of responsibility or a measure of success for achieving wider, quality-of-life outcomes that are contributed to by multiple parties.

How well the system works impacts people's overall wellbeing and could be considered an outcome or measure of progress in and of itself

What this would mean for measuring success and assessing outcomes

- > Measure success by asking people about their experience of accessing and receiving supports: not just what supports they receive. People often explained that the success of the system shouldn't be measured by the 'services delivered', but the outcomes those services achieve for the disabled community as a whole. DSS should also consider disabled people who aren't currently accessing support, or may have failed to do so, when measuring progress, rather than focusing solely on people who do receive supports.

Consideration of outcomes and wider benefits needs to account for individuality, and success may look different for different people

What this would mean for measuring success and assessing outcomes

- > People said that success in outcomes and wider benefits, as well as the relative importance of the wider benefits, differs greatly from person to person. This point suggested the need for a person-centered, planning approach so that the outcomes being worked towards, as well as the measures of progress, are self-determined.

1. Other outcomes and wider benefits for DSS to achieve or contribute to 750+ comments

Respondents were asked: *Are there any other outcomes or wider benefits that we should be achieving or contributing to?*

General comments and suggestions for outcomes and wider benefits (329)

Inclusion, accessibility, and participation – Connection and Contribution (93)

People urged DSS to focus specifically on removing or helping disabled people overcome barriers to participate, contribute, and develop meaningful relationships with their communities and wider society. The wider benefits of connection and contribution were often touched on or linked together within this topic. These outcomes were regarded as dependent on how inclusive and accessible the broader environment is (how many, and how high existing barriers are), as well as the extent to which disabled people are supported to overcome these barriers. People supported DSS to play a part in both aspects.

Another important outcome is genuine inclusion and belonging. For disabled children, success is not only about safety and basic daily living, but having opportunities to communicate, learn, develop skills, build relationships, participate in their community, and have a meaningful life that reflects who they are.

Disabled People should 'feel normal' and feel welcomed and included in the city (Dunedin). Ensuring that a city is including people. We want to see disabled people being visible in the community, and not just about wheelchair users – if places are accessible, they work for everyone... Feeling included is important and that you feel like you are not different from other people.

Both connection and contribution go both ways. The community need to also be willing to involve those with disabilities in their lives/organisations etc. At times it seems very hard to break those barriers for those with disabilities to connect into society and contribute without being judged.

While often interrelated, statements were also divergent as to how contribution and connection were considered, with the latter being linked to emotional wellbeing, relationships, and building broader social acceptance. These comments tended to describe a sense of belonging, inclusion or feeling included as the key outcomes. Community, social networks, and strong relationships were also noted as important parts of overall wellbeing.

Being able to feel comfortable in society, feel they belong and that they are valued.

Belonging and being valued: Connection is important, but it should mean more than being present in the community. Disabled people should have enduring relationships, be known and valued by others, and feel that they genuinely belong.

I would be able to feel happy, feel included and have goals that are important to me, like school goals. Society would be more inclusive, an active inclusion. I would be treated like a person not a diagnosis.

Discussion surrounding contribution, participation and accessibility tended to be more materially focused, with the overall aims of allowing disabled people access to the same opportunities as everyone else and to be able to participate in ways that are meaningful to them.

To access normal life- all the services, activities and options that non-disabled have.

Disability support is participation infrastructure. Like education, transport and public health infrastructure, its purpose is to make ordinary life possible. It creates the practical conditions through which disabled people can learn, work, maintain relationships, participate in community and cultural life, and exercise citizenship.

People also suggested that DSS could support accessibility and inclusion in education and employment, as pathways that provide meaningful activities for some disabled people.

If we want people with a disability to be gainfully employed, we must ensure they are treated fairly and any environmental barriers are removed. This affects people with a physical disability, but also neurodiverse people too.

A focus on an ability to access further education, beyond skills and knowledge "required". A lot of disabled people are well behind their peers but that doesn't mean they can't continue learning beyond the age of 21.

The defined outcomes of daily living and safety are too limited (55)

People in substantial numbers stated that while daily living and safety are important outcomes, on their own they are not sufficiently broad to enable disabled people to live a good life. This idea was coupled with the general sentiment that DSS should be aiming for more than the "minimum" in their provision of support to disabled people.

I also think the outcomes are very bleak. We're talking very bare bone stuff when it's 'essential supports' and 'safety' - yes these things are the most important, but people also need to have a level of comfort - warmth, freedom from pain, hunger, boredom.

We are encouraged by DSS's recognition that supports should enable disabled people to have choice and control, participate in communities, and achieve outcomes that reflect their aspirations. However, we consider the proposed DSS outcomes framework too narrow. The proposed primary outcomes of Daily Living and Safety are necessary, but these are minimum conditions for a good life rather than outcomes that disabled people aspire to.

Comments voiced concern that limiting DSS's responsibility to those two outcomes positions the wider outcomes and benefits as 'nice-to-haves', despite them being fundamental to quality of life. Less often, it was noted that the diffusion of responsibility for the wider benefits across a variety of sectors risks there being no accountability for achieving these factors.

The framing distinction between outcomes DSS is responsible for and benefits DSS contributes to is understandable from a machinery-of-government point of view. It is also, I would gently suggest, dangerous. The last thing the disability support system needs is another framework that lets any single agency point sideways when things go wrong. If Autonomy, Connection, Contribution, Growth and Experience are not the responsibility of DSS, whose responsibility are they?

If DSS is only judged on whether disabled people are safe and can manage the basics of daily life, then that's all the system will aim for. As the parent of a disabled child, I don't want my child to simply survive safely. I want them to have every opportunity to learn, make friends, be part of their community, build confidence, make their own choices, and live a full and meaningful life.

For disabled children, young people and adults, autonomy, connection, contribution, growth and positive experience are not optional extras. They are core elements of wellbeing, human development and citizenship.

People also advocated for DSS to commit to principles that reflect a more holistic understanding of the lives of disabled people, such as those outlined in EGL, Whānau Ora, and for the rights of disabled people outlined in the UNCRPD. The limited responsibility for outcomes was also criticised as contradicting existing commitments to EGL and UNCRPD. Similar concerns were expressed about how the outcomes of daily living and safety are currently defined, concepts that were argued to incorporate a variety of factors, including the wider benefits outlined.

In line with our commitments to EGL and the UNCRPD to support equal citizenship and participation and its own service specifications DSS is directly responsible for more than daily living and safety. In your own consultation document you state 'we

aim to support disabled people to have choice and control, live everyday lives, participate in their communities and achieve outcomes that reflect their aspirations' which is more than daily living and safety. The approach you are taking in relation to this question is far too simplistic - You can't have safety without connection, autonomy, contribution, growth and experience. Taking this compartmental contributory approach risks minimizing people's lives to existing as opposed to thriving. Disabled people have the right to be supported to live full lives including 'sex, drugs and rock and roll' not just the basics.

Daily living is not simply completing tasks. Daily living is life. Likewise, safety is more than the absence of harm. Safety includes freedom from isolation, exclusion, poverty, institutionalisation and lives that become smaller over time.

Social equity and cultural competency (49)

People suggested that principles of social equity and/or cultural safety should be included within the DSS's consideration of outcomes and wider benefits, and that these generally reflect outcomes that are important for the disabled community. Comments described the demographic diversity of the disabled community, as well as the inequities in outcome and access to support that harm marginalised groups. Respondents advocated that DSS should explicitly aim to mitigate existing inequities among marginalised groups and ensure that support services are culturally responsive.

Limited equity and cultural safety coming through in the consultation document.

Be aware that there is diversity within disability. Respect the differences and be willing to learn about other cultures. Need to understand can be disabled person and e.g. Samoan not or. Care and culture can go together; it's not one or the other.

A subset of this discussion specifically addressed equity and cultural responsiveness for Māori disabled people, calling for DSS to commit to Te Tiriti o Waitangi, incorporate the Whānau Ora vision, ensure that services reflect Māori cultural needs and address inequitable outcomes for Māori.

Working in partnership under Te Tiriti o Waitangi means recognising tāngata whenua as Treaty partners and ensuring Māori leadership, knowledge and aspirations are reflected in the design, delivery and continuous improvement of Disability Support Services.

Support for family and carers (42)

People advocated for DSS to also work towards outcomes for family and carers of disabled people, rather than supporting disabled people in isolation of their wider support networks. It was argued that the wellbeing of family and carers directly relates to the wellbeing of disabled people and is overall necessary for achieving the outlined outcomes and wider benefits.

Whānau and carer wellbeing. My partner has been my primary carer for most of the last twenty years. Their health, employment, and mental state are directly affected by the level and reliability of my supports. Treating carer wellbeing as an outcome (rather than a downstream effect) matters because it changes what is measured and what is invested in. The Royal Commission of Inquiry into Abuse in Care reminded us of what happens when whānau are treated as peripheral to the person.

Comments noted that carers, particularly family carers are currently under-recognised and under supported by DSS despite being a core pillar of the disability support system. Carers were often reported to be absorbing an unsustainable workload behind the scenes, including both care-work and the administrative labour of accessing and negotiating supports. People also pointed out that the success of the support system cannot be accurately measured if the labour and wellbeing of this group isn't considered.

Support should enable the disabled person's family and carers to remain well and continue their caring relationships without becoming exhausted or financially disadvantaged. In our family, I undertake most of the research, meetings,

correspondence, form-filling and coordination required to organise [family member's] supports. This unpaid work takes considerable time and reduces my capacity to undertake paid work. A service should not be considered successful simply because a family is absorbing an unsustainable workload behind the scenes.

Comments within this topic also suggested for carers and family to be viewed as partners in disability support provision, and that DSS should make a concerted effort to communicate, support, and engage them in decisions.

The current narrative and parallel legislative signals suggesting that family and whānau must exhaust all personal capacity before state funded care is triggered is dangerous for high needs families. Aging parents cannot indefinitely provide 24/7 high impact care, such as heavy lifting, managing severe behavioural challenges, or medicalized interventions, without structural collapse. Recommendation: DSS must officially recognize that family care is a partnership with the state, not an endless resource to be exploited to offset budget caps.

Enabling Good Lives (43)

People called for DSS to define its key outcomes and wider benefits to work towards in line with the EGL principles and framework. EGL was supported as a holistic, best practice and community-supported model for disability support. People advocated for EGL to be considered the “foundation” or “core” referen for drafting and measurement of outcomes and wider benefits. Comments supporting this point were largely garnered from workshop and emailed submissions.

Yes, all the Enabling Good Lives Principles. Why aren't they mentioned here?

Provide supports that help disabled peoples live their lives according to Enabling Good Lives principles- equitable, individualized outcomes...relevant to the individual and their family.

A lot can be solved if you can base things on EGL Principles. Solve many problems.

People noted that EGL is a better reflection of community aspirations and the role of DSS than the current definition of outcomes (note this topic was already touched on, above, under the heading ‘the defined outcomes of daily living and safety are too limited’). Comments also asserted that EGL needs to be implemented in practice, rather than solely operating as a guiding principle.

We ask you to consider the large amount of peer reviewed research, expert advice and work that has been put towards the EGL pilots and roll it out nationwide. That is the preferred outcome for the NZ disability sector. We want progressive disability support structures, not the regressive system transformation that seems to be happening at present.

The Enabling Good Lives (EGL) vision is listed as the first of the laws and principles guiding DSS's work, yet Outcome 1 is framed narrowly around providing “essential supports required for everyday life.” That is a bare-minimum, life-sustaining standard, not an enabling one. We recommend Outcome 1 be reframed to reflect the ambition of EGL – supporting a good life, not just meeting minimum daily needs.

Rights and dignity (37)

When considering other outcomes and wider benefits, a considerable number of people supported the addition of rights and dignity, overall conveying the idea that disabled people should be treated with fairness and respect when accessing supports. Thoughts on this ranged from not being made to “feel like a burden” to calls for dignity to be at the forefront of any interactions that people have with DSS or its service providers.

DSS should enable people to exercise the same rights and freedoms as non-disabled people, including choice, privacy, relationships, participation, movement, community life and personal decision-making. A system that only keeps people safe, but limits ordinary freedom and dignity, is not enough.

Dignity and Rights; supports upholding dignity, independence, and human rights of disabled people in line with the principles of the UN Convention on the Rights of Persons with Disabilities.

Dignity should also be an outcome. Disabled people should not have to justify their existence or prove their disability repeatedly.

Comments within this topic also conveyed that disability support should be rights-based, either in line with specific rights frameworks, most notably the UNCRPD, or that it should adhere to “rights”, or “human rights” generally.

Outcomes must be grounded in the UN Convention on the Rights of Persons with Disabilities, and the Enabling Good Lives principles. Disabled people’s rights must be embedded in primary legislation, not left to future Ministers.

DSS’s provision of support and relationship with disabled people (188)

A very large number of people, when commenting on DSS’s consideration of outcomes and wider benefits, focused on factors that would improve the experience of accessing support and interacting with DSS along with general evaluations of how the current system is achieving outcomes.

Ease of accessing support (53)

A substantial amount of commentary focused on the ease of accessing and navigating supports, including either suggestions around making the system easier to navigate or reported personal negative experiences or criticisms of the current system. The overall point was that system navigability is important for achieving the currently defined outcomes, so much so that it could be considered an outcome in-and-of-itself. Many of these were general comments that accessing support should be quick and easy, and that accessing support that is flexible is paramount.

I believe an important outcome is missing: accessibility and navigation. It does not matter how much funding or how many services exist if people cannot understand how to access them. Success should be measured not only by what support is available, but by whether people can realistically find and obtain that support.

Administrative accessibility should be an outcome. The system should not exhaust people with paperwork, unclear processes, or contradictory information.

Positive life experiences come from systems that work. People are more likely to feel hopeful when they can: Access timely assessments and diagnoses; Receive appropriate treatment; Obtain accurate information; Access the supports they need; Navigate government systems without unnecessary barriers; Have confidence that services work together. For many disabled people and their families, these basics remain difficult to achieve.

Specific suggestions for making support easier to access included: having greater coordination across sectors to prevent people from having to engage in repetitive processes; having flexible, less restrictive funding rules and defined criteria for accessing certain supports; making it easier to get in contact with DSS and support service agencies; and removing the requirement for people with permanent disabilities to repeatedly prove diagnoses. Additionally, we heard that navigation assistants or connectors are the key to ensuring that there is a trusted relationship: when people know what they can get and can obtain support to access those things, the understanding and responsiveness experienced can mean negative experiences (and possible consequent complaints) are avoided.

The system is very time consuming and draining to navigate. Someone to walk you through the application processes and help you understand your entitlements across the board would be incredibly helpful.

People should not have to repeatedly explain or prove their disability to different agencies. Assessment processes should be simpler, faster, and more consistent,

with clear information about what support is available and how to access it. There should also be better coordination between government agencies, health providers, disability organisations, and community services so that disabled people do not have to navigate multiple disconnected systems on their own.

Disabled people and family members detailed specific negative experiences or difficulties they encountered when accessing supports, often generally detailing that these have a high administrative burden, particularly when the outcomes are uncertain. Accounts also noted specific difficulties navigating inflexible criteria for support qualification, being delayed by wait and processing times, and navigating fragmented or changing systems.

Going through the residential care process is incredibly stressful. It's the logistics of making sure everything is in place for him when we can't look after him anymore, so that our other children don't feel they must shoulder this burden of responsibility in our place. The whole process of welfare guardianship is huge and expensive, and it took 4 months to get a legally binding document (son is non-verbal). Then two years ago, changes meant that funding was frozen, and after that we were told we'd have to start all over again. It's so frustrating when things change and people come and go, with no communication or information, and then you have to re-share and re-live your story all over again and build a new relationship with someone else. We haven't done any of this before, and no one else we know is doing it, and it's lonely and isolating, and then there's the whole guilt part that we're even doing it at all.

Reliability and consistency of services (33)

The belief that stability and consistency in services should be prioritised was noted a considerable number of times in response to the question about the wider benefits that DSS should aim to achieve. Simple statements like “continuity of care” and “supporting stability for people” were made alongside others in which people explained the frustration and fear of being unsure if funding or support services would remain available. One person was said to have “keenly felt the loss of flexible funding when it was taken away”, while others described personal situations.

Families need confidence that suitable support will remain available when parents or primary carers become older, unwell or unable to provide the same level of care.

Transparency around communication of information, and DSS's relationship with the community (29)

This group of comments mostly called for transparency; while this meant different things to different people or was a simple response such as “we want transparency”, for some transparency meant being told/asked about changes before they happen, being informed (e.g. about DSS plans strategies or goals so that submissions can be tailored appropriately, or, more commonly, being informed about what supports are available for people).

Trust and transparency should be included. People need to trust that NASC decisions are fair, consistent, and based on real needs, not budgets.

People also generally called for DSS to consider the disabled community as partners and support more opportunities for co-design of the disability support system.

More co-design with DSS when they start making changes – that is an element that has been lost.

Support for specific disabilities (24)

This group of comments addressed the needs of people that they felt DSS had not adequately supported, these included those with high or complex needs, young people, sight impaired people and Deaf people. Further, a range of additional specific situations were described in which people's disabilities did not attract the level of support required for them to lead a decent life, these include those with: invisible disabilities, cognitive issues, rare disorders, neurodivergence, chronic pain, and sensory issues.

Our survey results demonstrate a significant failure of Disability Support Services (DSS) to adequately recognise and respond to the needs of people living with rare disorders.

Healthcare (20)

A moderate number of people urged that physical health be recognised or prioritised, sometimes in the context that someone's disability can overshadow other health needs, and in other cases it was about free access to health or GP care, tests, or screening. The health outcomes of disabled people were said to be dire compared to the general population, and in addition to physical health, mental health services such as counselling and wellbeing support were called for.

You need to fund health professional services attached to the current suit of disability funded residential and community-based services. These services are by far best placed to provide health-based care that will benefit the entire health system by reducing GP and ED visits, preventable surgeries and extended hospital stays.

Other commentary

Remaining commentary included a moderate number who feared that a focus on cost saving was doing a disservice to disabled people (e.g. in the instance where supports do not meet people's needs, there is a problem with the system that can be 'fixed' with funding). Included within these was the sentiment that funding at present does not reflect the cost of living and the "real needs" of people using DSS services.

To begin with, the individual disability support funding needs to keep up with the cost of living and inflation.

Skilled support staff were a concern for a moderate number of people, mostly in the context that disabled people need support staff who understand people's needs and that handle themselves competently and professionally. A more stable workforce was called for, as was "competence with complex needs" and "appropriately trained" staff.

Lastly, more support at times of transition was noted by a moderate number of people. This topic is explored fully elsewhere in this report, though, it was important that supports can move with a person as their condition or situation changes in the context of DSS outcomes and wider benefits.

Commentary on existing outcomes and wider benefits (169)

A very large number of people supported, gave suggestions, or expressed criticisms regarding to the existing outcomes and wider benefits defined by DSS. People often made the point that the existing outcomes and wider benefits are inextricably linked together.

Autonomy and choice (79)

A sizeable number of people conveyed the importance of autonomy as a guiding outcome for DSS, often directly stating that it is the most important principle to abide by. Support for similar concepts including self-determination, choice, individuality and "having control" (e.g. over decisions, over routines, over providers) were also described, conveying the central idea that disabled people should define what a good and meaningful life looks like for them, as well as how they are supported. Consequently, people pointed out that the system needs to allow and support this flexibility and choice.

1. Self-determination: Disabled people and tāngata whaikaha Māori are recognised as experts in their own lives, with authority to make decisions about supports, goals, risks and priorities. 2. Choice and control: People have real authority over how, when, where and by whom support is delivered, including flexible funding that reflects individual and whānau realities.

Autonomy should be that the disabled person can choose who their carer is, where they live, whether it be with family or independently.

Less often, comments focused on disabled people being supported to develop greater independence in their day-to-day lives.

Disabled people should have genuine opportunities to live as independently as possible and participate fully in their communities. This includes access to appropriate housing, transport, technology, personal care, healthcare, education, employment, and social participation. Support should enable people to have control over their own lives rather than creating unnecessary dependence on services or institutions.

This topic also included emailed submissions where autonomy was ranked as the most important of the wider benefits proposed in consultation documents.

I dislike ranking these because they are interdependent – no autonomy without connection, no contribution without growth. However, taking the exercise on its own terms, and reflecting on twenty years of use, I rank them: 1. Autonomy – the ability to make decisions about my own life and household. Without it, everything else is done to me rather than by me.

Experience and support for daily living (44)

People conveyed that DSS should aim to support disabled people to live an ordinary life and that, as well as achieving essential needs, disabled people should be supported to engage in activities that are available to non-disabled people and lead a fulfilled life. This included general comments, as well as specific aspirations for aspects of daily life that would be, or are currently, made possible by support.

What good support makes possible: Time outside, and the ability to work, with the right, happy people in place to help. Help from friends and family and being able to ask for the support I need. Transport to access things, and to get to and from activities, work, and visits. Being able to choose the food I like and eat well, with someone helping me make good choices about nutrition. Support to plan where I would like to go and who I would like to visit. Support to access the activities I value, and support to exercise. Physical activity and sport, such as swimming and diving lessons. Support with everyday life, such as grocery shopping and budgeting, one on one – including having savings to use (for example, when I go to Australia).

Less often, comments emphasised meeting essential needs (such as housing stability, nutrition, and access to necessary technologies/equipment).

Yes, providing the health and disability related supports for people to get out of their homes e.g. a safe wheelchair, safe wheelchair access lift, etc.

Issues with outcomes and wider benefits (33)

A considerable number of people outlined specific issues they had with the outcomes as proposed; these ranged from descriptions of outcomes as too subjective, to criticising them on account of focussing on capability where personal capacity should also be acknowledged. Additionally, it was noted that outcomes are meaningless when basic supports cannot be accessed. Some stated that DSS is dealing with people's "whole lives" and therefore "full support" across all aspects of this is needed; similarly, some people asked questions of DSS about the purpose and intentions of the outcomes and wider benefits, commenting that aspirations are fine, but questioning how these might 'play out'.

Stop trying to make people 'good' members of society. People deserve respect [even] when they aren't able to contribute or grow. People have value because they are people.

We note it is important that benefits should be interpreted broadly enough to include people with rare, fluctuating, degenerative, complex and poorly understood conditions.

If we want disabled people to grow, contribute and experience positive lives, we must first ensure that the basic supports that make everyday life possible are accessible.

Other commentary

In relatively even proportions, a moderate number of people each talked about the importance of the following three aspects: wellbeing (having meaning, hope, good health, good lives), safety (both physical safety, e.g. at home and at school, and in the context that safety should precede all other aspects), and growth/development (being able to thrive, worship, achieve goals, learn, and progress to a level that is possible).

Health and Safety first and foremost. Me and my support person. Speaking for self and as advocate.

Ordinary life outcomes need to be factored in, life bigger goals such as travel.

A small number of people expanded on the wider benefits or agreed that “all of them” are integral for a disabled person’s life.

2. Importance of each of the five wider benefits

Respondents were asked: *Of our five wider benefits, which are the most important to you?*

Respondents could select: up to three options.

- > **Autonomy:** enabling people to grow, maintain, or regain autonomy in everyday life.
- > **Connection:** enabling meaningful personal, social, and community networks.
- > **Experience:** people can feel positive about their everyday life.
- > **Growth:** supporting people to grow skills and knowledge required in everyday lives.
- > **Contribution:** supporting people to contribute meaningfully to their communities.

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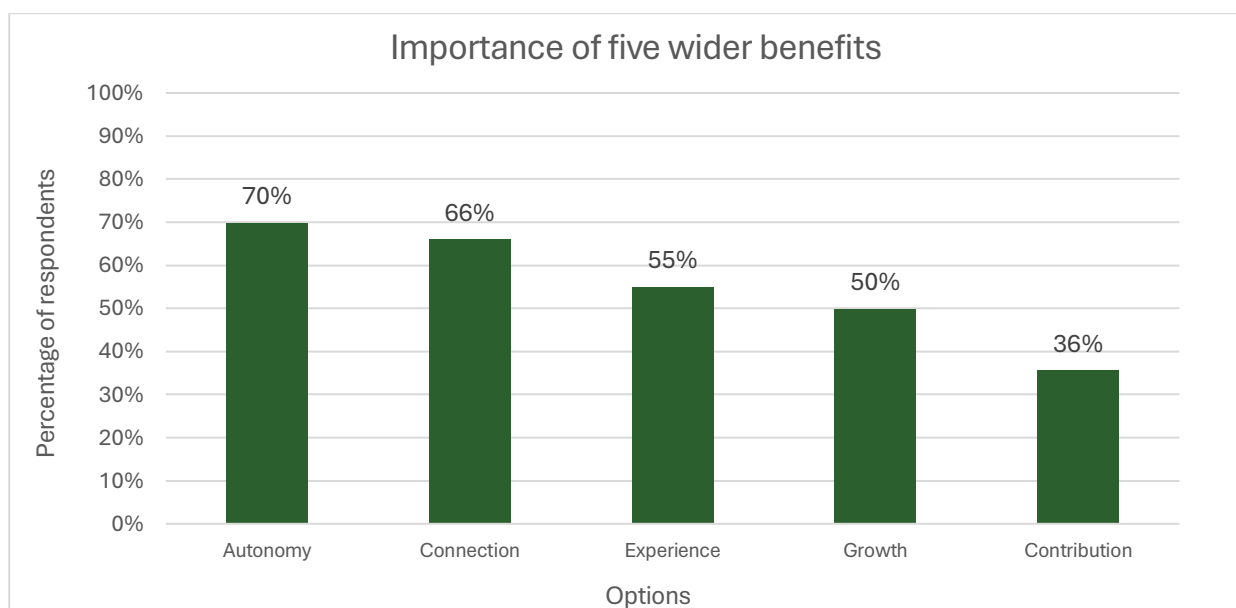


Chart 2: Importance of each of the five wider benefits

Findings

- > The wider benefit that most people identified as important was *Autonomy: enabling people to grow, maintain, or regain autonomy in everyday life* (70%).
- > Around two thirds (66%) of respondents selected *Connection: enabling meaningful personal, social, and community networks*.
- > Just over half (55%) selected *Experience: people can feel positive about their everyday life* as one of their three top choices.
- > *Growth (supporting people to grow skills and knowledge required in everyday lives)* and *Contribution (supporting people to contribute meaningfully to their communities)* received 50% and 36% support respectively.

3. Measuring progress

600+ comments

Respondents were asked: *We want to find ways to measure our progress towards the outcomes and wider benefits described above, what would tell us that things are improving in your life?*

Individual person's wellbeing markers (162)

The most frequently identified potential markers of improvement in disabled people's lives were related to personal wellbeing. People often framed this as an absence of undesirable factors (including stress, crisis, burnout, frustration, depression, and hardship) but as often, they stated that the presence of aspects such as happiness, functioning well in everyday life, joy, feeling calm, feeling positive, good relationships, and confidence of care were good markers for measuring progress.

Disabled people reporting increased wellbeing and satisfaction with their lives.

Reduced crisis points, such as fewer emergency requests, fewer last-minute escalations, and earlier access to navigation, respite and one-off supports.

Quality services are demonstrated by improvements in a person's life, including increased independence, meaningful relationships, participation in their community, achievement of personal goals and a greater sense of choice and control.

We would know it at system level too: fewer avoidable hospitalisations, better primary care access, less unmet mental health need, less loneliness, improved family wellbeing, better food security and reduced hardship.

A key point that came up repeatedly was the importance of relationships as a measure for improvement. Functioning and flourishing relationships and having social interactions with people, groups, and the community were all noted. Many people added that each person's own aspirations, situation, and goals will differ, in which case success should be measured against individual metrics.

Measure success through people's experiences of wellbeing, belonging, participation, relationships and personal aspirations alongside traditional service measures.

In our case for our [child] with significant intellectual impairments is a dual level response. For us, we are resourced and informed to be able to give him a good life, without sacrificing (further) the quality of our own lives (work, financial security) to meet his needs. For him, he would have opportunities in his specialized settings and mainstream, is happy, healthy and appears to be a valued member of community.

I know it is working well when I can fully access and be a part of society.

Success is measured through outcomes such as belonging, relationships, participation, wellbeing, contribution and choice, rather than simply through services delivered.

The system works well – supports are accessible and reliable (133)

Having appropriate levels of support was the second most cited marker of improvement; people stated in large numbers that having support and being certain that they will have support going forward was important. This type of comment ranged from simple requests that basic support be available to commentary around access to support needing to be there, be easy to obtain, be flexible, be readily available, and be appropriate for the person.

It also needs to be easy to access and for the disabled person be confident that the support they need is truly available.

Me and my family are in good health and not really tired from lack of support.

Support is maintained rather than assuming I can internalise skills to self-support.

Not having to spend hours organizing funding, less stress and dealt with quickly.

Fears that support would be discontinued featured prominently in comments: people want to feel secure that support will continue to be available, and that it will not be revoked or altered in life-changing ways. Others argued that proof of improvement would be if it were easier to access support. Continuity of care was also raised in the context of having consistency in support workers, this is discussed elsewhere in this report.

For parents and whānau, support would be working well when they can: Feel confident that their disabled family member is supported by consistent, skilled, and trusted support workers.

I don't have to worry about whether my IF respite will be cut, and what I can use it on...My rangatahi can get funded assistance such as wheelchairs, home modifications, Total Mobility without fearing that those services will be withheld or cut.

Ask and listen to disabled people and their whānau and carers (75)

A sizeable number of people stated that improvement could be measured by finding out from disabled people and their families, whānau, and carers what is required to adequately support them. People urged that DSS should listen to the community, and statements like the following were made alongside “you need to ask us”, “listen to my family’s voice” and “regular check-ins”. The overriding theme of these comments was that the disabled community knows best what is needed, and that progress must be measured against people’s own feedback about how they, and their supports, are faring.

[We] would also recommend checking in with every DSS client regularly, to find out if DSS services are working well for them, and what could be improved.

Disability Support Services should not decide what success looks like. Disabled people should.

Measure good qualitatively alongside quantitatively - do a thematic study.

While consultations were one way that people could feel heard, people also wanted to have opportunities by way of a yearly assessment or questionnaire, “monthly catchups”, a phone call or other personal, meaningful contact method.

Sending a monthly email to my support staff asking if anything has changed for me.

Just ask. There's really nothing more needed. If you want to know how X program is going on, ping the person and ask how they're going. Please do this using a casual tone though - you should not be grading the disabled.

This approach [EGL] uses measurement to track how the whānau is going at different stages of their journey. At the moment the system is based around someone else making a determination of what they think you and your whānau need. It's around the wrong way.

Autonomy and having choice in decisions (69)

A substantial number of comments were made stating that more choice and autonomy for disabled people is an improvement marker. Being independent, having autonomy, “being in the driver’s seat”, being the one to make choices and having these choices respected and acted on were all mentioned.

The ability to be included and the opportunity to have a choice of what supports best suit my needs rather than be dictated to.

Happiness that comes from using funding allocation as we see fit without having to have a plan.

Disabled people are actively involved in decisions about their lives and receive the support they need to make informed choices. Trust that supported decision-making is valued and embedded in practice, ensuring the disabled person remains at the centre of decisions that affect their life.

Choice was most often talked about in general terms, but when specific mention was made, the following aspects were noted: choices in housing arrangement, personal goals, choice of carer/support worker, choice of where and how to allocate funding, and choice in service provider.

Disconnect the funding from outcomes, simply calculate what is required and allocate it; it's the disabled person's role to decide if the outcome is meaningful.

Families, whānau, carers are considered alongside the disabled person (38)

A considerable number of people talked about whānau wellbeing as an improvement or success marker. It was important to these people that families and carers are supported in their role as both family member and carer. The concept of sustainability was used in this context to convey that such relationships can be maintained over time only if all parties are appropriately supported. The responses below follow the question of 'what would tell us that things are improving'.

Reduced carer burnout.

Support does not depend on unrecognised, unsafe or unsustainable levels of unpaid family labour.

Fewer parts of life depend on crisis response or exhausted family labour.

Assessments that recognise whole-of-whānau context, shown through plans that include carer sustainability, cultural identity, fluctuating needs and the cumulative load of supporting multiple disabled adults.

Things are difficult at present (37)

A considerable number of people took the opportunity to note that systems, services, and supports are, at present, lacking and that this – as opposed to being a sign of improvement – is actually an indication that situations are worsening.

Personal situations were relayed as evidence of this, including access to/from homes being restricted due to lack of ramp/lift, cost-of-living pressures resulting in children with disabilities "missing out", and an inability to access supports or services when attempts have been made.

You need people who understand when you are having a bad day - we are only human. Lots of us are stressed out on the daily and on high alert.

Commentary on this topic revealed a sense of dissatisfaction that supports feel fickle or indeed, have been removed, and that such actions have impeded people's ability to conduct their life as they would like to.

Skills development and personal growth (36)

A considerable number of people talked about progress as being evident in a person's development of certain skill, or growth in some area. Metrics such as employment, training, study, creative pursuits, confidence, communication, physical activity, and participation all featured.

Feeling that life is moving in a positive direction and that goals, aspirations, and personal achievements are recognised and valued.

Growth and supported independence. The person develops, maintains or regains skills, confidence, communication, mobility and decision-making capability.

Evidence based skill building, like managing social interactions, managing emotions, etc.

A small number specifically referenced young people for this measure, for example stating that 'support working well' means that aspirations can be explored, such as via education or

relationships, but most comments in this topic referenced that a good measure for improvement is that all disabled people can access meaningful pathways or growth.

Are able to pursue opportunities that matter to them.

Access and removing barriers (33)

A considerable number of people made points related to access: specifically access to schools, education, churches, groups, clubs, communities and employment as a measure of improvement. Barriers and aspects of having a disability that make access difficult were addressed as impeding success, and as getting in the way of growth and development. Statement such as “fewer barriers” and “staying in education”, “access to affordable transport” were all mentioned.

Better wheelchair access in all community spaces such as beaches and being able to access the buses safely.

We know support is working when the person's world gets bigger, not smaller: more people know them, more places welcome them, more roles become possible, more choices are genuinely theirs, and fewer parts of life depend on crisis response or exhausted family labour.

Having the ability to have our children settled in school environments so we have the ability to work.

4. Extent to which outcomes and wider benefits reflect needs of users

Respondents were asked: *How much do you agree or disagree that our outcomes and wider benefits reflect the needs of all people that access DSS support?*

Respondents could select: one option.

- > Strongly agree
- > Somewhat agree
- > Neither agree nor disagree
- > Somewhat disagree
- > Strongly disagree
- > I don't know

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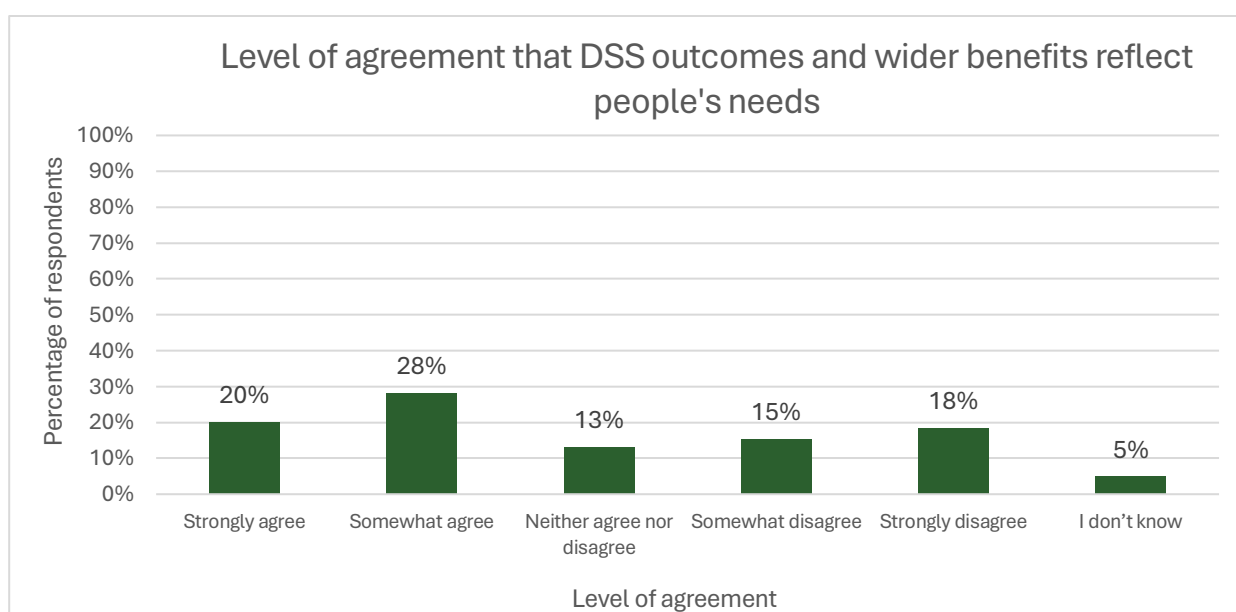


Chart 3: Extent of agreement that DSS's outcomes and wider benefits reflect people's needs

Findings

- > Almost half of respondents who answered this question (48%) *agreed to some extent* that the outcomes and wider benefits identified reflect the needs of people accessing DSS supports.
 - o One in five respondents (20%) *strongly agreed* that the outcomes and wider benefits identified reflect the needs of people accessing DSS supports.
 - o However, a similar proportion (18%) *strongly disagreed*.
- > Over a third of respondents (38%) *disagreed to some extent* (15% *somewhat disagreed*; 18% *strongly disagreed*).
- > A smaller proportion (13%) *didn't have an opinion either way* or stated that they *didn't know* (5%).

4a. Explanation of previous response 300+ comments

Respondents were asked: *Please tell us why you think that (whether or not you agree that outcomes and wider benefits reflect the needs of all people that access DSS support).*

Although there was slightly more agreement than disagreement that the outcomes and wider benefits reflect the needs of all people that access DSS support, people who disagreed were more likely to make a comment to explain their position.

People's needs vary (75)

The greatest number of points made in explanation of answers was that everyone's situation is different and this uniqueness makes it difficult for all needs to be met. In a sizeable number of comments, similar points were made to the effect that a 'one size fits all' approach cannot meet all needs, that no list can reflect the needs of all people, and that everybody is different. Such commentary supports a plan-led, individual response to people's circumstances and needs.

We all need help, but the 'how' differs from person to person and their unique circumstances.

Disabilities are unique to the individual and I find that we are categorised into what suits the service nor the person.

The outcomes need to place stronger emphasis on individual choice, identity, belonging, culture, relationships and having a meaningful life. Disabled people are not all the same, and their needs, goals and aspirations are different.

Commentary that people's needs vary came from across the spectrum of those that agreed and disagreed with the outcomes reflecting people needs. The majority were from those that disagreed to some extent, and few were from those that strongly agreed.

Outcomes not being met (40)

A considerable number of comments were made around the current situation being unsatisfactory or difficult, or expressing scepticism that the identification of outcomes will translate to disabled people getting sufficient support. People stated things such as that they or 'people' get no help/support or not enough support, or that funding doesn't currently meet needs.

Comments mainly came from those that strongly disagreed that outcomes meet the needs of those accessing DSS support; however, several came from survey respondents that somewhat agreed.

As a support worker I have seen the system fail many people over the years. There is a very one size fits all that needs to change. Access to care for those who are disabled seems to vary greatly depending on the disability and many people have had to fight tooth and nail to get what they have, and some are still failing and struggling to get the care they are entitled to.

It is difficult to ensure all needs are met if the funding is not available.

It is easy to create aspirational outcomes. It is not something that is translating into the lives of people who are living in residential services.

You make your decision based on funding and not what is helping and working for the individual.

General agreement that the outcomes are comprehensive (34)

A considerable number stated that yes, the DSS outcomes and wider benefits generally reflect people's needs. They stated that the outcomes align well with EGL principles, that they cover the basic rights for any human being, or that the person themselves are content at present with things and/or have been adequately supported.

Each individual will come with different needs but in general those are the basics.

Because without those 5 outcomes, I wouldn't be able to live the life that I have got.

Several people agreed, but with a proviso, such as that the outcomes need some more (unspecified) work, that though they fit personal situations they may not meet everyone's, and that if broadened to include some other aspects (some of these are discussed below), they would reflect people's needs well.

They are great aspirations, but they need to have more official rights connected to them to have real change.

Current outcomes too narrow (32)

A considerable number of statements around the extent of the outcomes were made; people wanted to see broader application of outcomes that encompass personal goals and needs in life. This ranged from things over and above basic needs such as fitness, life skills and hobbies, to catering for emotional and psychological needs.

Some characterised the outcomes as too simplistic, while others claimed they do not recognise the extent and breadth of needs that exist for people.

The outcomes are very narrow and don't consider the idea of living a fulfilling life for everyone.

They need to better account for people whose disability is complex, invisible, episodic, degenerative, or fluctuating.

It still focuses on increasing capability, very little in the way of supporting low capacity (energy wise).

The proposed outcomes need more detail, clearer definitions and a stronger recognition of families, carers, community, education and the wider systems that influence whether disabled people can genuinely live good lives.

Applying for and accessing support is difficult (27)

People made comments about the outcomes in relation to the difficulties in actually obtaining support, whether due to a lack of information on what is available, or due to interactions with DSS or service providers proving frustrating, unfruitful, or administratively burdensome. They stated things like that it is not easy to get help, that "DSS is too controlling" and that wait times are excluding people from getting support.

There are very blanket rules around support, whilst it is done case by case ultimately the diagnosis appears to dictate the supports one is eligible for rather than the actual circumstances and challenges they face.

Most people I know who access such help don't get complete and accurate information up front. Many are given information that later proves not to apply to them. Hope that's pulled away.

Certain groups are excluded (21)

A moderate number of people described situations in which they, or people they know, are unable to access DSS support and that this is the reason they feel the outcomes and wider benefits do not meet people's needs. Those with hidden or invisible disabilities were noted, people whose needs are not adequately met because of having age-related conditions, and young people whose default carers are their parents were all mentioned.

Opinions differed as to which groups were excluded from receiving support.

Providing correct funding for people with autism will help to ensure that individuals with autism have a better chance of experiencing outcomes 1 and 2 and the proposed five wider benefits outlined in the Disability Support Services (DSS) Bill.

Other commentary

Several people noted that the outcomes and five wider benefits are universal, or are applicable to all people, inferring that this is not something that needs to be applied to people with a disability. Additionally, several noted that the needs of carers and whānau are not reflected in the outcomes and wider benefits. Lastly, several people added that service providers do not necessarily prioritise the realisation of the proposed wider benefits, thus rendering them moot.

The proposed outcomes also do not adequately recognise the importance of choice and control, dignity, long-term stability of supports, and the role of families and whānau, who often provide substantial unpaid care. These factors have a significant impact on the well-being of disabled people and their support networks.

5. Additional thoughts about what DSS is aiming to achieve 250+ comments

Respondents were asked: *Can you provide us with any additional thoughts on the questions you have just answered, or more generally about what DSS is aiming to achieve for disabled people?*

DSS currently not adequately supporting disabled people (55)

A series of criticisms was levelled at the present system for not adequately supporting disabled people. A substantial number of comments were made in which people expressed fears such as that rather than being there to support disabled people, DSS operates as a government entity that prioritises cost-cutting. Additionally, the point was made that the mental health of disabled people is a concern owing to the uncertainty and stress that supports will be withdrawn.

Frustration was expressed at repeated consultations with little tangible change for the better, and some described personal situations in which support was lacking for themselves, a dependent, or a disabled person in their lives. Lastly, the levels of support available for people with a disability was in a few cases compared with what people who have had an accident receive; in all cases the person receiving DSS support would rather be under ACC.

It would be nice if DSS was an advocate for disabled people and supported us through the morass of government agencies that are supposed to "help" us but only make our lives harder.

These outcomes or wider benefits sound ideal, but in reality, government policy over the last three years has systematically undermined all of these.

We also note the significant impacts on the physical and mental wellbeing on disabled individuals, family/whānau and informal carers around the changes of disability support services changes highlighting the need for stable funding and supports.

These comments, offered as additional thoughts on what DSS is aiming to achieve for disabled people, convey a sense of frustration that not enough is being done to assist disabled people to live their lives.

Supports need to prioritise flexibility (51)

A considerable number of comments were made urging that support be flexible and/or able to target specific needs for each person. This was strongly linked with autonomy and choice, and it demands a system that is responsive to individual circumstance. Statements such as "success looks different for different people", "flexibility is absolutely essential", and that the new funding tool "does not treat people as individuals" were made to convey the idea that bespoke and targeted funding models are preferred.

A truly person-directed system recognises the whole person and coordinates support across services, rather than expecting individuals and families to navigate fragmented systems.

Flexible funding should be protected and expanded, not narrowed. Disabled people should not be made to feel like a burden, a cost, or in competition with others for support. DSS funding should help people exercise the same rights and freedoms as non-disabled people, including choice about daily life, relationships, participation, where and how they live, and how they access support.

Navigating system is difficult (35)

A considerable number of statements touched on the experience of navigating DSS systems in general; people wanted to see a system that invites contact, that assists rather than gatekeeps, and one that does not require repetitive completion of lengthy paperwork.

The administrative burden of applications, proof of disability or continual changes in needs was said to add stress to an already stressful situation.

DSS should aim to create a system where disabled people feel safe, respected, and supported, not scrutinised or doubted. The goal should be long-term stability, especially for people with lifelong disabilities who should not be repeatedly reassessed as if their conditions will disappear.

To improve on contacts so we can ask for help.

Funding and support arrangements are fragmented and confusing.

Systems do not talk to each other, ongoing exhaustion due to having to continually advocate.

People wanted to know where to go for support, and they want to be able trust that support will be available without needing to go to multiple departments or agencies. Simplified access to supports and information was the desired outcome.

Support should allow dignity and target improving lives (23)

People talked about having meaningful lives, about DSS needing to make lives easier, not harder, and about support being directed towards improving quality of life. Simple phrases such as “better life” and “not just survive” as well as frequent reference to dignity and strengths-based, mana-enhancing approaches.

It is important that outcomes focus on the whole person and not only on daily care needs or safety. A meaningful life includes having relationships, belonging, opportunities to contribute, learning new skills, being part of the community, and feeling valued and respected.

Listen to disabled people and their support people (22)

Additional thoughts on outcomes that matter for disabled people also brought forth a moderate number that stated disabled people and their whānau should be listened to and trusted to know what they require and how supports should be provided. This encompassed developing systems alongside disabled people, trusting people to use the system honestly, and removing decision-making powers from people who have no experience of disability.

Autonomy and independence are paramount. We deserve to be listened to and respected as individuals with individual needs, and our choices as to what will be of most value to us should have high regard.

I would like to see more meaningful engagement with disabled people, their carers, and their families when designing and evaluating services. Their lived experience is essential to understanding what works and what needs to improve.

Hearing and listening to the voices of disabled people was considered vital if systems and supports are to be effective going forward. It was important of this group that meaningful partnerships were used to progress the aims of DSS.

Needs assessments and assessment omissions (21)

Several people noted that aspects are missing from support as described by DSS; this included spiritual, opportunities to contribute meaningfully (e.g. being able to genuinely connect with people and/or groups), inconsistencies in outcomes from different NASC assessors (including fear of supports withdrawal), and the inability to obtain a review were all noted.

If the primary outcomes are simply "daily living" and "safety", then almost any level of basic support could be considered successful.

I strongly support assessment processes that formally recognise the unpaid contributions disabled people and whānau already make, rather than only measuring deficits that qualify for paid services.

Other commentary

Several people made positive statements about DSS supporting them or stated that the intent of DSS was to be lauded. For example, “I appreciate the hours I get from my support worker”. Several others called for a better trained workforce, often citing that training and experience (or lived experience) in a support role are crucial to the provision of safe care.

Good support work should not be considered an entry level job, disabled people should be able to have access to sufficient and trained workers to provide their care.

Topic 2: A more proactive approach to support

DSS prompts used in engagement

Introduction to survey questions 6 – 8

Alongside the delivery of everyday support, we want to get better at planning for, and supporting, people's needs at transitions or milestones in their lives. These are some examples of when DSS might provide additional or proactive support:

- at key points in the development of children and young people
- when people want to experience greater independence in the community
- support to maintain independence when a condition is progressing
- when people are experiencing the effects of ageing
- when a parent or primary carer's ability to provide support changes
- when people are entering or exiting hospital services.

Relevant workshop discussion points

Topic B: Flexibility of supports: What does flexibility look like for you? And, how might we better reflect this in the services we deliver?

Topic C: Carers: Thinking about the services that DSS provides to carers and whānau, what is missing, or what else could we provide that could support you and your whānau?

Key findings on proactive approaches

Overall summary

Disabled people, carers, whānau and the wider community consistently wanted to see flexibility in supports so that it is easy to upscale support, including at short notice, and that support can be secured in advance of anticipated changes.

So far as service improvements are concerned, people stated that for this to occur, agencies that provide support need to be easy to find (knowing where to go), they need to be easy to make contact with (communicating within a reasonable timeframe), and it needs to be easy to secure places/funding/support (ensuring that contact is made with a person who has decision-making authority).

Survey respondent preferences

- > Flexibility was the most popular preferred change for a more proactive approach, selected by 76% of respondents. This was followed by being able to contact DSS providers to access additional support when needs change (73% of respondents).

What people said

Additional supports at key transition points in people's lives

- > The main suggestion for transition support was to improve people's experience navigating the system by providing a dedicated connector to assist, or by making the process easier generally by improving cross-agency coordination.
- > People also frequently emphasised that there should be proactive monitoring and planning approaches to pre-empt upcoming changes rather than manage them

reactively. Similar proportions wanted to see assessments carried out in a timely fashion and that they be easier to access.

Additional thoughts on the right supports at the right time

- > People frequently stated that early intervention and investment, planning, and proactive communication are key hallmarks of a more proactive system.
- > In slightly lower proportions, people discussed issues with the current system and expressed the need for more timely and personalised support.

What we heard

Provide a key contact, or navigator, to support transitions and help establish plans for the future.

What this would look like for transition support

- > Someone who can provide information about what to expect during transitions, what supports are available, and how to access it – catered to the needs of the disabled person and their family.
- > A dedicated person responsible for managing transitions, to provide practical help coordinating new support when people's needs change or when they age out of (or into) certain services. They would ensure that there are no lapses in support and facilitate smoother transitions.
- > Someone who can help develop a plan with disabled people and families for likely periods of change, including contingencies for emergency situations.

Consolidate and coordinate between services when changes occur

What this would look like for transition support

- > Information-sharing and cooperation between services when things change, or when a person is transitioning from one service to another. Ensuring that multiple relevant agencies can respond from the outset to ease transitions and prevent gaps in support, reducing the need for people to re-apply, re-explain and re-negotiate access to it. This relates to provision of a holistic support system across sectors, such as education, health, and disability-specific services or when transitioning from one support service to another.
- > Transitions can come with uncertainty about which agencies/services are responsible for providing support, for instance when supports change from youth to adult. Clear communication pathways and information about who is responsible for what, as well as what next steps look like could help orient people with a new system: if one agency can't help, then that agency connects people to one that can.

Provide clear information and communicate proactively about what people can expect during transitions, and what support is available

What this would look like for transition support

- > Providing clear information related to transitions in advance, including a complete directory of what is available (ideally one that caters to the individual's context), rather than leaving people to find out on their own.
- > Clearly outlining the steps involved for accessing supports, transitioning between supports, and what to expect or consider during transition periods. This includes guidance for whānau caregivers. An example raised was that DSS could provide a relevant support package in advance of transition points, for instance related to transitions out of education, or into elderly care.

A proactive system should support monitoring, assessment, planning, and early intervention in anticipation of changes

What this looks like for transition support

- > Structured transition and planning support provided in advance of key transition points, so that disabled people and whānau can be assured that support will continue to be available and is catered to changing needs. This includes planning for when caregivers are no longer able to support, or to create a plan of action for potential emergencies. Practical support, clear information and processes, and proactive communication are key aspects of this.
- > Assessment provides a valuable opportunity for tailoring support options and to help plan for when needs change, enabling people to receive the right supports at the right time by informing people about what is possible and actively connecting people to opportunities, rather than serving as a barrier to support. This is contingent on needs assessments being trusted as processes which enable rather than hinder people's ability to secure supports.
- > There needs to be easier access to assessment generally, as well as opportunities for *ad hoc* review.

6. Preferred changes for a more proactive system

Respondents were asked: *In a more proactive system, what would you want to see happen differently from how the system or services work with you now?*

Respondents could select: all that apply.

- > *I have a plan for my disability supports which identifies the milestones or transitions where my needs might change in the future*
- > *My plan is flexible, so more support is available when I need it*
- > *DSS providers contact me or my family to see if I am properly supported at known or agreed milestones or transitions*
- > *I can contact DSS providers to access additional support when I know my needs are changing*
- > *DSS has information available about the additional support that is available during transitions*
- > *I don't know*

n=315

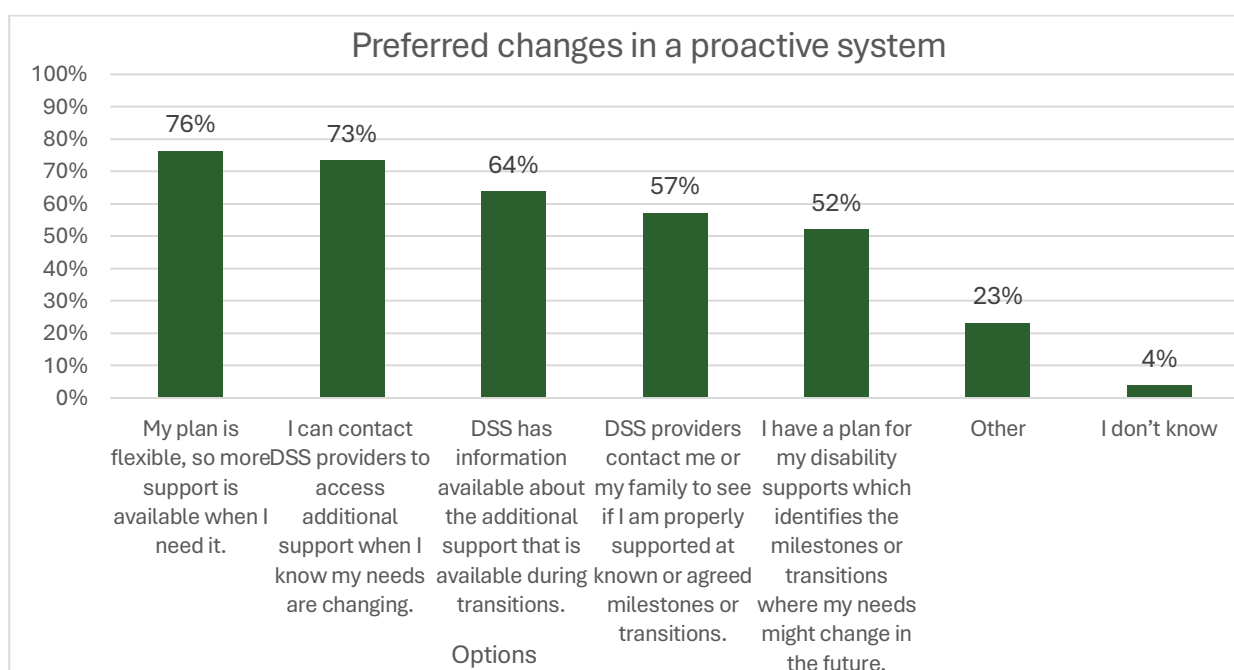


Chart 4: *In a more proactive system, what wanted to happen differently*

Findings

- > *Flexibility* was selected most often, by over three-quarters (76%) of respondents.
- > The next most popular preferred change, selected by 73% was: *I can contact DSS providers to access additional support when I know my needs are changing.*
- > *DSS has information available about the additional support that is available during transitions* was selected by almost two-thirds (64%).
- > Less commonly selected, but still over 50%, were *DSS providers contact me or my family to see if I am properly supported at known or agreed milestones or transitions* (57%); and *I have a plan for my disability supports which identifies the milestones or transitions where my needs might change in the future* (52%).
- > Less than one quarter (23%) of respondents selected *another preferred change.*

Points made by those who selected *Other*.

- Individualised, flexible support that reacts to needs changing (10).

- Recognise whānau context, including the impacts on and labour of family carers. Compensate family carers fairly and provide adequate respite (8).
- Proactive support and information to anticipate major transitions (7).
- Clear information about what support is available and how to access it (6).
- Quicker processes and responses when support needs change (6).
- Having in-person check-ins, a point of contact such as a connector or navigator, that can help when needs change (5),

Other comments made by five people or less included: Make support easier to access generally; directly consult and listen to the disabled person; the current level of support is not adequate; enact Enabling Good Lives; ensure consistency and equity in provision of supports; improve communication and engagement from agencies and service providers.

7. Additional supports at key transition points in people's lives 800+ comments

Respondents were asked: *What additional supports could DSS provide at key transition points in people's lives? For example, one-off funding to invest in technology, facilitative support that aims to reduce over time, assistance with navigation, planning, and connection.*

General suggestions for transition support (496)

Inter-agency coordination and support navigating system (84)

The largest amount of commentary regarding transition support was that around the need for assistance with navigating existing systems. This was often generally described as “navigation support”, or assistance connecting to other services. Comments noted that this is a particularly important service during transition periods, when things are changing and steps going forward are uncertain. These comments also alluded to or directly described difficulties experienced in navigating current systems.

A lot of it is finding the right people or agency who can help. There are so many agencies that it's a nightmare plus there are too many in some physical locations and nothing in others. A lot more could be done to get things online in ONE spot.

Comments tended to either focus on improving navigability at the system-level, by improving system-wide coordination between sectors, or by providing a dedicated support “navigator” or “coordinator”. This was described as an individual who understands the specific needs of the disabled person and their family and is responsible for helping them access and understand what supports are available to them.

DSS should fund trusted navigators who build ongoing relationships with disabled people and whānau, helping them understand their options, make informed decisions, access the right supports at the right time, and navigate changes in circumstances. Effective navigation reduces stress, inequity and unmet need, ensuring people can confidently access the services and supports they are entitled to without having to become experts in the system themselves.

Just someone to talk to about it and get information and walk beside me support.

Comments emphasised that the relationship between the navigator and disabled person should be a positive, enabling one, based upon helping people access support rather than being a barrier to it.

Just as important was the role of assessors, service coordinators, and navigators. CAG members want staff who listen, understand their circumstances and work alongside them to plan for the future. Their role should be to help people navigate the system, not to act as gatekeepers to it.

Monitoring and planning (61)

A substantial number of people generally wanted help with planning for transitions and supported a proactive approach. The main point being that change should be anticipated and planned for rather than managed reactively, or ‘once a crisis has occurred’. Comments maintained the importance of plans being individualised to the person and being developed alongside the disabled person and their family. Comments also directly referenced this idea as giving effect to EGL’s proactive, early intervention approach.

DSS should also support person-centred planning (that is not restricted to planning paid support and funding allocation). This is identified as best practice by international research. Planning could help disabled people and whānau identify what matters to them, strengthen natural and community supports, build relationships, and make choices about the lives they want to lead. This broader approach would better reflect Enabling Good Lives by recognising that good planning is about self-determination, belonging, and ordinary life outcomes, not just funded support.

This idea prompted a variety of suggestions, including that DSS should actively reach out to families in advance of predicted transition points, incorporate regularly scheduled reviews, or that investment should generally begin “early”. At times, people described a distinct ‘planner’ role, in a similar vein to or incorporated within the role of ‘navigator’.

Proactive check-ins at known milestones (e.g., leaving school, changes in health, carer stress points, housing changes, employment shifts) so support can adjust early.

To be proactive, the DSS systems must develop their resources and processes to include a. All people supported by DSS having access to a person who knows them and their situation and is in regular contact to engage in conversations to detect upcoming changes that can be proactively reassessed and supported. This is the purpose of the EGL connector/tūhono, and if available to every disabled person (whether with a NASC or EGL), DSS would ensure every person has access to a more proactive approach to support.

Facilitator commented as below, with general verbal agreement from participants: “So, I’m hearing you say that maybe a dedicated package or established practice for transitions like leaving home, school or going into residential care. And a plan and supports for when parents get older.”

People also made the point that many of these transition points can be reliably predicted, such as for young people aging into or out of education. There was also general support for predicting possible future changes or ‘trajectories’ in health and disability.

Families often recognise these changes well before additional support becomes available. A proactive disability support system should therefore plan alongside disabled people and their families before predictable transitions occur, rather than requiring repeated reassessments after circumstances have already deteriorated.

Proactive planning should consider the person’s complete disability, health and wellbeing needs, including how these may change over time, rather than responding to each issue in isolation.

Assessments should be funded and timely; Issues with NASC (58)

A substantial number of people advocated for easier and more timely access to assessments to improve the responsiveness of supports to changes in disabled people’s lives. Comments generally emphasised that the responsive support required during transition, makes timely, accessible assessments a necessity.

Providing more timely assessments, especially for equipment and housing modifications and following assessment, provision of equipment and carrying out housing modifications in a timely fashion. Currently, the lag in assessment and provision means disabled people often spend some years unable to move at home or in residential care.

A considerable number of these comments included direct criticisms of NASC and current assessment processes, particularly the waiting time to get assessed and the lack of timely communication from staff. This was often described as “reactive” as opposed to proactive and alongside the comments below, indicates a desire for timely assessments, quick response times from NASC, and an approach from NASC coordinators that is more sensitive and empathetic to the needs of the person they are interacting with.

The way assessment has changed is good. But waitlist to get assessment and reassessment is taking too long. People shouldn’t be waiting 8+ months for their first assessment even for their reassessment.

Other less common critiques included the administrative workload, lack of adequate staff training or knowledge about certain disabilities and health conditions, and issues with the general approach of the assessment or the communication style of the assessor.

Only moved because in crisis. Took an entire year to re-establish due to different NASC process. Had to go into all the details to re-establish support [this was] traumatising. NASC assessors need a lot more training...A lot to be done around staff being trauma informed, culturally responsive. Need relationship building over multiple years.

Support needs to be responsive and flex with need (57)

A substantial number of people described the importance of flexible supports when undergoing transition periods, expressing that the system needs to respond quickly when people's circumstances change. Comments also noted that greater autonomy and more flexible funding rules would allow people to respond accordingly as changes occur. This overall point about what good support during transition periods would look like relates to the previous critiques of assessments as slow or inaccessible. People also made the point that important changes, such as emergency situations, were difficult to predict and therefore accessing support to cope during these periods needs to be quicker and easier to access.

Disabled people in the community have a hell of a hard time accessing anything in the community as most of it is still catered to the non-disabled. Funding should be flexible enough so that the person gets what they need and should have access in addition to one off supports such as bulk funding for specialised education that is unfortunately way under supported in the mainstream system.

Greater flexibility in funding during transition periods would also allow people to respond to changing needs without unnecessary delays or administrative barriers.

Flexible support was also supported by the point that everyone has their own unique needs and circumstances, requiring an individualised approach rather than a prescriptive one. Several people made the point that some people will require more extensive and ongoing support, and the expectation that supports should decrease over time is unrealistic.

Assistance and support does not always reduce over time. Some of us have progressive debilitating conditions which worsen over time and require more support as time goes on. DSS needs to acknowledge this and make it less fraught to ask for, and receive, additional support. It is very humbling and frustrating to have a condition which deteriorates. It shouldn't be made harder to struggle and fight for extra support as needed.

Assistive technology and therapies (57)

A substantial number of respondents expressed support for DSS funding assistive technologies, modifications, and various therapies for key transition points. It was often noted that this kind of early investment reaps significant rewards in quality of life and future outcomes, as well as mitigating potential negative outcomes. Consistent with other topics, commentary emphasised that this should be offered proactively to prepare for changes or that such supports should be easier to access generally.

Invest early in assistive technology and home modifications, on the evidence that timely investment usually reduces the need for higher-cost residential or in-home care later.

Mobility vehicles are a huge one. accessible housing and accessible kitchens and hoist equipment and things would be a huge help in needing less support.

While some comments expressed support for "one-off funding" for technology, others advocated for continual investment, stating that ongoing maintenance, training and technical support may be required. Comments also frequently indicated support for funding of technology or other specialised therapies without mentioning the type of funding model.

For people with vision disabilities, support could include access to one-off funding for technology, equipment and tools that increase independence, participation and confidence.

It is important to realise that while technology and assistive devices can be life changing for many disabled people, enabling independence and freedom, it will also need to be repaired or replaced over time as the technology or device becomes outdated or wears out or is outgrown. Losing access to technology and assistive devices such as a power wheelchair after building your life around it is extremely harmful. Support needs to be provided to maximise the benefit of any new technology which may require rehabilitation, training or upskilling.

People also made specific suggestions for the types of technologies they would like to see funded, or specific considerations that should be made for different groups.

I want to say that I think assistive technology that currently comes under the job and training support funds, at least for blind people, should come under DSS. This is because often if we need a braille display, we need it in general, not in some way that is only tied to work or study, and not having this access often also inhibits our work or study possibilities. So, for example, after high school that would be a key time that it would be good to check if a blind person needs more assistive technology.

Information about what to expect and what supports are available (46)

A considerable number of people expressed the need for more information about what supports are available and what to expect during periods of transition. This was mostly framed as navigation assistance, with people requesting clear information about how the system works, as well as where and how to access supports, for instance when people transition out of services and into new ones. Diagnosis was also noted as an important time for people to have access to clear information and to be introduced to the system.

It should tell us which government departments you can go to for different life stages, which funding that is available and who does what. People starting these journeys have no idea.

Much clearer information that tells people what is available rather than us having to find out about it from other disabled people or their carers.

People reported experiencing gaps in communication and support provision, generally struggling to find clear information about what next steps are, where to go, what to look for and what services are offered. Several suggestions were given, the most common being that DSS establish a source of clear information, and to proactively contact disabled people or their family to inform them about their entitlements.

Proactive communication from NASCs and DSS would help prevent situations where people are left without support because they didn't know they could ask for help.

Write down the options available and share it to everyone. At the moment it's "need to know". What really happens is that the providers say they will do things, which they do for the easy cases and the hard ones, like the ones who are so mild they don't get noticed, or so complex they scare providers off, get dropped. I heard the government services call that "unders and overs". It's a way they just basically stonewall you until you give up. They just help the ones that fit the formula easily.

Support for carers and family (38)

A considerable number of people proposed that carers, including family carers, should be supported and their wellbeing monitored during transition periods to prevent burnout and give opportunities for respite rather than providing this reactively, or after a crisis occurs. Suggestions were also given for allowing trials and flexibility in respite options, so as to make them easier to access. Note that these topics are explored in further detail in Topic 4: Better support for carer respite and breaks.

Support for family and whānau carers, including information, training, respite, and planning assistance, recognising the vital role they play in sustaining disabled people's wellbeing.

I need DSS to prevent crisis, caregiver burnout and unsafe situations before they occur, especially for whānau Māori like mine who carry high levels of unpaid and under-recognised support

A specific point related to transition support was that these periods can coincide with increasing responsibilities for carers, such as when a person has increased health needs or when a person ages out of school services. People generally suggested that someone should check in with caregivers during these periods or generally ensure that support is available to them.

Support for carers at transition points is critical, especially when a parent or primary carer's health changes, or when caring responsibilities increase suddenly.

People also articulated the need for carers and family to be provided administrative help with transitions, making points consistent with the above topics: information about what to expect and what support available, better inter-agency coordination, and support navigating system.

Support for families and carers: Transitions create a substantial workload of research, meetings, correspondence, form-filling, travel and coordination. In our family, this work falls mainly to me and reduces my capacity for paid work. DSS should provide practical administrative help and flexible respite during major transitions, rather than relying on families to absorb this work without recognition.

Additional one-off or short-term funding (33)

A considerable number of people were in favour of a short-term increase in funding, or provision of one-off funding generally to accommodate for changes. Most of these comments were general calls for “short-term”, “intensive”, or “one-off” support adopted as needed.

Short-term facilitative support that can be scaled up or down as needs change.

Comments echoed similar points relating to the need for support to be flexible and responsive, suggesting broad funding categories for needed technologies and modifications, extra staffing support, or for sudden emergencies or other changes.

Flexible short-term funding and follow-up support after major life changes would help ensure people do not experience gaps in services during periods of transition.

Other topics

Several people generally expressed support for the examples of transition support indicated in the question prompt, for instance stating they would like to see “all of the above”.

A similar proportion of comments called for DSS to ensure that transition support and planning is responsive to individual cultural needs.

When to support (309)

Along with general comments and suggestions, people noted specific transition points at which they would like to see additional support offered. This often came with suggestions of what support should look like at these times.

Changes in health and disability needs (43)

A considerable number of people highlighted that extra support is often required when people experience a change in their health or disability status. Many of these comments simply noted this as a key transition point, often within a list of points to consider in relation to providing extra support.

Better support when a person's health, mobility, caring responsibilities, or family circumstances change.

Comments included a variety of specific considerations related to this topic. The first is that people should develop specific plans for or receive extra support during hospital admission and discharge, including transport to and from hospital.

Times of illness are when most people struggle the most, with many of us preferring to get well at home rather than going to hospital, however very few of us have the support hours needed to cover 24/7 care and the only option then is hospital where we are fully reliant on nursing support. You go to hospital to recover from surgery or severe illness and not because you have a disability, with your equipment and care support not available to you throughout your stay as these are for independent living at home.

Consideration on how we are financially drained for regular travel to hospitals for scheduled treatments.

Transition out of hospital was noted as a point where people may struggle to keep continuity of care. People also talked about the need for funding to access rehabilitation services outside of immediate crises.

People living with disabilities should have equitable access to rehabilitation services to address disability-related needs that impact their ability to participate in everyday life. Just as ACC funds rehabilitation for individuals with long-term injury-related impairments, people with lifelong disabilities experience changing functional needs over time and require access to targeted rehabilitation to address emerging barriers to independence, safety, and participation.

Repeat hospitalisations. Each admission is a de facto transition. Discharge planning is a persistent weak point.

Another point was that it is particularly important for sudden health changes and emergencies to be accommodated for, precisely because they are difficult to anticipate. During these periods, support needs to be particularly responsive and easily accessible.

Change in health – it's very important that the system is flexible to quickly meet the changes – e.g. a nasty fall because you are low vision means you need more support while you recover.

Conversely, people also described the importance of proactive planning for those whose health and disability changes are slower or more predictable, such as those associated with degenerative conditions. People also generally noted that changes may require increasing support worker hours and related funding allocated.

For me my personal care is important in keeping me well. I am only allocated 4 hours a day of support, and there should be two people for those 4 hours but often [I get] only one. Home care is very different to a medical model regarding the time it takes to do personal care. In a medical or hospital setting all the equipment and tools are there, but in a home setting that's not the case and therefore things take longer.

Diagnosis and early progression. From walking to wheelchair use over a few years. There was no facilitated planning conversation. My family and I worked it out on our own, from Google and from other MS whānau.

Finishing education (41)

A considerable number of people generally noted that finishing education, or aging out of education services, is a key transition point where people need more support and guidance. People noted this as a gap within the current system, describing a general lack of services and support options available once a disabled person has left the school system.

The current system and funding for transition from school is inadequate and does not meet the needs of either young disabled adults or their family in my experience. This system needs complete overhaul and investment to better meet the needs.

Carers often raise the issue of support provided at school, which stops when they leave school and they and their family member are just left adrift. (e.g., no more speech language therapy, no occupational therapy etc.) This 'falling off a cliff' is not acceptable.

Within this group of comments, general calls were made for an increase in assistance, funding, and available opportunities to accommodate this transition and compensate for supports that were suddenly dropped for their being tied to education services. Comments also touched on a lack of support for young people leaving school and entering employment, although others noted that this shouldn't be the only option available.

When you leave school, the system needs to change to help transition out of school into life after school, tertiary studies and employment.

Something, anything, for our kid to transition into after school finishes. There are no services, nothing for them to go to, no plan and apparently no money unless they are training for employment? What about our kids who may not ever be employed? If there are no local services because the govt has cut all the funding for community groups, that is not helpful.

Carer no longer being able to support (39)

A considerable number of people expressed the need for stronger transition planning for changes in carer circumstances, or for when a primary carer passes away or is no longer able to carry out care work. Parents and primary caregivers expressed worry thinking about what would happen to their disabled family member if they passed away without a good plan for what future support would look like.

And at the other end of life, we are aging and what will we do? There's no plan or information out there about how to make this work. We tried residential care for [name] but it didn't work for her – her life just got so small. And she was abused (by another resident). At some point we won't be able to carry it on. How will we make it work. Who will help us make it work?

People also noted that a carer's capacity may reduce over time, for instance, if a family carer becomes sick, or too elderly to provide the required support, or if they need to attend to an immediate family member. Overall, people expressed a need for proactive, accessible planning assistance, and accessible respite options for temporary changes in carer capacity.

When a carer is aging and cannot provide the same level of support, there needs to be an easy-to follow process on how to prepare for this transition. What legal steps can be taken to ensure their loved one is safe and taken care of when they are gone. Have a facilitator in place to help put a plan in place for this transition. Make sure the plan is flexible because people and their preferences can change.

Employment (35)

A considerable number noted in general terms the need for specialised support when transitioning into or out of paid employment. People often felt there was a need for intermediary and supported employment options for those trying to enter the workforce, including providing specialised supports for people with certain disabilities. This was particularly noted as a gap for young people, including those leaving school.

Assistance into meaningful paid employment. Most places like WINZ are not aware of what different disabilities need as support in the workplace.

More proactive support around helping young people move from school to employment (including financial support for autistic people who take longer to find employment that works for them) would be very beneficial.

A couple of comments noted that there was more support needed for the transition out of paid employment, and accessing public support services.

Personally, I fear losing my paid employment after 30+ years and having to transition back to a benefit lifestyle, especially as I age slowly towards the 'older persons' support services, and I wonder how DSS could be positioned to better support people to not only access available supports but to position themselves as paid mentors to young disabled people seeking employment without it impacting negatively on their financial situation?

Moving out and leaving home (31)

A considerable number of people noted changes in living arrangements was an important time for DSS to provide transition support. This was particularly emphasised for people moving out of their family home for the first time into a residential facility or into a flatting situation.

I previously lived at home, now live with my partner. Big life change. Transitioned from home with Mum and Dad. I had good support previously. Used to do housework, going to work, and to the gym. Biggest change since flatting – feels the support is not as good now.

Entering education (29)

A similar proportion of people discussed entering education as an important time to receive transition support. These comments also tended to express that transitions between education stages, such as primary school to intermediate, as well as transitions between schools were also important.

When you're trying to enrol a physically disabled young child and get told they can't attend pre-school and the only way to get it is to go through a private organisation like Montessori. It's the education system. Pre-school, access to school - and then leaving school, there's the black hole.

Other transition points

A moderate number stated that transition support was needed in transitions to adulthood, or in adolescence (e.g. where social, emotional, and behavioural needs might be changing).

A moderate number of people discussed the need for transition support to facilitate independence, life skills, as well as working towards the specific aspirations of the disabled person. Several comments indicated that support needed to be provided for elderly disabled people, including coping with disability changes that come with aging, support to remain living independently, as well as accessing supports available to older people generally.

Other transition points noted in several comments each included support getting out into the community, transport support, and support around diagnosis.

8. Additional thoughts on proactive support

300+ comments

Respondents were asked: *Can you provide us with any additional thoughts you have on the questions you have just answered, or on how we can better provide the right support at the right time?*

Support for early intervention, planning, a proactive approach (52)

A considerable number of people advocated for a more proactive approach to support, further specifying that planning, proactive communication, and early intervention are the key actions needed to achieve this. This idea is equivalent to that expressed in the previous question's topic: monitoring and planning. Along with admonishing the current system's 'reactive' approach, people expressed in generalised ways that DSS should provide support, invest, and check-in early, focusing on prevention and anticipating future changes to better embody a proactive system.

A more proactive system should identify and respond to changing support needs before individuals and families reach a crisis point. This could include reducing delays in funding approvals, providing earlier access to specialist supports following diagnosis, and ensuring families receive timely information about available services and supports.

Giving the right support at the right time is about constant communication and being proactive with support, not reactive

Comments voiced a variety of ideas for prevention, including supporting disabled people and their families to establish a plan for likely changes in the future, as well as contingencies; generally reaching out to people and providing extra assistance in advance of predictable life transition points, such as entering or leaving education; providing more extensive support for young people; taking a wider view that includes the sustainability of the whānau context and preventing burnout in carers; and developing a plan for increasing supports as people age or their condition progresses.

I think having a plan for my disability supports which identifies the milestones or transitions where my needs might change in the future, needs to include that the plan is flexible and can change easily as needs change, and is used as a guideline to the person's support rather than a fixed plan of action.

Many of the changes that affect support needs are predictable, including educational transitions, changes in health, ageing carers and significant life events. Planning for these changes before families reach crisis is likely to improve long-term outcomes while making better use of public resources.

In select cases, people also gave specific suggestions for how to identify transition points, such as the following comment:

A proactive system requires two data foundations DSS does not currently have. The first is a defined clinical and functional trajectory for each condition category, agreed with clinicians and lived-experience representatives, so that anticipation is grounded in evidence rather than guesswork.

Issues with current system and accessing supports (42)

People related experiences of being passed between agencies, difficulties to stretch limited funding to cover personal needs, being denied support, carers experiencing stress and burnout, waiting excessive periods for assessments, and generally being confronted with an inflexible system at every turn when trying to attend to needs that are dynamic.

Everything about my experience of DSS over twenty years has been reactive. My needs assessments have been triggered by crises: a fall, a hospital admission, a piece of equipment breaking down, my partner burning out. Each one required

advocacy, phone calls, letters, and long waits. By the time the reassessment was done, the crisis had passed or become the new baseline.

These accounts were diverse, representing a series of concerns related to challenges accessing support, knowing what support is available, knowing how to access support, carer-specific problems, and problems with NASC; each of these are expanded on in their respective sections of this report.

The overall tone of comments was reproachful of the disability support system, corresponding to the difficulties and constant changes reported. There was also a sense of anxiety evident about whether things would become more difficult or if supports would be taken away entirely. For primary carers, concerns extended beyond these to what would happen to their loved one once they were unable to care for them.

You could provide certainty about what funding is and when. I support a daughter with complex needs, we have no certainty. our family is falling apart. we are literally too scared to ask for more funding because we are told it means you might take it away.

With so many changes over the last 2 years fear and anxiety are rising. I have even heard older parents say they will have to take their disabled adult child with them when they pass away. A frightening thought in what is supposed to be a caring decent society... Change is a challenge for any family but especially scary for those with a disability and their families.

Flexibility and responsiveness of supports (40)

This topic complements the previous; people shared their aspirations for a responsive support system that attends to the fluctuating and individualised nature of disability needs. People were left with the impression, from their own personal experience or that of their community, that the current system denies this reality. While timeliness was the most emphasised outcome generally, people also made the point that more day-to-day control and choice over what supports are provided, and at what level, coincides with support that responds to individual needs “at the right time”, rather than relying upon a person’s effort, knowledge, and any external assistance they may receive to negotiate the system into providing it.

Funding should follow the person and families should not have to be constantly worried about funding reductions with every change to DSS.

Please understand what people plan for their life, is rarely what happens. Please ensure that a quick response can be needed at any stage of life.

The right support at the right time can be done with more flexibility of the funding. Give the disabled and their carers the right to choose over their own lives and you will have way less admin. Autonomy and respect are what we need, not more rigorous micromanagement.

Provide dedicated navigation support (31)

Consistent with previous suggestions to make accessing support an easier experience, a considerable number of people agreed that DSS should provide dedicated assistance. People requested either generalised help for specific tasks, such as for applications and planning, or described an individual role, variously labelled a “navigator”, “connector”, “case worker”, or more specific to this topic, a “transition coordinator”, to help people access support generally as well as provide assistance for any changes in people’s lives. People expressed the desire for someone who knows their situation to “check-in” to ensure that they are managing changes and can access the support they need.

Need a trained workforce who have in-depth knowledge of the meaning of Transition, a personalised approach and a knowledge of community opportunities.

If you want whānau and disabled people adequately supported there needs to be a clear designated person/s that can support the whānau through these changes,

because I would assume it can become overwhelming for MOE, MOH when they do not have the answers the family seeks.

Listen to, respect choices of disabled people and their families (22)

A moderate number of people stated that listening to disabled people and their whānau would help people receive the right support at the right time and improve outcomes for the community generally. People often encouraged a perspective where disabled people and their families are positioned as the “experts”, and who “know best” their own situations, how to be supported during changes, and what support should look like. At times, this sentiment was related to specific aspects, such as needs assessment or the use of funding.

You need to listen to disabled people and their families. they are the best people to decide when transitions need to happen, are happening, or milestones need support and where to go from here. I think people need to listen more to what we are asking for as we are the ones who know best what we need in order to live a life where we feel connected in a way that works for us and can contribute as much or as little as works for us.

Listen to us, investigate from our perspective (no off pat answers, dictating, or just saying "NO" like some NASC persons do).

Information should be easier to find, and be clearer (22)

Another point of improvement noted in moderate numbers was that DSS should provide more clearly articulated information that reaches a broader audience than it does currently, as well as proactively communicate with people about what supports are available or what to expect during changes. While comments on this topic, consistent with a similar theme in the previous question, often requested information and communication specific to transitions, many comments expressed this need for clear information and processes more generally.

Information should also be provided automatically during transitions rather than expecting families to know what questions to ask. When someone receives a diagnosis, begins receiving disability support, starts school, leaves school, enters adulthood, moves into independent living, experiences changes in health, loses a parent or primary carer, or enters hospital, families should automatically receive clear information about available supports, funding, legal responsibilities and future planning. Families should not have to discover these things by chance.

Other commentary

A moderate number of comments were in favour of consolidating processes and improving coordination and information-sharing across agencies to make accessing support easier. This idea is recurrent throughout engagement feedback.

The second is a common client-held record accessible across DSS, Health New Zealand, ACC, and MSD, so that a change in one is visible to the others. Without those, 'proactive' will remain a slogan.

A similar proportion of comments made the point that a more proactive system would conduct more regular check-ins and opportunities for assessment to get a better idea of what kind of support is needed.

Better checking in with me and my support network. Sometimes I don't know what to ask for because I don't know what is available.

A similar idea, shared by several people, was that establishing contact with DSS should be easier, including that DSS should proactively reach out to people, and generally adopt an enabling and positive relationship.

Be available, be kind and understanding, attend meetings with us. Make us feel like we have someone alongside us not on our own.

Several other people advocated for more involvement from the disability community in making system-wide decisions, as well as making support more culturally responsive.

Topic 3: Better feedback and complaints processes

DSS prompts used in engagement

Introduction to survey questions 9 – 17

We want the services we fund, that are delivered by providers, to be the best they can be. To do this, it needs to be easy for you to tell DSS-funded providers when things go well.

Relevant workshop discussion point

Topic D: Information and advice, feedback and complaints: How can we improve the way information flows both ways so it works better for you – both when you're seeking advice or support, and when you want to give feedback or make a complaint?

Key findings on feedback and complaints

Overall summary

Feedback and complaints were typically addressed as a process that is engaged with as a last resort – people do not want to have to make a complaint. However, if/when feedback or complaints are activated, people want the process to be easy to engage with, respectful of the issues raised, and, they want to see that the feedback or complaint has been acted on (e.g. via visible changes or resolutions). Complaints and escalations processes were not well known.

Importantly, disabled people in many cases sought acknowledgement that making a complaint can, in and of itself, prompt fears about the ways in which relationships between the disabled person and the provider/ support worker/carer might be impacted. It was evident that very real concerns exist about the possibility of supports or funding being downscaled in the event of complaints being made – this adds weight to the arguments for building trust in relationships, for offering regular opportunities for feedback (so as to reduce stigma around making contact) and for the provision of independent advocacy.

Survey respondent preferences

- > **What matters most when receiving support:** Though not directly related to feedback/complaints, more than three-quarters of survey respondents each indicated that *reliability* (78%) and *choice and control* (77%) matter most to them when being supported.
- > **What matters most when feeling safe from abuse and neglect:** The greatest proportions of survey respondents indicated that *being listened to and taken seriously* (56%) and *being treated with respect and dignity* (55%), were the most important aspects when thinking about feeling safe from abuse and neglect.
- > **Awareness of how to provide feedback about services:** 39% stated they *know this process*, 33% indicated they *don't know*, and over a quarter (27%) were *unsure*.
- > **Awareness of how to make a complaint about services:** 39% of survey respondents indicated they *know how to make a complaint*, almost as many (37%) stated they *don't know*, and 24% indicated they were *unsure*.

- > **Awareness of how to escalate complaints:** 28% indicated they *know how to escalate complaints*, while almost half (47%) indicated they *don't know*, 25% indicated they are *unsure*.
- > **Thoughts on a regular feedback survey:** 68% of respondents were in favour of this to some extent (37% *strongly* and 31% *somewhat*), while 17% opposed the idea (6% *strongly*, 11% *somewhat*).
- > **Preferred methods for providing feedback:** The most popular preferences were *email* (45%), *disability advocate or support organisations* (40%), and *talking with a team leader or manager* (36%).

What people said

What would give confidence in a DSS provider's complaints process

- > The main factors people identified in a complaints system they can have confidence in is a complaints process that it is easy to understand, easy to access, and easy to engage with.
- > People also wanted to see a system that is impartial, independent, transparent, and thorough; one where outcomes are known and changes are made as a result of feedback. People sometimes suggested independent advocacy.

Additional thoughts on feedback and complaints processes

- > Consistent with responses to the above question, people expressed the need for a feedback and complaints system to be easy to access and use and to outline a clear process.
- > People also were in favour of DSS providing regular opportunities for disabled people to provide feedback about the services they receive.

What we heard

Due to highly formalised processes and lack of knowledge about how to go about it, it can feel intimidating to provide feedback or make complaints

What this would look like in an improved feedback and complaints process

- > Normalising giving feedback could assist the creation of communication pathways where disabled people feel comfortable and are more likely to raise issues.
- > A feedback and complaints process needs to be easy to find, easy to activate, and easy to track progress on; this might mean visibility on DSS materials, accessible formats, and sector-wide promotion of and knowledge about processes.

There is a lack of trust in current feedback and complaints process

What this would look like in an improved feedback and complaints process

- > Additional measures to protect complainants from retribution and ensure continuation of support, for instance regarding confidentiality. Improving people's confidence by detailing the process involved to prevent harm.
- > Ensure that complaints and feedback pathways are impartial and independent to the provider, including options for independent advocacy support.
- > Communicate with the person giving feedback throughout the process. This includes any outcomes reached, feedback on the process and outcomes, and meaningful pathways to escalate or review.

9. What matters most when receiving support

Respondents were asked: *Thinking about the support you receive from a DSS provider now: what matters to you most when you are being supported?*

Respondents could select: up to five options.

- > Reliability
- > Consistency
- > Responsiveness
- > Safety
- > Choice and control
- > Care that reflects your culture and values
- > None of these
- > I don't know
- > Other

n=258

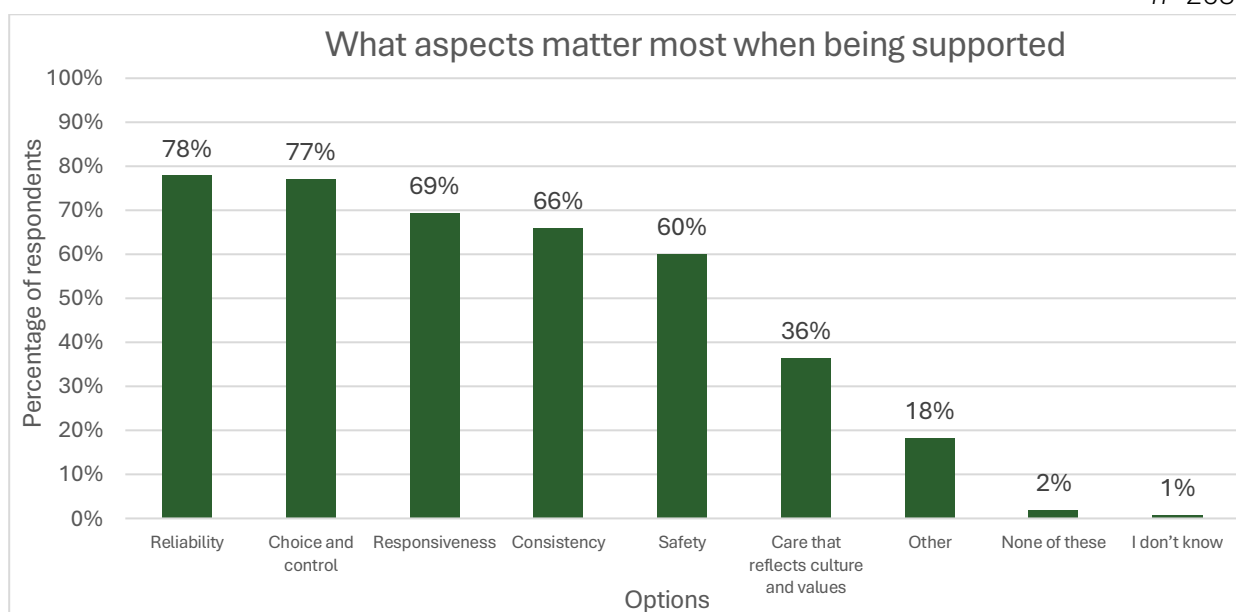


Chart 5: *What matters most, when considering support from a current DSS provider.*

Findings

- > Reliability (78%), Choice and control (77%) were each selected by more than three-quarters of respondents who answered this question.
- > Responsiveness (69%) was also frequently selected as an aspect that matters most when receiving support.
- > Two thirds of respondents (66%) selected Consistency.
- > Safety was selected by over half of respondents (59%).
- > Care that reflects your culture and values was selected the least frequently, by over a third (36%) of respondents.
- > A very small proportion of respondents selected None of these and I don't know (2% and 1% respectively).
- > Under a fifth of respondents (18%) indicated another aspect that matters most when being supported.

Points made by those who selected Other.

- Staff are kind, respectful, and honest (9)
- Individualised support that reflects needs (9)
- Accurate, clear and timely information and communication from DSS (6)

- Autonomy and flexibility with support and funding (5)
- Staff are skilled, trained, and knowledgeable about my disability/condition (5)
- Need a sufficient level and quality of support (5)
- Fewer than five respondents selected that the following as important:
Support being easy to access; Certainty and knowing support will be available when needed; All of the above.

10. What matters most to feel safe from abuse or neglect

Respondents were asked: *When you think about feeling safe from abuse or neglect in disability support services, which of the following are most important to you?*

Respondents could select: up to five options.

- > *Staff treat me with respect and dignity*
- > *I am listened to and taken seriously*
- > *I can access a process to restore the relationship*
- > *I can make my own choices and decisions*
- > *My cultural needs are understood and respected*
- > *I feel comfortable speaking up if something is wrong*
- > *I know how to raise a concern or complaint*
- > *I trust that concerns will be acted on*
- > *Staff behave professionally at all times*
- > *I am not afraid of consequences if I speak up*
- > *My whānau or trusted people are welcomed and involved*
- > *I receive support in ways that feel safe for me*
- > *Other (please write)*
- > *None of these*

n =258

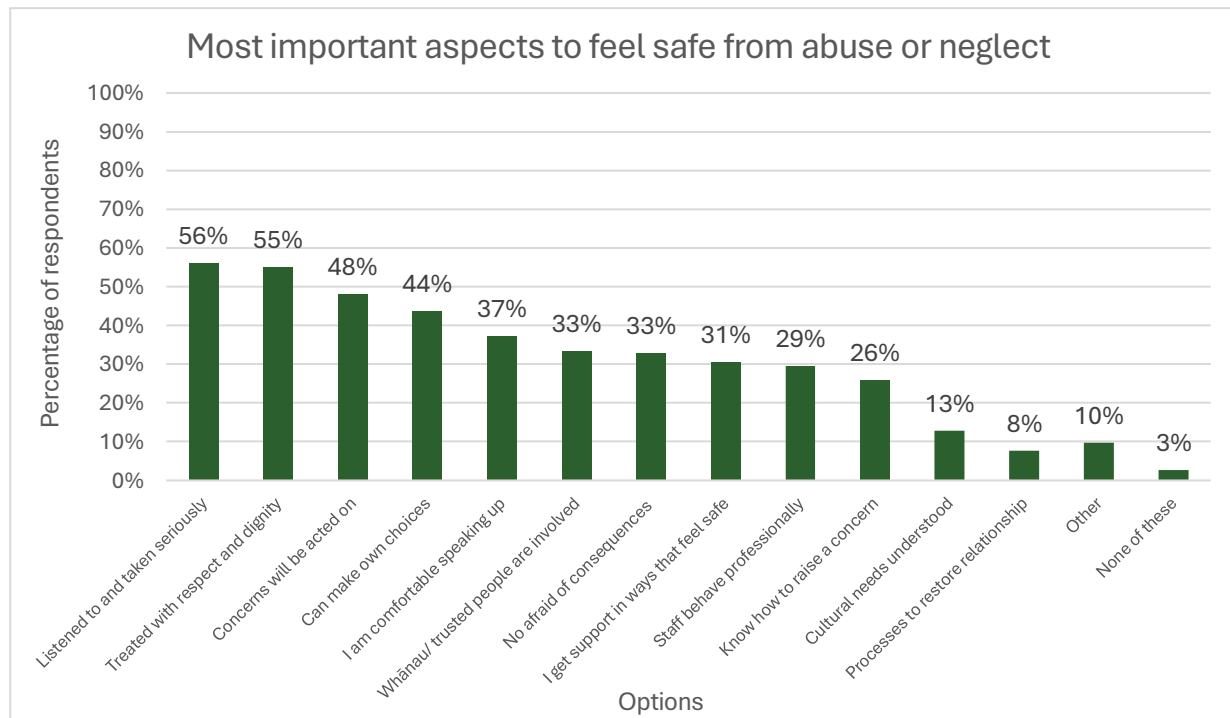


Chart 6: Most important factors to feel safe from abuse or neglect in support services

Findings

- > Aspects that mattered most when thinking about feeling safe from abuse or neglect were *I am listened to and taken seriously*; and *staff treat me with respect and dignity* (56% and 55% respectively).
- > *I trust that concerns will be acted on*, and *I can make my own choices and decisions* attracted similar levels of importance, with 48% and 44% of respondents selecting these options respectively.
- > Over one third of respondents (37%) selected *I feel comfortable speaking up if something is wrong*.

- > Both *my whānau or trusted people are welcomed and involved* and *I am not afraid of consequences if I speak up* were each selected by a third of respondents (33%) as important for feeling safe from abuse and neglect.
- > Other options were selected by under a third of respondents each, with *I can access a process to restore the relationship* selected the least often (8%).
- > Ten percent of respondents (10%) selected *Other*.

Points made by those who selected *Other*.

- 'All of the above' (6)
- Professional, well-trained workforce that treats me well (5)
- Fewer than five respondents each noted that the most important thing for them was: better or more appropriate levels of support; family involvement; advocacy; individualised support; being treated fairly; and that agencies collaborate so that better care is provided.

11. Awareness of how to provide feedback about services

Respondents were asked: *Do you know how to give feedback about the services that you receive from a DSS provider?*

Respondents could select: one option.

- > Yes
- > No
- > I am unsure

n=251

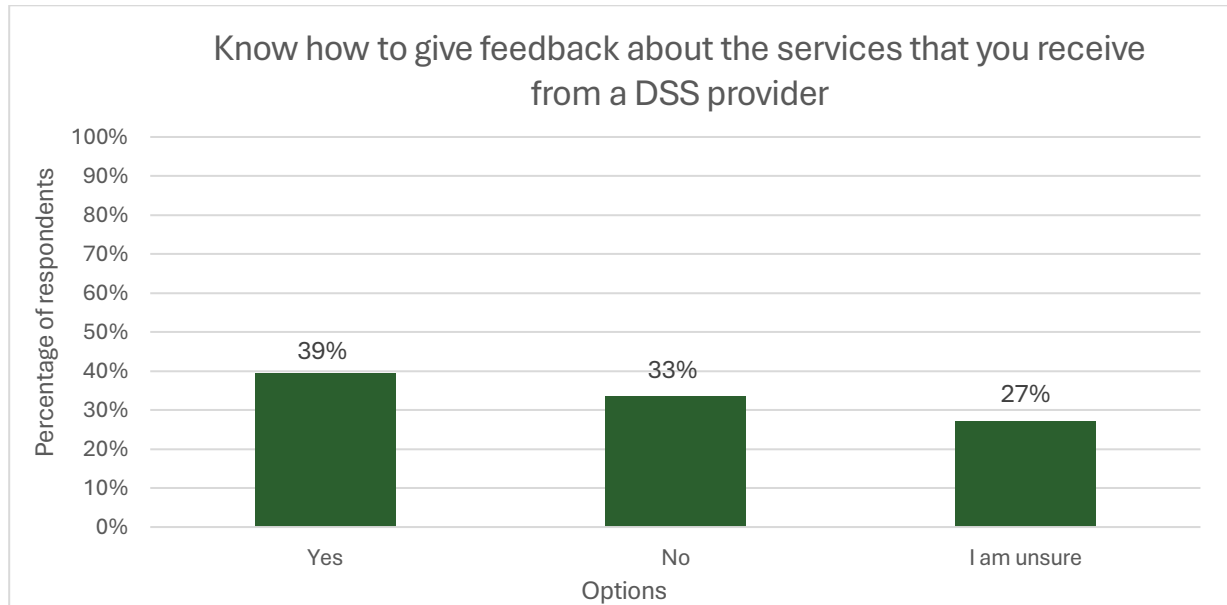


Chart 7: Knowledge of how to give feedback about DSS service provider

Findings

- > Over a third of respondents (39%) indicated that they *know how* to give feedback about services received from a DSS provider.
- > A third of respondents (33%) indicated that they *do not know* the process for giving feedback.
- > Just over a quarter (27%) indicated they are *unsure*.

12. Awareness of how to make a complaint about services

Respondents were asked: *Do you know how to make a complaint about the services you receive from a DSS provider?*

Respondents could select: one option.

- > Yes
- > No
- > I am unsure

n=254

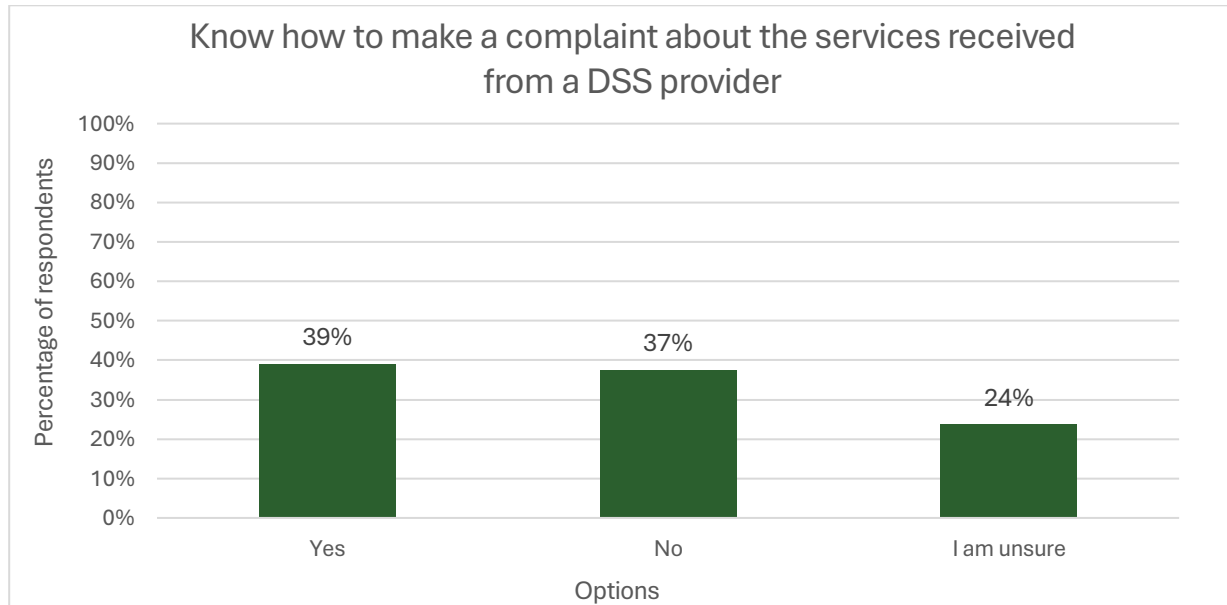


Chart 8: Knowledge of how to complain about services received from a DSS provider

Findings

- > Similar proportions of respondents *know* and *do not know* how to make a complaint about services received from a DSS provider (selected by 39% and 37% respectively).
- > Just under a quarter of respondents indicated they are *unsure* (24%).

13. Awareness of how to escalate complaints

Respondents were asked: *Do you know how to escalate your complaint when a DSS provider does not address your concerns?*

Respondents could select: one option

- > Yes
- > No
- > I am unsure

n=253

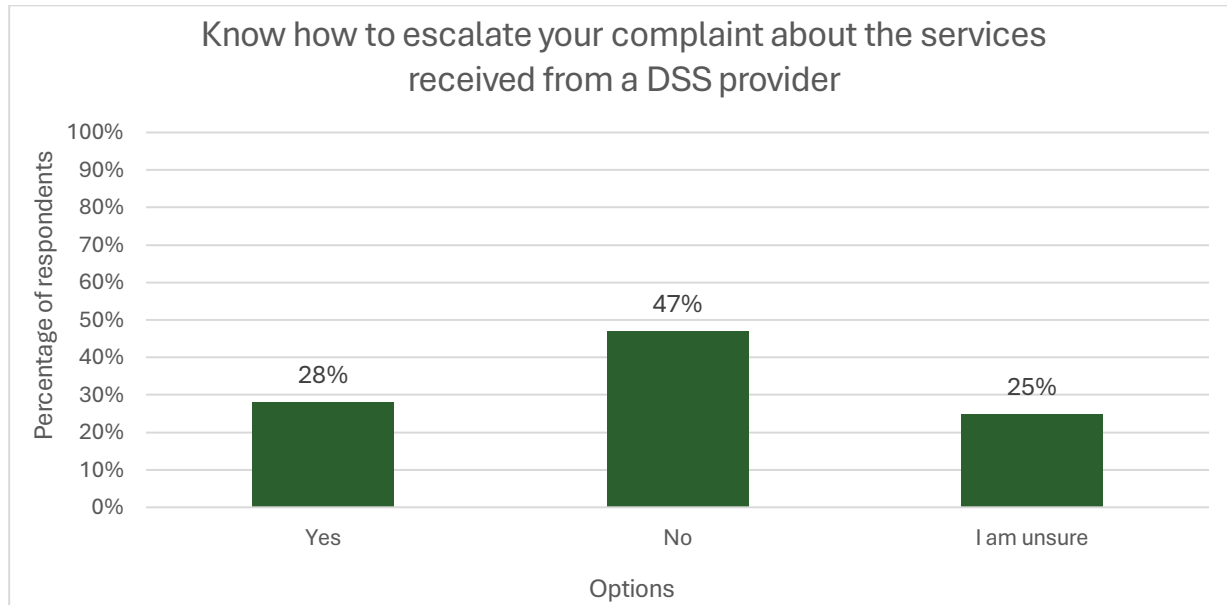


Chart 9: Knowledge of how to escalate an unaddressed complaint about a DSS provider

Findings

- > Close to half of respondents (47%) indicated they *do not know* how to escalate their complaint in the instance that their issue remained unaddressed by a DSS provider.
- > Just over a quarter (28%) of respondents signalled they *do know* how to escalate their complaint.
- > A quarter (25%) of respondents indicated they are *unsure*.

14. What would give confidence in a complaints process

600+ comments

Respondents were asked: *What would give you confidence in a DSS provider's complaints process?*

Accessible system, ease of interaction (122)

A large number of people commented that confidence in a DSS provider's complaints process would come from the system being accessible; that is, easy to find, easy to complete, "not overly prescriptive", clear, and visible. People want to see processes clearly outlined and information provided as to how to complain, where and to whom the complaint will go, and what will happen from the point of complaint onwards (e.g. how complaints will progress or be escalated, and who is responsible for this).

Some stated that accessible formats (for information) were paramount to this, while others emphasised that potential complainants need to understand the process in order to be confident to progress a complaint. Ease of interaction included that the process not require a lot of time or administration; as well, people stated that having an idea of who they were making a complaint to would assist them in feeling confident.

Similarly, people reported not knowing how to complain, or where to go to make a complaint in their comments.

A complaints process should recognise that the people who need to use it may already be carrying a significant load. It should be clear, easy to understand, and designed so people do not have to fight to be heard.

We welcome the focus on improving the quality of services and ensuring feedback mechanisms for people are simple, visible and easy to use.

Simple, visible and easy to use complaints processes of DSS providers. Clear dispute resolution process. Fairness of services.

Knowing there is a key place I can go to make a complaint with easy to follow instructions, independent from time with my support worker.

How many portals in DSS are there for complaints? I find where to go to make a complaint is confusing. What should I take to DSS?

Impartial, independent, thorough investigation (106)

Second to an easy, accessible complaints process, a large number of people felt that confidence in making complaints would be improved if it were clear that an investigation would be carried out in an impartial way. This was phrased in some cases as independent advocacy, while in other instances people talked about independent oversight or independent monitoring systems.

Transparency was cited multiple times (in approximately one in five comments under this heading), though this concept was not frequently expanded on.

People stated they want advocacy in some form that is independent from the supports they receive, this distance was said to be integral to being able to trust the process, and is related to the topic discussed below, being protected from repercussions for making a complaint.

Complaints should be transparent, independent, and lead to meaningful improvements.

We want the benefit of the doubt and to be given information and support. We don't want to feel like DSS are the "police". No mixed information and the right of reply.

Easier forms do not fix power imbalances. Need room for an ally/advocate in the process, not just a simple survey. Rather than surveys asking for details, there should be an

opportunity to ask if they want someone to contact them to discuss their supports. Many disabled people do not have skills for surveys.

Listen to feedback and provide evidence of outcome or remediation (94)

People generally expressed that a feedback and complaints system that they would feel confident in is one that listens and implements changes in response to feedback to improve the experience of not only the complainant, but other service users. These comments emphasised practical actions be taken to rectify issues, often simply stating that a good system would be one that “actually fixes problems”, or that complaints are “listened to and acted upon”.

Feeling listened to and the issue is fixed/doesn't happen again.

Rather than explicitly focusing on actions, people also expressed that they wanted to be listened to, treated fairly, and their feedback taken seriously rather than being simply acknowledged. People wanted to see providers be “accountable” or “responsible”, including giving an apology if necessary.

Being listened to and taken seriously: People should feel that their experiences are believed, respected, and considered important, rather than being treated as a problem to manage.

That the DSS provider acknowledges and takes accountability for the issue and takes action to rectify the situation and issues an apology if needed.

Comments also often indicated the importance of communicating to the complainant any actions taken to rectify the problem or mitigate future issues. At times, people expressed a desire to be involved in the process for reconciliation, or in identifying future steps for improvement.

Demonstrating how feedback has led to service improvements and positive change.

Having the opportunity to talk about what is wrong, and what can change in the future (and then those changes are made)

Complainants protected, not penalised (81)

A sizeable number of comments were made addressing the fear that making a complaint may result in a reduction in support, reprisals of some description, or that the complainant be stigmatised in some way. People genuinely feared repercussions from making complaints, or that negative consequences could result.

Confidentiality was cited in a few cases, and it was important that people felt safe to complain and that they could trust that making a complaint would not impact them or their support negatively.

Free from consequences. I need to know that raising concerns won't affect my support hours, my relationship with staff, or how I'm treated.

Quality and safety are only possible when I, and others in similar situations, can speak honestly about concerns without fear that essential supports will be reduced, delayed or withdrawn.

Many disabled people, myself included, hesitate to complain because they fear retribution, a worker being reassigned, a service being reduced, a difficult reputation attaching. That fear is not paranoia; it reflects an asymmetric power relationship. Any complaints process needs an explicit anti-retribution guarantee and independent oversight of its operation.

[Complaints processes should] be mana enhancing, easy to use and free from reprisals.

Response or resolution provided in adequate timeframe (75)

A complaints system that is responsive and timely was called for in a sizeable number of comments. People stated they would feel confident with a complaints system where

timeframes were known, where action was taken, and where communications were open between the complainant and the body in receipt of the complaint.

Some referenced lengthy timeframes and others simply called for a timely resolution or escalation of complaints. Communication was closely related to timeliness, in particular where complaints had been made and complainants had not heard back about progress or outcomes.

Follow-up communication that shows what action was actually taken, not just that a complaint was received.

Someone listening to the issue/s and having someone aim to address things in a timely manner within three months.

Be quicker at resolving complaints, otherwise people lose faith in the system.

Lack of confidence in present system (32)

A considerable number discussed the present system, deeming it unsatisfactory for a number of reasons or that there is little confidence in the current complaints system. People reported feeling like there is nowhere to go; they described how they had been in situations that warranted complaints and consequent change in processes that led to the complaint, but that things had not been escalated past a certain point, or that no change had occurred as a result.

It is a challenge making a complaint as so concerned it will affect the person esp. as non-verbal so no way of knowing. It takes a lot of time and guts to put in a complaint.

At present it feels like most people working in these agencies ultimately have the governments mandate as their priority not the disabled person which is always going to put a complaint outcome back in favour of the government.

I have contacted the Health and Disability Commissioner: can't help. The Ombudsman: can't help. Why can't they help? Who can?

People complain because they want change to the system however the current complaints process is not working... Report on complaints to HDC – Health & Disability Commissioner shows that disabled people and whānau report failures in reasonable accommodations, inaccessible communication, inadequate engagement with family and support people, and poor coordination between systems. Trust is not created by slogans. It is created by systems that listen, repair and change

Other commentary

A moderate number of people made points that complaints processes need to be responsive to the needs and circumstances of disabled people, such as by being disabled-led, mana-enhancing, or by having disabled people directly involved in the development of such processes.

A similar number of comments were made suggesting the importance of being able to talk with someone personally (in person, or via phone call) and that having a personal interaction was valuable in any situation where feedback is concerned. Similarly, automated phone services were not favoured. Lastly, several noted that staff training or knowledgeable staff with a good understanding of disability, culture and trauma could assist in a smoother complaints process.

15. Thoughts on regular feedback survey to monitor service delivery

Respondents were asked: *How much do you agree or disagree that a short, regular feedback survey would be a good way for my DSS provider, and for national agencies, to monitor how well my supports and services are working and respond where improvements are needed?*

Respondents could select: one option.

- > Strongly agree
- > Somewhat agree
- > Neither agree nor disagree
- > Somewhat disagree
- > Strongly disagree
- > I don't know

n=254

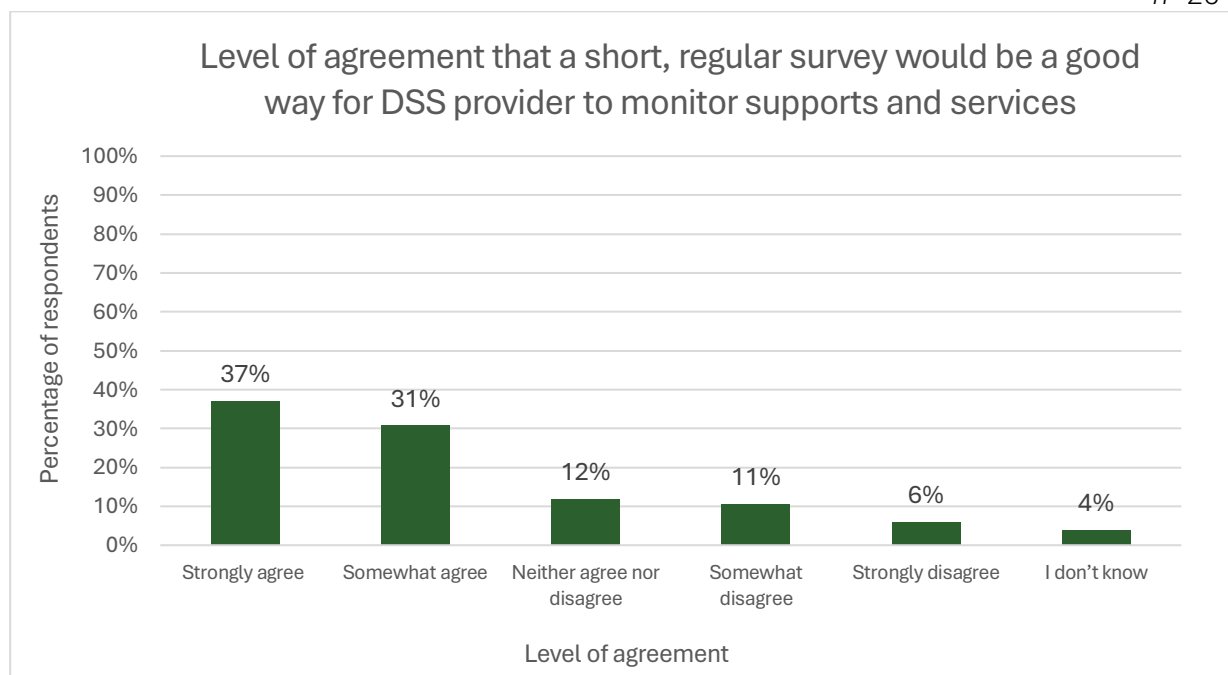


Chart 10: Opinion on a short, regular feedback survey to monitor supports and services

Findings

- > Most respondents (68%) *support* the idea of a short, regular feedback survey as a good way for DSS providers, and for national agencies, to monitor how well supports and services are working and respond where improvements are needed.
 - o The majority of support was *strong agreement* (37%).
- > Almost one in five (17%) *disagreed to some extent* that this would be a good idea.
- > Twelve percent (12%) *neither agreed nor disagreed*, and 4% *did not know*.
- > **NOTE:** several people answered this question via a submission or workshops they attended. Though the above question was not available to them, the following points were made in relation to a short, regular survey being used by DSS providers to monitor supports and services:

A survey was mostly supported but with provisos such as that:

- o a short regular survey *not be* the primary mechanism for quality monitoring;
- o that any survey *not be* administratively burdensome;

- that a short survey be included at the end of every phone call (for an opportunity to provide immediate feedback);
- that any survey capture qualitative responses as opposed to scales; and
- that any survey be available in accessible formats.

16. Preferred methods for providing feedback

Respondents were asked: *If something went wrong (for example, you felt unsafe, or caused you harm or distress) or you wanted to give feedback (for example, ideas, suggestions, or general comments), how would you prefer to do that?*

Respondents could select: up to five options.

- > Online form (website or app)
- > Email
- > Phone call
- > Text messaging or messaging app
- > Talking with a staff member
- > Talking with a team leader or manager
- > Through a trusted family/ whānau member
- > Through a disability advocate or support organisation
- > Anonymous option (no name required)
- > In person meeting
- > Video call (Zoom / Teams)
- > Alternate formats (Audio, Braille, Easy Read, Large Print, and NZ Sign Language)
- > None of these

n=258

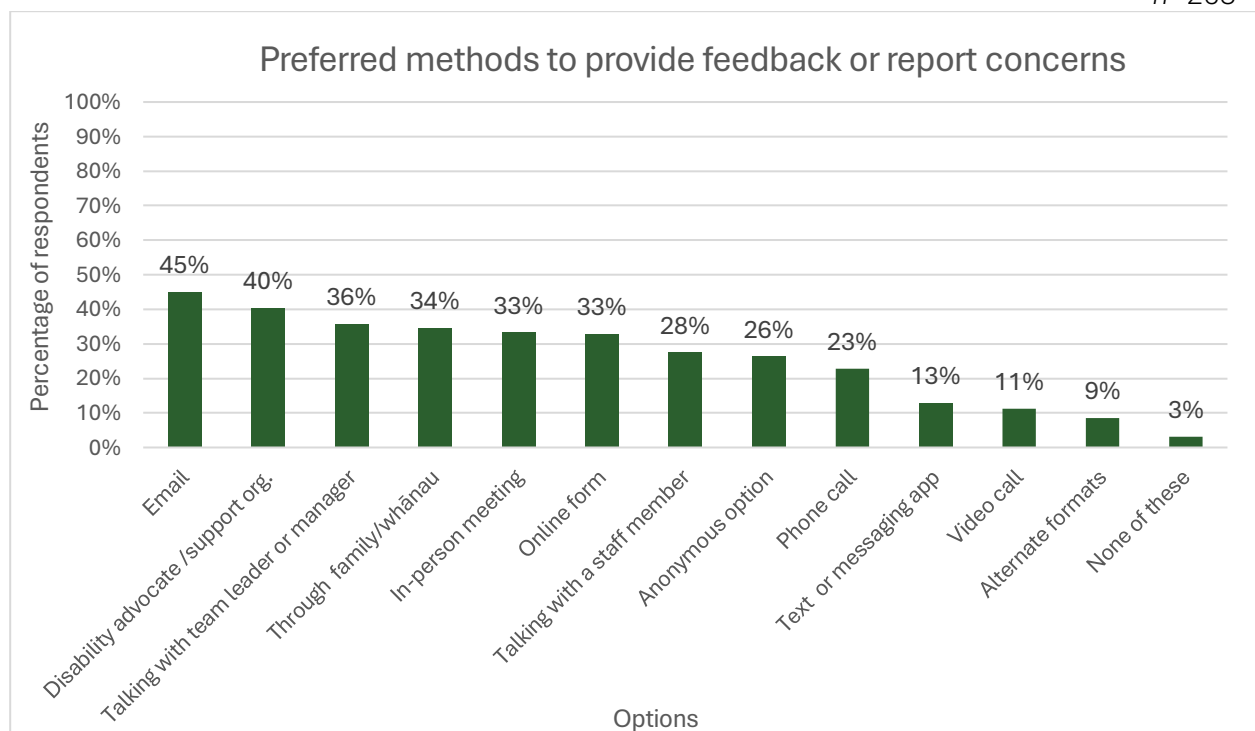


Chart 11: Preferred methods to provide feedback or report concern

Findings

- > *Email* (selected by 45%) was the most frequently favoured way to give general feedback or communicate if something went wrong.
- > Giving feedback through a *disability advocate or support organisation* or via a *team leader or manager* were selected by 40% and 36% respectively.
- > Both *in-person* meetings and *online forms* were selected by a third of respondents.
- > All other modes were selected by less than a third of respondents, with the least popular method being via *video call* (11%).

17. Additional thoughts on the feedback and complaints processes 300+ comments

Respondents were asked: Can you provide us with any additional thoughts you have about the questions you have just answered, or on feedback and complaints processes for DSS providers?

Accessible, easy to do, clear process (60)

Additional thoughts on the topic of complaints and feedback were mainly about having a system that is accessible, clear, and easy to use. A substantial number of comments were made to the effect that any complaints system (or method of giving feedback) should be simple, easy to find, and should include an array of options that can accommodate a variety of communication preferences. Comments such as the following were frequently made:

Feedback and complaints processes need to be accessible, available in multiple alternate formats and designed around the diverse communication needs of disabled people and their whānau.

Complaints and advocacy information should be easy to find and should be provided in plain language and accessible formats.

There should be clear escalation pathways, and people should not have to repeat their story multiple times.

Suggestions for accessibility mainly included having multiple options (by phone, in writing, email, verbal, online form, survey etc.) but also knowing where to go and how to make a complaint or give feedback (e.g. one suggestion was to have a flow chart displayed to show the process). People reiterated that the process should be easy and/or welcoming, sometimes stating that procedures can feel overwhelming which can deter people from engaging with it.

Regarding complaints, it's like I said before, is the information accessible? If you can't understand the process, how can you engage with it?

Families should not have to repeatedly follow up, phone different people, or work their way through an organisation to find someone with authority to respond. Every provider should clearly identify the first contact, the escalation contact, and the independent external pathway.

Regular opportunities to give feedback (40)

There was general support for DSS providing regular opportunities for disabled people/whānau to feed back about services they are using. Note that a moderate number of these comments specifically addressed DDS providing a regular feedback survey to monitor service deliver – this was covered in Question 15 and is summarised above.

The majority of the comments calling for regular opportunities to feed back typically supported feedback channels that made them feel welcomed and invited to participate, and that the process be generally encouraged (e.g. as a part of improving services and systems). While there was support for a short survey (for example), this was often with a proviso that any feedback mechanism be genuine in its intent to make improvements (sometimes expressed in opposition to 'tick-box exercises'), be accessible, and not be overly time consuming.

Feedback should be encouraged through surveys and direct emails - perhaps on a 6 monthly basis to ensure people are feeling safe and supported.

Regular opportunity to give feedback i.e., yearly feedback form.

The idea was expressed that providing regular feedback be an accepted part of using DSS services, and that this may go some way to improve trust as well as the services and systems that are used.

Independent pathway, advocacy service (26)

A considerable number of people mentioned the importance to them of independent pathways for complaints, some adding that an advocate or independent advocacy service could assist in this. A clear expression of this is demonstrated in the following quote:

We need ADVOCATES that are funded it is a constant thing people need, people don't want to cause friction.

People wanted a complaints and/or feedback process that was independent of the DSS service provider they use (or WINZ, or MSD, or of a family member who is a carer). In most cases simple statements such as “we need independent advocacy” were made; when expanded on, in some cases this was viewed as an integral part of a complaints process so that the disabled person does not have to have their version of events filtered through another person.

More independent advocacy to speak on behalf and with regarding natural supports, protocols to ensure those with high needs are supported so that all control is not solely coming from just the provider.

Protection from repercussions for complainant (26)

Another considerable number of people commented that a complaints process must ensure that the complainant is free from repercussions if they make a complaint. The concept of a power imbalance was raised in several of these comments, with people making the point that oftentimes the disabled person is at a disadvantage which can leave them feeling very vulnerable. The threat of supports being removed or that relationships will sour as a result of having given feedback or made a complaint was said to be real, and again, to act as a deterrent.

Currently, parents feel that raising a complaint against a provider leads to defensiveness, bureaucratic stone walling, or subtle retaliation, such as the provider threatening to withdraw services because the client is too difficult.

Often going to the manager is extremely nerve-wracking and puts some people off bringing up concerns.

Privacy respected, vulnerability respected.

Confidentiality, privacy, and anonymity were noted as a way to assure complainants their rights will be protected.

Ensure outcome is reached (26)

A degree of scepticism was expressed that making a complaint or providing feedback will result in changes, this, alongside statements to the effect that evidence of improvement or changes needs to be seen after complaints are made, show that people fear that the process is futile. People talked about wanting to “see real action”, assuring people that “feedback they gave had a tangible impact”, and wanting to see “strong follow through”.

Tāngata whaikaha/people with disabilities and whānau need to see that their feedback leads to improvements. Feedback without visible action undermines trust.

Transparent and tangible outcomes achieved for those taking the time to engage.

When I do need to make a complaint I get no further than a 'sorry' from the receptionist. Nothing changes and I doubt that those higher up are even aware of the stressful issues they have contributed to.

Listen to, believe, and involve disabled people (26)

Involving disabled people in the complaints and feedback process was important for this group of commenters; people talked about involving families and disabled people, and about respecting their accounts and believing them in the instance where concerns are

raised. A few people talked about not being heard when raising concerns and needing to call on reserves of resilience to take matters further, this was deemed unacceptable given the stress such interactions can cause.

Need to feel safe and that will be believed. Need to know things will change.

Ensuring families feel listened to, respected, and valued when they raise concerns.

Disability advocates play a big part, as do carers of disabled people as they are often the voices for their loved ones.

Criticisms of current processes (20)

Current processes were commented on as a way to highlight where improvements can be made. This included statements such as that institutional trust is low (this applied to both providers and complaints processes), that providers each have different views on what entitlements are (and that this leaves those who interact with them confused and frustrated in interactions), and that in some cases the genesis of a complaint is in staff who chose not to de-escalate a situation when they could have.

In my experience it depends on the staff in the agency and their policies. Current agencies are okay, but a previous provider was difficult to deal with. [They] seemed to be more focussed on punishment for behaviour rather than support.

Descriptions were offered about delays in people getting back to them, frustrations and stress building for people who cannot access the support they need, and in feeling lost as to how to proceed in making a complaint.

Complaints processes are unsafe and I have no trust that DSS or the Commissioner will improve.

Other commentary

A moderate number talked about the importance of cultural safety in any complaints process, almost all stating this in simple terms, though a few noted that, for them, this meant accommodating different ways of communicating or an understanding that some cultures may shy away from 'making a fuss'.

Pacific whānau: avoid complaining and may downplay issues. May make own adjustments in response to a situation.

Many people complaining is not part of their culture (whakamā) so they just disengage and create their own navigation and networks to replace the system that didn't work.

Several people noted that receiving updates or regular communications about the status of a complaint or feedback is an integral part of the process. Several other people noted that DSS providers should be held to a high standard, and that complaints and feedback are a valuable means by which improvements can be made.

Feedback should not only be used to resolve individual concerns but also to drive continuous quality improvement across the disability support system.

Topic 4: Better support for carer respite and breaks

DSS prompts used in engagement

Introduction to survey questions 18 – 20

Building on the Draft Carers' Action Strategy Plan (available here: <https://shorturl.at/r58aC>), we want to think about ways we can improve our existing services to improve the health and wellbeing of carers.

Relevant workshop discussion point

Topic C: Carers: Thinking about the services that DSS provides to carers and whānau, what is missing, or what else could we provide that could support you and your whānau?

Key findings on carer support

Overall summary

The provision of services to improve the health and wellbeing of carers was overwhelmingly viewed as dependent on the provision of more, and more suitable, respite options. Disabled people, carers, and whānau as well as stakeholders, consistently reported that a lack of services in their area, at the desired times, and that could cater to the specific needs of the disabled person were what was making accessing breaks for carers difficult.

What people said

Issues faced when accessing respite care, day programmes, or other DSS services that support carers

- > The overarching issue identified in response to the issues that are faced in accessing respite care, day programmes, or other DSS services that support carers was a lack of services to accommodate disabled people.
- > A similar issue also mentioned frequently was the lack of *suitable* services/staff to provide care for people with specific disability needs, or that it is hard to find respite that aligns with age and stage, interests, and cultural needs. This was reported for people seeking mainstream services and independent carers to provide in-house care.

Changes to services for carers that would make it easier to take a break when needed

- > People wanted to see more respite services and a wider variety of options for respite, including more flexible options, to accommodate for the issues previously outlined.
- > The other main suggestion was that people should receive more funding for respite, and similarly, that it should be cheaper so that carers can have better access to it.

Additional thoughts on the support DSS provides for carers

- > Overall, people wanted to see carers receive more acknowledgement and support from the disability support system, where carer wellbeing is managed and maintained rather than reacted to in times of stress.
- > People want to see carers treated as partners rather than taken for granted as low-cost care providers.

What we heard

More respite services are needed both generally and for specific cohorts

What this would look like for respite support

- > People stated in definitive terms that there need to be more options for respite care; in addition to simply requiring more respite options, respite services need to be able to accept people of many ages, and to cater to those whose needs are high (which may include the need for specialised equipment and/or staff who are appropriately qualified).
- > Relatedly, it was suggested that well-trained, experienced staff be employed in respite services so that carers can feel comfortable that the person they care for will be well looked after.
- > People stated they will forego taking a break from care work if they cannot trust the respite provider to provide top-quality care; this again points to the need for trusted options and good relationships.

Respite options need to be known about, easy to secure places in, and funded

What this would look like for respite support

- > People want to see respite services available across the motu, and they want to be able to find out about them, see clear eligibility and funding criteria, and have certainty that places are available without having to complete multiple forms, talk to multiple people, or navigate conflicting information.
- > Rural respite options, school holiday options, emergency or late-notice respite options are all deemed an important part of a well-functioning support system.

Carers want to feel supported

What this would look like for respite support

- > Carers can find support from others in similar situations, perhaps in a peer support network or other informal situations and can count on DSS to assist in forming and maintaining these networks.
- > Carers feel supported by DSS and, rather than being the default support, are viewed as part of a network that works to support the person requiring care.
- > Carers report that proactive and simplified pathways to respite services will support their own mental health and wellbeing and prevent burnout and strained relationships.

18. Issues for carers accessing respite care

600+ comments

Respondents were asked: *Can you tell us about the issues you, or your carers, face when accessing respite care, day programmes, or other DSS services that support carers?*

Lack of services or knowledge of services (158)

People frequently identified and described that access to respite was limited because of a general lack of services available. People described there being “no” services or that there was a lack of choice in options. People claimed that even when carers do have access to funding, there’s no guarantee they will be able to use it due to the lack of respite services available. Comments often specified that this was particularly apparent in rural communities.

Live in small community that doesn't provide any or is hard to access it. Because we live rurally and due to some of our son's requirements, we really struggled to find a suitable carer.

People also described a general lack of awareness that respite support is available. These comments detailed issues finding specific information, for instance about what services are “out there”, what the options are for respite and use of funding, and how to access respite support options.

The holder of the information is very limited and inaccessible for the wider community. Who is eligible? Who can give us the information or guide us to the correct portal for respite? How long is the process? how hard is the process? what sort of details are needed?

Existing services were sometimes said to be operating at capacity, having no further availability, or quickly becoming booked out. This was linked to administrative difficulties, such as long lead times for booking or an inability to make future plans.

There are no holiday program near my house during school break. Or places get full quick.

We have been approved for up to 28 days rest home respite care annually but only managed to access it once...The problem is that here in Marlborough (due to supply) you cannot plan for a break as the homes won't take bookings for set dates in advance but may call when a room comes available with approx. a weeks notice so if you plan to go away or do something special that requires pre planning /booking its impossible (I had a 5-month lead time so had to make private arrangements). Too much stress to discover a week out that it's not available.

Comments also discussed related issues including a lack of flexibility in services and the ability to accommodate for emergency situations, after hours (overnight, weekend, or holidays), as well as a general lack of specialised services/trained staff.

Lack of services or trained staff that can address the specific needs of the disabled person (118)

A large number of comments, often from the perspective of primary caregivers, stated that there were few respite options that were suitable, or that it was difficult to find trusted independent carers to provide in-home respite. People often simply described it being difficult to find respite in either case that is “appropriate”, “suitable”, “trustworthy”, “skilled”, “trained”, “experienced”, “reliable”, or “safe”.

Have not found a facility appropriate for care of child.

We regularly receive complaints about the lack of access to local, age-appropriate respite services, along with concerns about the expertise of services and the quality of care received.

Just over half of these comments were related to formal respite providers. People noted that services are often unable to accommodate for people with specific disabilities or conditions, largely due to lack of staff training, but in some cases due to a lack of specialised equipment or accessibility measures. It was also reported that people with high-needs, or complex disabilities were turned away by respite providers at times.

Don't like the options to send her away. She is not verbal and [is] vulnerable. Due to the equipment she needs, she can't sleep anywhere but at home.

I was told there isn't a respite facility that would take him as his needs are too high.

Another issue specific to respite providers detailed in comments was that the existing services, day programmes, or residential facilities often aren't age appropriate. For instance, rest home providers were said to be unsuitable for younger people.

In some cases, they force people into retirement village for respite. A 13yr old going into a retirement village is not okay.

Respite environments need to be appropriate. Teenagers don't want to be in hospital, children elder care type spaces.

When he was 15 years old, they had to use a respite service with 7-year-old children; The person felt hungry because the food amount was for little children, not teenagers.

People also shared difficulties finding respite that aligned with the specific personality, cultural needs, goals, and interests of the disabled person.

Difficulty finding appropriately skilled carers and support workers who are well matched to the needs, strengths, and aspirations of disabled people.

Primary caregivers reported in substantial numbers the difficulties finding an independent carer to provide in-house respite. Carers expressed concern about the quality and safety of care being provided while on respite, making it hard for them to truly take a break. People noted that this was particularly so for disabled people with complex or high support needs. A related issue was that respite funding was insufficient to afford carers or services with an adequate level of training, or to fund enough staff, this is discussed in greater detail under the next heading (titled *Cost and financial access*).

Difficulty finding quality support staff to use our respite funding. This is a significant and ongoing issue.

Support workers unfamiliar with my transfers, my pressure care, my continence needs and my medication timing have caused avoidable falls and skin injuries. The trust cost of a bad respite episode is significant it can be a year before we try again.

At times, difficulty finding respite carers was due to there being a lack of rapport, or an established relationship with the disabled person, often resulting in other family members taking on the responsibility for respite care.

We pay a family member to provide care so we can take a break. Respite is unhelpful and has so many rules. Our child would not be okay with strangers, so it has to be a trusted adult who can show up regularly, and who is culturally safe.

People also found it difficult keeping someone long-term, due to the irregularity of hours and respite needs. Furthermore, people also described undertaking significant time and effort to interview, reference-check, and then on-board new carers.

We have a team of carers who are invaluable to us. It's hard though to find the right people (I advertised, interviewed, recruited, trained, and paid for 7 who either weren't right or chose not to continue in the past year). It's hard because of the schedule changes and carers wanting set, regular hours. [...] The times he needs a change up and I need a break are unpredictable.

Nine out of ten times the whānau will create the training material themselves. They will have everything written down and laminated. The Onus is on the family members once again. DSS or the DIAS could help with designing manuals, they could help people get access to training and navigation. At the moment, family members are doing everything.

I just simply do not know anyone who I can pay with our carer support funding to support my daughter and I. I don't have the capacity to seek someone out.

Cost and financial access (60)

A substantial number of people explained that cost and financial concerns were a barrier to accessing respite care, the majority making the point that the funding is insufficient to provide adequate respite and is only enough to cover a few hours, let alone a day or more. People also noted that the allocated respite funding hasn't increased to meet the rising cost of living over time.

Difficult to find someone who is willing to care for the person for such a little amount of money - less than half the minimum wage. The subsidised amount provided for 8 hours care (\$80) is cost prohibitive for accessing care from anyone other than a family member (as it does not cover the cost of anywhere near 8 hours of care). The fact we have to top up the funding contribution. It's costly.

Resources to be funded appropriately. It is only \$10 more a day than it was 20+ years ago when clearly no other costs have even been close to staying at this rate. It feels mean to suggest this is all the wellbeing of caregivers is worth.

My own IF was cut, and so was my rangitahi's, even though their needs have massively increased.

People also pointed out that respite care includes costs other than for caregiving hours, including transport considerations, and accommodation for the primary caregiver.

If we do have someone come into my home for respite, I still have to fork out as well to go and stay somewhere [else].

Not enough funding to pay for day programmes. The total mobility subsidy has been reduced so it is now much harder and more costly to get to day programmes.

This cost was noted to be particularly prohibitive for those with high or complex support needs requiring additional staff or a high level of carer expertise. In other cases, primary caregivers noted that there wasn't enough funding to cover multiple disabled family members, so meaningful respite was limited.

For people with high and complex needs though, we need to know what they are capable of doing. For example, are they first aid trained? Do they know how to provide the oxygen etc., and that's not cheap. [...] The difference for us is that he gets the same dollar value of respite allowance but the level of support he requires is very different. They are all treated the same. Some can stretch it but some can't where the needs are so complex. Respite budgets need to allow for higher needs people. [...] Regarding qualifications, when I employ someone, most of them see the oxygen and run a mile. People are scared off. I understand that but it doesn't make it easier for me.

Several people raised issues with funding criteria, with several costs associated with respite being ineligible for funding, such as transport costs, or being unable to use an IF budget to supplement respite. It was also noted that these criteria imposed a fixed idea of what respite can look like. A couple of other comments advocated for EGL to be reflected in respite provision.

Had a casual conversation with host to utilise kid's funding to get a massage, response received was that the activity has to be meaningful for budget owners. Has two slipped discs and a compressed discs due to insufficient support to lift and move younger son who requires it as part of his care. Instead of going to ACC, is

attempting to manage condition with massages instead. Attempting to access funding to get a massage but was declined due to it not being fulfilling for the disabled person whose fund she was accessing. DSS is not giving any ability to access funds so that she may access respite that she needs.

When we weren't allowed to use respite money for hotels it became even harder for those of us whose children need to stay in the family home for respite to get a break. It was a short-sighted view and isolated carers even more overnight!

Carer wellbeing and proactive support for carers (54)

A substantial number of people emphasised that generally there should be a more proactive approach to supporting carers wellbeing and preventing excessive stress and burnout down the line. The premise that the current system for respite is mostly reactive, only available once a carer is in crisis, was also frequently stated within this topic. Overall, people wanted to see a greater amount of ongoing support and outreach for carers by DSS, including increasing funding or reducing barriers for respite.

Proper paid supports and financial supports need to be available to families in the first place. That would minimize the need for respite as burnout would be reduced.

More regular check-ins and proactive support from DSS would help identify when carers need a break, rather than waiting until they are struggling.

Families described needing sustainable support every day rather than only receiving help once they reach exhaustion.

People urged there be a broader, more flexible view of what respite can look like that allows primary carers to get respite in ways that work for them and their families.

Carers need more respite, and short breaks to maintain their wellbeing. Cares should be offered more opportunities in different ways to release their stress.

Respite can mean different things e.g., yoga, getting nails done, or going to a concert. Opportunities for people to do things separately and have time out, this is important. And it will look different for different people. It is important to be able to be spontaneous and flexible – being able to do what I want, when I want to. Respite can be providing a service so family can go out.

Administrative burden of access (52)

A considerable number of people, largely primary caregivers, described the administrative burden of managing and organising their own respite, and related caregiving arrangements for their loved one(s) as an impediment to getting a proper rest. The main idea expressed was that this administrative work builds stress, and is a significant undertaking for carers, who are often doing so when they are already in need of a rest. A supporting point was that it is hard for carers to predict when they will need to take a break.

The system in getting my husband into respite is quite an exhausting process. There is so much paperwork to go through and extra work involved in getting all the medications checked in to the rest home system that it almost puts me off applying for respite in the first place.

Accessing respite is often stressful and inconsistent. It's not clear what we're entitled to, how to apply, or what the criteria are. When carers are under pressure, the system expects them to navigate complicated processes, chase NASCs, and repeat their situation multiple times. This defeats the purpose of respite, it adds more stress instead of reducing it.

My carer has trouble using the carer support allowance. Our weeks are so busy that it's hard to organise a break for him, which is our problem, I know. It's why we have only used 3 days of the allowance this year.

People described the complexity and inflexibility of criteria about what the funding can or cannot be used for, as well as at times feeling judged, or scrutinised when accessing respite

entitlements. People also had trouble understanding and keeping up with new rules, or changes to the system.

Too many hoops to jump through. Too many gate keepers telling carers and families that they can and can't do just makes to all too difficult to access.

Trying to find ways to use my funding within ambiguous rules that make zero sense. And then being scolded when something changes, without us realising and nobody telling us, because we tried to continue to use that support.

Comments also related difficulties with finding clear information about eligibility and access to respite funding, as well as potential respite providers, or stated that they didn't understand how it all works.

Lack of understanding how it works. I don't know about my entitlements to respite care, do not know who does respite care. We're not actually sure if we qualify for respite care, and we don't know how to access it if we do.

The process of researching, booking and organising respite was also described as a distinct hassle, exacerbated by the low availability of services, and the difficulty finding something that was a right fit.

A service is not automatically a break: Time spent organising, transporting, preparing [daughter] for a change, resolving problems and helping her recover from an unsuitable experience can outweigh the time supposedly provided to the carer. A genuine break exists only when the support is reliable, safe and appropriate enough that I do not have to remain on alert or manage it continually.

Need different carer situations acknowledged and catered for (45)

A considerable number of people conveyed that the current system for respite is inflexible and does not respond to the diversity in carer circumstances and family needs. People noted this as an issue with the rules and official processes for funding, as well as a product of the rigidity and lack of choice in available respite services. Along with considering the diversity of needs among disabled people, people advocated for the diverse needs of carers and the family unit to be reflected in the respite care system.

In terms of respite, accessibility and flexibility remain significant barriers. For many families, particularly single parents and those supporting people with complex needs, finding respite that is appropriate, available and trustworthy is extremely difficult. Flexible respite is essential because every family's circumstances are different. One approach will never meet everyone's needs.

Consistent with other topics, people supported greater flexibility in considering what 'counts' as respite. People often noted that respite shouldn't be an 'all-or-nothing' approach, solely defined by the carer being given time away. A common example was that respite could involve the carer being supported with certain tasks or that respite could be a family being supported to take a holiday together. Several people expressed a preference for in-home respite.

Respite for me would look like, food, some in-home support for her (she is not able to do standard home activities like laundry). Respite would be me not having to do two people household chores, having someone cooking for me. Sometimes we cannot cook for ourselves and have to get takeaways and the costs add up. Respite doesn't need to be a big thing sometimes it is getting the little things.

Not looking at respite as only a break, respite is a family experience, doing things they love with a helping hand, someone takes the pressure off by supporting the adult with their personal cares, but still get to enjoy experience; I'll do the personal care - someone who takes a load off for the not so fun tasks.

More in-home respite (a support worker takes over in the disabled person's own home) as an alternative to facility-based respite. For people with complex clinical needs, in-home respite is usually safer and less disruptive.

While specific considerations differed throughout the commentary on this topic, general concerns related to respite options not fitting family schedules or not considering the needs of large families, carers who are disabled themselves, carers who are single parents, elderly caregivers, carers with multiple dependents, carers from different cultural and ethnic backgrounds. It was also noted that the availability of natural supports, including family carers, should not necessarily be assumed.

Respite is not normal in some cultures, how culturally sensitive is some of the information and the assessors to the needs & the environment?

There are lots of examples where family schedules and needs don't match the supports offered, and this is even more of an issue in regions with fewer service options.

The carers in my family are unsupported and do not have access to anything. Because our disabilities are invisible and we're independent, many people don't understand what we do on a daily basis.

Waiting lists and delays means accessing respite takes too long (27)

A considerable number of people expressed that the inflexibility and delays around booking and access to respite prevented carers from getting a break when they really need it. Again, people made the point that it was difficult for carers to predict when they would need rest that far in advance.

One of the biggest challenges for carers is finding support that is flexible, accessible and available when it is needed. Caring responsibilities can change over time, and it can be difficult to access respite or breaks before carers reach a point of exhaustion.

Other topics

A moderate number of people made the point that respite was difficult to access in last-minute or emergency situations, and generally that after-hours respite support was scarce. A similar proportion of people generally insisted that carers rarely get a break and are consistently operating when burnout or exhausted due to inability to access respite.

Several other comments similarly expressed that accessing respite is "impossible" or generally hasn't happened due to the barriers carers face in accessing it.

Several people shared various criticisms, arguing that the inaccessibility of respite, difficulty navigating the system, the constant changes are indicative of an under functioning system.

A similar proportion of people noted the inability to access or afford accessible transport was a key barrier in getting access to respite.

19. Changes to help carers take a break when needed

450+ comments

Respondents were asked: *What changes to services for carers would make it easier for you to take a break when you need it most?*

More respite services and options for respite needed (130)

The most common response to this question was simply that more respite options are needed, and over and above that these options need to exist, they must be flexible to accommodate certain times or days, and they must cater to the needs of the disabled person. Survey respondents in particular phrased this in succinct statements such as “actually have the services funded and available”, “more flexible respite options”, and “expand respite services”.

More availability of organisations/support workers that can provide respite.

Access to temporary replacements.

Having more accessible and appropriate respite options.

Suitable respite does not currently exist, and there has not been any available for over a decade.

More detailed comments outlined that respite services must be able to accommodate the times that respite is needed (such as weekends, after school, or at short notice), that services must be made available in rural or under-serviced areas, and that respite services must be able to cater to the needs of the disabled person – many of which are critical to the safety, health, and wellbeing of that person – and which include cultural, medical, mobility, and disability-specific needs.

Having people able to adequately handle a high needs, violence prone child. More training and support for those who are supporting primary carers! It's not a break if I have to worry about getting a call.

We recommend: • Greater investment in respite services. • Increased flexibility in how respite funding can be used. • More emergency respite options. • Expanded day programmes. • Increased support for carers under the age of 65. • Better access to respite in rural areas.

We also need more flexibility in day programmes, as these also provide respite for carers by giving them a regular break. Be good to 'hero' up the really good day programmes, which are often small and bespoke. Use them as examples of what good can look like. Often these are community funded and provide better services than the larger DSS contracted services.

The availability of staff was also raised in the context of respite services being available so that carers can take a break. The entire disability sector requiring more and more well-trained staff features throughout many topics in this consultation, in this case, people wanted to see a workforce that is sufficiently trained and capable, so that accessing respite does not invoke anxiety about the wellbeing of the person using that service.

The availability of excellent well-funded respite and support services so carers can feel reassured their special needs person is well looked after.

I think staff should be paid more money - so they could then take us to more places we want to go e.g. on weekends. Only a few staff on weekends so we can't go out.

Costing, IF, and financial access to respite (94)

Better access to respite was, for a considerable number of people, about making it cheaper or funding respite services more so that cost and access to the user are reduced. People most often made simple statements that reiterated that more money was needed for

respite services. Statements such as “extra funding” and “more respite funding” were made alongside the following.

Again, this comes down to the reality of the funding available. Does it provide enough resource to enable a level of respite which gives carers enough of a break?

More funding so they can get regular breaks.

Appropriate levels of funding to help cover actual extra costs to the disabled person and their families/ primary carer.

Adequate funding that reflects the needs and the enabling good lives plan.

Another considerable number of people stated that being able to pay family carers is integral to having a sustainable, fair arrangement to compensate for care work. Such an arrangement was said to provide good outcomes for all, to “work”, and, when not occurring, was described as being disproportionately burdensome on women.

If I can continue to pay friends and family from my respite hours from MOH. I have really appreciated the way this has worked for us.

I like to see my family as often as possible but they don't get paid for providing respite support. My family are busy and need to pause things in their lives to support me when I come to visit. I want an option for family members to be paid for providing respite when I leave my residential service for a visit.

Anyone that is looking after [name] needs to be employed including sick pay, holiday, KiwiSaver.

Additional comments about funding for carer respite include a moderate number stating that the importance of IF cannot be overlooked (many noted that this system works well and that disabled people and carers can be trusted to use it for purposes that best suit individual situations), several commented that funding could go directly to the carer to be disbursed for respite support, and lastly, some felt that having a portal or place to see DSS-related balances would be useful.

Increased flexibility in how respite funding can be used.

Carers to receive and hold lump sum of funding to be able to have maximum flexibility to hire respite care/carers.

Flexibility in how carer uses funds for a break (69)

A substantial number of people talked about carers needing to be able to decide how funds are used so that they can get a break and feel refreshed. This was deemed part of a trust model that centers the disabled person and their support network in what works best for them. The point was made that caregivers also need to be able to live a fulfilling and meaningful life, and that having a break from caring is a necessary part of this. Carers described personal situations of being “burnt out”, of not having had even short family holidays, and of being unable to access appropriate respite for a disabled person so that they might get a break.

Allowing carers to choose support that best suits their circumstances.

More resources and for them to have access to breaks away, well-being and therapeutic care.

Carers should have more respite/more support for parent of disabled children. E.g., looking after child so mum can go out and do things. Haven't used respite as it didn't work, [need] choice about where carer can take respite.

Flexibility is being able to have a break when needed.

As the carer - I want to work and earn a decent wage, I had to give up [career] to be a fulltime carer of disabled child, now we live just above/at the poverty line and my

mental health is terrible, it is relentless and exhausting. There are no funds to take a break and the funding doesn't cover that. Especially not for carers.

A moderate number of comments were made that carer breaks could come in the form of community supports such as coffee groups, counselling, massage vouchers, mentoring, peer support opportunities, and other connection opportunities. The rationale for these was that the caring role is often an isolating experience, and one that can feel relentless at times. People emphasised that having an opportunity to share this experience with others is an important way to ensure that the carer is able to continue in that role.

A pool of courses/services around resilience and anxiety management, anger management mindfulness etc. To have a pool of vetted professionals who have specific strengths with PTSD and special needs parenting would be amazing as sometimes I feel like professionals I have used in the past are totally out of their depth and our mental health needs are in the too hard basket.

Continuity, consistency, reliability in respite and support situations (54)

Continuity of care, trusted relationships with respite carers, and confidence that support services will remain into the future were serious concerns for people. A substantial number of comments were made urging that people should be able to trust that respite support will remain available in future. Reliability of access to respite was viewed as something that alleviated stress in and of itself; that is, the uncertainty of whether carers would even be able to take a break was itself a source of stress.

Respite care days should be regular and reliable. Any changes need to be communicated well ahead of time. Recognise that self-care for carers a need not a want.

In my experience as carers age the pressure becomes overwhelming and the fear of what will happen to loved ones once you are unable to care for them increases. The uncertainty around law changes have increased these fears hugely.

Short-term or inconsistent support can be difficult, especially for young people with autism, intellectual disability, anxiety, PDA-style needs or communication differences. Services should allow for rapport-building, flexible pacing and activities that are meaningful to the young person.

Knowing that respite care and other services will still be available months or even years from now, and that DSS will still provide the necessary funding and support, is invaluable.

Similarly, people wanted to see consistency with staff so that disabled people can trust that their personal situation is understood, and that appropriate care and attention is given that is relevant and safe. This also extended to requests that staff be paid better in the hopes that this would encourage a workforce that views care work as a career as opposed to a short-term vocation, and that consequently, good, long-lasting relationships could build. A few people suggested a database or agency of respite workers, while others simply stated staff turnover was disruptive and potentially unsafe.

A more clear coordination among staff so that there is better replacement by competent staff members during shifts during the carer's time off.

I need to know that [name] is safe, well supported, and with staff who understand her communication style, routines, health needs, and intellectual disability.

It's invasive having heaps of people come into our house. My son cannot adjust to new support workers. We are constantly having people in our home. New staff we have to trial and no funding available to train support workers.

Greater understanding of family and whānau needs (33)

A considerable number of people made points related to the need for household, family, and whānau situations to be front of mind in decision making about respite, and other support needs. Checking on, knowing, or finding out about the needs of the “whole family” was said to be important, as was offering support that is non-prescriptive.

Always consider the wider family and the impact of disability.

Whānau are partners, not unpaid infrastructure, whānau are too often treated as informal providers, navigators, administrators and crisis absorbers, a resource to be exhausted before support is offered. EGL requires something different.

Listening to and partnering with family carers, acknowledging that they often know their disabled family members best.

Whatever works for the family – that’s what matters. Don’t be prescriptive about what “respite” is – you’ll limit the services available and it won’t work.

I am the carer, I need support to enable my son’s development, but because I can’t access support, employment or guaranteed housing, my son only has a frazzled rat on a treadmill who can’t be present for constant worry.

Additionally, people talked about the needs of siblings and parents (disabled and non-disabled) in households where someone is using DSS services; this was in the context of whole household support.

A proactive approach must also recognise that disability affects entire families. Many conditions, particularly neurodevelopmental conditions, have strong genetic links. Parents, siblings and extended whānau may also have disabilities, health conditions or support needs of their own. Supporting carers to stay healthy, financially secure and emotionally well is one of the best ways to improve outcomes for disabled people.

Transparency and ensuring people know what carer supports are available (29)

A considerable number of people talked about the need to advertise what supports are available for carers; this included the following ideas: pamphlets in GP waiting rooms, plain-English information, written information at initial support meetings, a cross-agency portal or chat-bot to give advice on what services are available, and reference to the importance of “attendant care” in DSS communications.

EGL should/could be educating the rest of us in ways of using attendant care. We could use videos/make videos e.g. ‘This is how I manage my support staff’ so share information.

NASC should know what respite services are available within the area. The letter following assessment should show what services are available.

Several people made the point that they did not know what was available or that they did not know how to access respite for carer support.

Administration associated with accessing respite is a deterrent (43)

Simplified or easier booking, removal of barriers, and general easier access to respite care were noted in a considerable number of comments as a change that could help carers take a break. Suggestions included that a navigator (or coordinator/case manager) could assist this, or simply that systems be set up to make it easier to access respite.

Less paperwork, a simplified booking system, and taking issue with the administration and rules around being required to “be an employer” on top of managing all the other administration duties that come with accessing support were all noted.

Respite needs to be easy to access, flexible, and available when needed, not only when the system decides it’s appropriate. Carers should have clear information about what respite options exist, how to book them, and what the process is.

Reduce the number of rules for the disabled and carer. Reduce the friction rather than adding more.

Support with decision making. We're all burnt out our close to. Decisions are really hard in that state.

Practical support with navigating paperwork and the systems. Flexibility around respite that genuinely works. There is so much to do in a short time, the parents may be aging and need more respite time.

Other commentary

Other comments on this topic included several in which people stated that they lack the support they need to take a break (including being assigned only one carer when two were required, the statement that “I get absolutely no support for my child”, and the impression that carer burnout must escalate to extreme situations before assistance is offered).

A final set of comments noted that it is important to reduce the stigma associated with requiring respite so that carers can take a break. Some felt community education could help with this, while others felt that limiting unhelpful commentary from politicians would at least be a start.

20. Additional thoughts for support provided for carers

250+ comments

Respondents were asked: *Can you provide us with any additional thoughts you have on the questions you have just answered, or the support DSS provides for carers?*

More respite services, and more funding for respite (37)

Supplementary to the key point around carer respite seen in feedback for previous questions, a considerable number of people advocated for DSS to provide more respite services and funding to ensure that carers can take a break when needed. These comments often mentioned that existing services are often full, that the allocated funding doesn't cover a full day, or that it's hard to find services that accommodate specific disability needs.

Make more placements available. Contracting more providers. Sophisticated level of support. Some families try to access additional level of respite, but it is very expensive and can chew through IF quickly. IF rate is not pitched at those [with] very high complex needs.

More specifically, people noted that more flexible respite options were needed, that accommodate last-minute emergency situations, weekend, and overnight respite. Comments also reiterated the need for respite services that are age-appropriate and can accommodate people's needs so that carers can take a break without fear.

More respite options for different age groups and needs levels, not everyone that needs respite is old and dying.

Carers need more acknowledgement and support (61)

People generally agreed that carers are under recognised and unsupported by the broader disability support system and advocated for higher wages and better working conditions for carers generally, including easier access to respite. The point was also often made that carers are an essential part of the disability support system, providing the bulk of support that disabled people receive that allows them to live daily life. People commenting on this topic wanted to see greater priority given to maintaining carer wellbeing over time, rather than solely reacting to crises.

Carers provide an essential role in supporting disabled people and should be recognised as partners in achieving positive outcomes. The wellbeing of carers has a direct impact on the wellbeing of the person they support, yet many carers experience exhaustion, stress, and uncertainty because they struggle to access timely support.

People also admonished DSS for not providing sufficient support to and resources for carers, including family carers, given that much of the labour that goes into providing support goes unpaid. Comments emphasised that carers be regarded as "partners" by the disability support system rather than their provision of support being taken for granted.

DSS needs to recognise carers as part of the support system without treating families as an unlimited or permanently available resource.

Suggestions for supporting carers (32)

A considerable number of people shared various suggestions for how better to support carers and better maintain carer wellbeing. Again, the theme for preventative and sustainable support options for carers was commonly seen throughout comments, including the idea that assistance should be given to help carers establish a plan for and access respite, as well as regular check-ins with carers to see what kind of support they might need.

DSS should: assess the carer's wellbeing and capacity as part of regular planning; offer support before exhaustion, illness or crisis occurs; provide predictable respite

as well as an emergency pathway; recognise the effect of caring and coordination on employment and income; reduce the number of systems, contacts and forms families must manage; plan for ageing, illness or changes in the primary carer's capacity; ensure that support remains available during major transitions; monitor whether allocated respite can actually be used.

It was also pointed out that meaningful respite for carers isn't 'one-size-fits-all', with comments encouraging a wider allowance for use of respite funding, allowing for carers to get physio support, or having partial respite arrangements where carers receive help for certain tasks.

Carers need flexibility in what constitutes respite for them, as it's often very hard to find respite carers, so they made need to think outside the box to get a break.

Someone to support with life things not just go out, take some of the weight off working households, practical task help.

Other ideas included peer support, coaching, counselling, funding for healthcare costs, education and employment support, and assistance for family members employing carers.

Sometimes letting caregivers have someone [they] can talk to after hours.

Make respite support easier to access (24)

A moderate number of people related the administrative burden associated with being a carer, including the difficulty accessing respite specifically. People described difficulties understanding complex processes, including eligibility and guidelines for funding, as well as the need to repeatedly apply and explain their situation to a disparate group of agencies and services. This echoes grievances with administrative processes for respite seen in earlier topics.

Across regions we need clarity and easier access for tamariki with long-term chronic illness. We used to be with [fundholder] for our child but now we are back with the Ministry. It is very hard to get things processed, especially the claim form, it's an ineffective process and it needs to be addressed, updated, and made easier for tāngata whaikaha and their families to access and use.

It all feels too overwhelming and difficult to navigate the respite care space, let alone finding care that doesn't require booking months in advance.

Need a trained and skilled carer workforce (22)

A similar proportion of people advocated for more investment into professional development for the carer workforce, including specific training opportunities to grow disability-specific skills. Comments also generally advocated for better pay to attract and retain skilled staff in the profession. The main idea driving this suggestion was that primary caregivers require available, trained and skilled care support to access respite, as well as reduce any anxiety about the quality of care and safety of their disabled loved one.

Investment in vision impairment competency, so families can trust their child will be safe and supported, not just supervised.

Other commentary

Several people argued that there needs to be more widespread communication about what supports are available for carers, including that there is support available, as people often find this too difficult to work out currently.

I have no idea where I can find out what is available to support me. I have talked to our IF provider but they don't know or won't tell me. My rangitahi has a rare condition and I can't get even normal disability supports like ramps, wheelchairs and grab bars for them, let alone time away to recharge myself. I have no natural supports.

A similar proportion expressed concern around the use of terms “respite” and “natural supports”. People noted that the language and framing around the term respite gives the impression of disabled people as a burden to their families, when the emphasis should be on carer wellbeing. The concern over natural supports was that this had become a term that assumes that available family members will occupy a support role long-term, without consideration of people’s actual situations.

Changing the word respite to temporary care and support would change how some disabled people will feel about being a burden on their family. The last 2 years have caused so much trauma, it will take a lot of understanding for bringing trust back.

The language of 'natural supports' should be used cautiously. Families vary greatly in size, health, geography, income, culture and capacity. A support plan that assumes unpaid family availability can create inequity and obscure the Crown's transfer of responsibility. Family love and commitment should not be converted into an unlimited, compulsory labour resource.

A small number of people expressed criticisms about the disability support system as a whole or critiqued specific aspects of the survey.

There is a huge gap between all these words and what actually gets delivered.

People in small numbers praised flexible funding and maintained that family carers should be allowed to be paid with this funding.

Topic 5: Offering more choice and control in services

DSS prompts used in engagement

Introduction to survey questions 21 – 24

The community has told us that they value flexibility, but don't always want the additional administrative burden of the flexible funding options we currently provide. We want to make flexibility, choice and control available to everyone who receives support funded by DSS.

Relevant workshop discussion points

Topic A: Outcomes that matter for disabled people: What would you be able to do, or what experiences would you be able to have, at different times in your life, if support were working well, and how do you know when it is working well?

Topic B: Flexibility of supports: What does flexibility look like for you? And, how might we better reflect this in the services we deliver?

Topic C: Carers: Thinking about the services that DSS provides to carers and whānau, what is missing, or what else could we provide that could support you and your whānau?

Key findings on more choice and control

Overall summary

People highlighted the importance of flexibility and choice in the services provided to ensure that support is personalised, holistic, and can quickly respond to changes in need (allowing for spontaneity).

For people, flexibility and choice is predicated on (1) knowing that support is there and what options there are, (2) having enough funding to access support, (3) the ease and timeliness of accessing supports, including sufficient flexibility for how funding can be used, and (4) having an adequate number of and meaningful variation in quality support options to choose from. Suggestions related to all four of these aspects.

People advocated for simpler administrative processes and fewer restrictions as well as guidance to understand and navigate support options to make access easier, particularly regarding funding. People also wanted to see more support services and a more diverse range of services to choose from.

Survey respondent preferences

- > More options and more smaller providers were selected by more than half of survey respondents as ways that DSS could offer more choice and control in accessing services. More support to help access mainstream services was selected less often, but still by 42%.

What people said

How DSS could improve or add to services so they work for all

- > Improving funding, mainly having less restrictions on the way that funding can be used, was the most often reported way that DSS could improve services to work well for all users.
- > Secondly, but still a large topic, people supported improving service delivery by having more providers, and more support when it is needed or at times where there is currently a shortfall such as at weekends, evenings, or rurally.
- > Streamlining the processes required to access supports was another suggestion frequently raised, as was providing support that is flexible and responsive to need.

Considerations for children and young people

- > With regards to children and young people, social and community connectedness were considered important aspects, as was feeling a sense of belonging and being supported in education.
- > Milestones and transition points such as adolescence, in and out of school/education, and into housing or flatting situations were pointed to as important things to consider for young disabled people, all requiring proactive support and attention.

Additional thoughts on flexibility and range of DSS services to help deliver better outcomes for disabled people

- > Additional thoughts about the flexibility and range of DSS services typically mirrored previously stated points, however, problems navigating 'the system' were frequently emphasised, as was the need for more, or more flexible, support options.

What we heard

Providing services that work well for all users primarily comes down to allowing more flexibility in the ways that people can use funding

What more choice and control would look like

- > People have real choice in who, when, where, and how they access supports.
- > People are trusted to use funds on which aspects are a priority for them, and if/when priorities change, funds can easily be directed elsewhere.
- > In contrast to funding that is tightly tied to certain uses, people want to be trusted to apply funding to what their needs are.

A holistic view of people's lives is needed when considering disability supports

What more choice and control would look like

- > Funding must account for unstructured, "in-between" support as well as the bigger, more obvious needs; fragmented funding does not always match the realities of day-to-day life. This might mean making time and budget allowances for disability-related fatigue, or the time it takes to build relationships and trust.

Providers need to be (a) available, (b) well-staffed, and (c) be good quality if disabled people and whānau are to feel comfortable using them

What more choice and control would look like

- > There must be more providers that offer a range of support services; many feel that services are lacking for either themselves as a disabled person or for someone they are caring for.

- > Daytime, weekend, overnight, after-school, in-home, respite, or any situation in which a disabled person is accessing support needs to be staffed with people who know routines, that are reliably and consistently present, that are professional in manner and adequately trained.
- > The reduction of support interactions to transactional encounters where disabled people are positioned as passive recipients of care can compound over time to an overall unpleasant experience; managing this requires support staff with emotional and professional competence so that people are actively involved in their own support, rather than being acted upon.

21. Improving flexibility and choice when using funding

Respondents were asked: *Currently there are two main options for DSS support – flexible funding budgets, or a fixed range of services available from the providers that DSS funds. What could DSS do to give you more flexibility, choice and control in accessing services – without full responsibility for managing a flexible funding budget?*

Respondents could select: all that apply.

- > Support to help me access mainstream services
- > Offer an increased range of options for care so I can choose who provides care and when it happens
- > DSS could fund a broader range of smaller providers that I could choose from, such as a friend or someone in my community
- > Other (please write)
- > I don't know

n=316

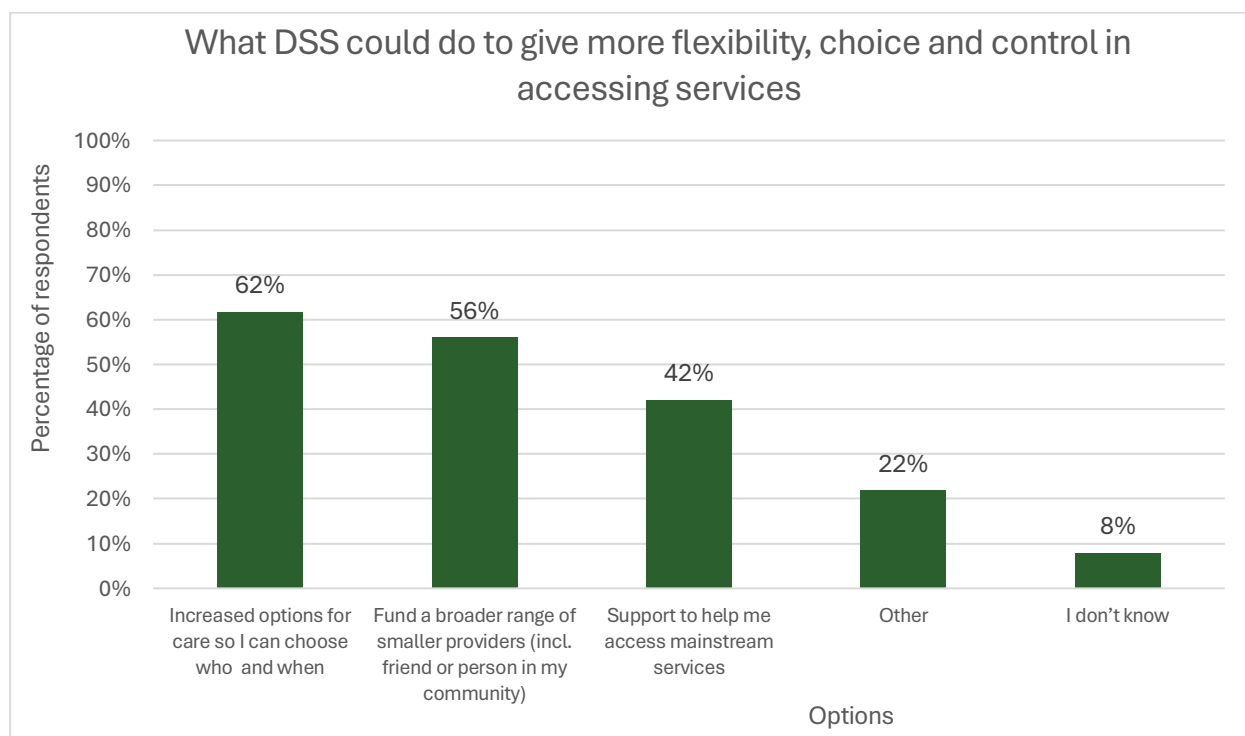


Chart 12: What DSS could do to give more flexibility, choice and control in accessing services

Findings

- > The most popular selections, chosen by 62% of respondents who answered this question, was to *offer an increased range of options for care so I can choose who provides care and when it happens*.
- > A similar proportion (56%) selected *DSS could fund a broader range of smaller providers that I could choose from, such as a friend or someone in my community*.
- > Less than half (42%) selected *support to help me access mainstream services*; considering that respondents could select as many responses as they wanted to, this option represents the least popular choice.
- > A small proportion (8%) stated they *did not know* and just over one in five respondents (22%) offered *another perspective*.

Points made by those who selected *Other*.

- More autonomy, choice, flexibility in how I use budget for support, including making it easier to do so via removing barriers/admin (36)
- Assistance in navigating the system (11)
- More choice in providers (6)
- Four or fewer respondents made additional comments or requests such as more funding, help to do more activities, more information on respite, and, assistance to find work.

22. Providing services that work well for all users

950+ comments

Respondents were asked: *How could DSS improve, or add to the services we provide, so they work well for all users?*

Funding improvements (255)

A very large number of comments were made on the various ways in which funding impacts on the way that services are provided.

Less restrictions, more autonomy, choice, and flexibility (153)

A large number of comments assessed DSS funding as too restrictive, rigid, inflexible, or not responsive to the needs of disabled people. Often this sentiment was paired with a call for DSS to trust disabled people and their whānau to manage their funding with full autonomy and choice to meet their needs. A significant barrier – as argued by a considerable number – was the administrative burden of accessing IF.

Not being questioned for all purchases (and need to be answered) [Host] ask the same question for each purchase.

Many families do not necessarily want full responsibility for managing a flexible funding budget. They simply want enough flexibility to make decisions that genuinely work for their circumstances without unnecessary complexity or scrutiny.

Further, many supported the notion for funding eligibility criteria be expanded and to remove restrictive categories of support. Implementing direct personal budgets through EGL principles to facilitate full choice, autonomy, and flexibility was supported by a moderate number.

I enjoyed my EGL funding where I have one personal budget and I can tailor it to my needs, which change often.

A moderate number of comments were made that supported having the ability to directly pay whānau as paid carers as opposed to an agency. The main points articulated in support of this were that family and whānau understand the needs of their loved one best; that this is a more trustworthy and convenient system; concern over the high cost of using service providers; and a general embodiment of more choice and flexibility within daily lives.

The current system tends to favour formal providers, but that should not be the only option available. Families should have greater flexibility to use trusted people who already know the disabled person and have existing relationships with them, where appropriate safeguards are in place. For my son, trust and familiarity are extremely important.

More funding and financial support (40)

In the context of providing services that work well for all users, a considerable number of comments were made simply stating that more funding and financial support is needed. This applied to the disabled person themselves, carers receiving more support, and generalised support for services to receive more funding. The example below is one of several where people outlined the high cost of items required simply for daily living.

[Name]'s iPad (primary means of communication) cost \$1000 and he has three to keep up with flat batteries and usually one is always in repair. He is really lucky we have fought for funding for one and self-fund the others. iPads and communication therapy for non-verbal people should be a right.

Some made broad requests for “more funding”, while others elaborated, for example that increases in financial support be linked to inflation, that support not be taxed, that it is difficult to afford to get the supports that are needed, and a few who stated that funding

needs to increase just to meet basic needs including adaptive equipment. A few made reference to funding cuts.

Provide more funding so that we can actually afford the supports that work.

Having the right amount of funding to meet support need.

Praise for, and support for maintaining IF (18)

A moderate number discussed their positive experiences with IF and were in favour of DSS maintaining flexible funding options. IF was said to be “fantastic”, it was appreciated, and the removal of restrictive purchasing rules was said to be a “real and useful” change.

For us and for lots of others, the beauty of Individualised Funding is being able to pay family but also to step out of that and pay carers when they are available.

Taking away this convenience will trample on people’s choices.

Other commentary raised in relation to funding improvements included a request to be able to pay their cleaner directly, as well as vocalising concern for funding cuts if they did not use it all within a year and should not be interpreted as a change to the person’s functional needs.

Improve service delivery from providers, hosts, fund holders (141)

A large number of comments were made about the ways in which providers, hosts, and fund holders could work to improve the experience for all users. Having a wider range of providers, a wider range of better providers, and extending the availability to access these supports was frequently discussed. People often simply wanted there to be more providers and support workers, more choice in receiving supports from smaller organisations, and more options at times outside of the typical nine-to-five working day.

More support services available in smaller areas. Only the bigger cities tend to have well set up services with good staffing numbers. More resourcing and effort needs to be put into smaller areas.

The quality and cost of [some] facilities is appalling. I feel most of the clients using these facilities would be hostage customers (i.e. only using them because they have no other options).

Similarly, people wanted to have more flexibility and choice as to *when* they received support, *how* and by *who*. People would like to create their own schedule for their support times, including choosing the service and support workers, as opposed to feeling like they are being dictated to. Consistency, continuity, and good communication with support workers and providers was also expressed as being important in improving service delivery from providers.

Exercising our right to choice and control with support worker agencies raises the risk of being seen as difficult and having this service withdrawn.

One person that I can trust and depend on to do everything – rather than different people from different agencies.

Support workers receiving better pay and training was mentioned, as it was throughout other sections of the consultation, as a way to offer better, safer, support for people using DSS services. Other points raised elaborating upon this point included: vetting of support workers, receiving supervision, and providers investing in more robust training for their staff. People report that the highly personal nature of the support worker’s job requires a skilled employee but that this isn’t always what the disabled person gets.

Ensure the funding reflects the costs so staff can be remunerated at appropriate and equitable rates and the providers are able to fund improvement and training which then helps with safeguarding and consistency, choice and trust.

It is increasingly difficult to get good support workers, and this means we are often forced to employ support staff who are not ideal or go without hence increasing the burden on family/whānau.

Support workers need more resources. Losing support workers due to lack of pay and respect. Need to validate the role of support workers.

Additional commentary and unique points included that transparency, specifically in relation to funding allocation, payments, and remaining balances disappearing at the end of the year, was an issue. People also talked about the need for DSS funded agencies to have regular auditing and monitoring, as well as publishing information on workplace turnover. Other points raised focused on ensuring agencies are inclusive in their recruitment for support workers, as well as a critique for agencies not allowing support workers to drive which restricts disabled people's access and participation in the community.

Fund holders take a percentage of the disability budgets with varying degrees of success. My personal experience has been staff that don't know or understand the funding rules or the difficulties families face. This is a real concern as it means 2 people with the same budget may be getting vastly different support and treatment depending on who is administering their budget.

Streamline processes and information (118)

Coordination and consolidation of services (42)

A considerable number illustrated the point that improving multi agency coordination and consolidating information would ensure all users receive the right support at the right time. Statements such as "more consistent across New Zealand" and "better coordination to address issues, i.e. health services 'pigeon-holed'" were made alongside broader descriptive accounts of the ways that this impacts people's ability to access services.

This suggestion was often given in light of frustrations shared by people about navigating a fragmented system and having to continuously repeat their stories.

Consistency of information on a national level and communication between agencies and regions were also suggested.

Government interactions create inflexibility – Ministry of Education funding ends which creates service discontinuity which can be challenging, particularly when the disabled person relies on consistent relationships. That approach is not person centred. Agencies are siloed and that needs to be addressed to create flexibility.

More information about services available (39)

A considerable number of people talked about having more information about services, while frequently calling for consistency of information, ease of navigation, and having greater understanding of about their eligibility.

Tell people what services are available and who provides them in their local area - travelling across town with a child when you work full time is too expensive and time consuming.

Less administration, quicker outcome (34)

A considerable number of people called for a more responsive system by which choice and control should not be contingent on a person's administrative capacity. People also frequently called for processes to be easy to navigate, and predictable, as well as that outcomes should be known in a timely manner, alongside justification for decisions made.

Reducing administrative burden and ensuring decisions are made more quickly.

DSS should offer responsive, low-bureaucracy adjustments to hours, workers, funding use, and support types.

Suggestions for more supports (115)

Broader range of support for disabled person (81)

A sizeable number discussed various ways in which support could be broadened for disabled people, with the most common point articulated being more community services and supports. A considerable number specifically requested more investment in peer-based support groups in the community. Others noted they wanted to see more opportunities for community accessibility and involvement.

Peer support programmes led by disabled people, funded stably rather than by short project grants. The most useful advice I have ever received about living with MS in a wheelchair came from other people in the same situation, not from clinicians or NASC assessors.

Providing and funding a range of transport options was supported by a moderate number.

Lotteries is the only current avenue for adapted transport owned by an individual. Shouldn't be a "roll of the dice" to see if you will receive a grant to pay for accessible transport. Without access to fundamental needs, I cannot be successfully engaged in my own community.

Other suggestions for a broader range of support for disabled people included support to be culturally responsive, for specific conditions, advocacy support, wellbeing and mental health support, as well as greater access to adaptive equipment and technology.

More support for caregivers, parents, carers (34)

While suggestions were offered for a broader range of support for carers and whānau, people also emphasised that support should also come in the form of acknowledgement for the obstacles family carers face. People expressed the need for improved coordination, earlier intervention, upholding carers' rights, adequate funding, and better respite options. Regarding a broader range of support, more opportunities for coaching, mentoring, and peer support networks for carers was supported. A holistic understanding of the whole family's needs was also illustrated as being of high importance in this commentary.

Exhausted mothers are supporting disabled children while managing their own disabilities. This is impacting on safety of children and also mental wellbeing of the parents. It is not just about funding. It is about the whole family. Need to take on board the Whānau Ora model. It is about the whole whānau, not 'us and them'.

Support being holistic and responsive to need (109)

Flexibility is an integral theme interwoven throughout most of the commentary in this engagement. Comments summarised here are those that reference flexibility in a holistic, generalised sense, with the most prevalent point being that support should be responsive to need. People frequently conveyed that services need to be person directed, facilitate meaningful choice and autonomy, embody genuine flexibility and be less restrictive. A key sentiment expressed was for support to be responsive to the diverse and changing needs of disabled people and their whānau; goals and aspirations; and life circumstances. People sometimes underpinned these points by stating that choice and control only exist when disabled people are trusted to make autonomous decisions about their lives.

To work well for all users, DSS services need to be accessible, flexible, and designed around the diverse experiences and goals of disabled people. While a standardised approach can support consistency, services also need enough flexibility to respond to individual circumstances, identities, cultures, support needs, and life stages.

A moderate number offered suggestions for how the above could be implemented in practice. More choice and control to who provides support as discussed prior, in addition to measuring flexibility through outcomes, instead of fixed service models and inputs. A way to achieve this is through embedding EGL principles into DSS funded services, and establishing trust through communicating with disabled people in person-centred ways to increase their sense of self determination and choice.

Tailor some examples, share some flexible ideas. Pictures, accessible info, how does it work?

Collaborative partnership with disabled people and whānau (70)

A substantial number of comments were made that emphasised the importance for greater collaboration and partnership between DSS and people using DSS services. Disabled people and their whānau want to be active participants in decision making about their support and not seen as passive recipients. Acknowledging and recognising that disabled people, carers and whānau are experts in their own lives was commonly expressed, as well as DSS being responsive to family's needs as a whole. People also conveyed the importance of culturally responsive, safe, and mana enhancing partnership with disabled people and their whānau.

Ensure ALL whānau using the services of DSS have the full capacity, ability and accessibility to consult on ALL decisions made for and about tāngata Hunga Hauā by determining what's best for us and our needs in all areas and in all processes; including the services we require.

Parents advocating and hustling to make things happen. We were not being listened to. We want DSS to be our allies – come alongside us and help us with this situation. Trust that you will help us. Assume competence with the families.

Criticisms (30)

Criticisms varied in severity, however most discussed feelings of mistrust, confusion, inconsistencies, power imbalances, gatekeeping, and displeasure of changes to the disability sector in the last few years. People felt that outcomes for disabled people have worsened, and that increased responsibilities and administrative complexities continuously burden disabled people and their whānau.

The last few years have been rough on the disability community. We would like things to stabilise. We are triggered every time our budgets are up for review, afraid that funding will be taken if we don't say the right things. Please treat us with respect and care. We've been through a lot.

Then there's a bit of jealousy on people working, oh, you're on the benefit, but it's like, I have a disability. What the hell are you on? You don't know my life. You don't know me. You don't know how bad it is. Like, you don't know how hard it is for me to stand here and talk to you right now. It hurts.

Assessments and reviews (24)

A moderate number of people made various points about needs assessments and reviews. The main sentiment expressed was that assessments, reassessments, and reviews should be more flexible and responsive to the needs of the person as opposed to a standardised approach. Sometimes paired with this sentiment was the notion that reviews or reassessments can induce anxiety.

Annual reviews should not be mandatory for people whose needs are stable or who do not want a yearly review.

Require [provider] to assess based on the need not the name of the condition so people with similar needs (e.g. for wheelchairs) can all get them, even if their conditions are different.

Assessment should have a little more nuance to it, it should consider the impact of disability. Impacts of disability should be funded under a personal budget.

Competency and training of assessors was also mentioned, with one person noting assessors should be knowledgeable about local community supports in their area.

Other commentary

Several people showed support for connectors, and educators to help people navigate supports. A small number requested additional information and support for specific disabilities.

23. Considerations for children and young people

300+ comments

Respondents were asked: *Are there specific considerations or different types of services we should make for children and young people?*

Social and community connectedness (51)

A considerable number of comments were made calling for greater consideration of the need for and benefits of young people having more opportunities for recreational activities, social development, and services in the community. Recreation activities were frequently discussed, such as camping, holiday programmes, sport, gym programmes, trips and outings, with a request for accessible transport and funding to do so also noted.

Yes. It would be great to have access to more affordable holiday and weekend programmes for young people with disabilities. Currently, if my son wants to attend community activities, I need to pay for both a support worker and the activity itself, which makes participation very expensive. I have recently started driving him to the nearest city once a month so he can attend a group activity. While he enjoys this and benefits greatly from the social interaction, it also involves significant costs, travel time, and transport expenses. As I am required to remain nearby while he attends the programme, it often takes up the entire day. Although I am happy to support him to access these opportunities, the process can often feel more like a logistical challenge than an enjoyable outing. However, I continue to do so because social connection and community participation are extremely important for his wellbeing.

Further, people discussed the importance of opportunities for support and services to extend beyond “basic care” and to encompass more opportunities for relationship building, cultivate independence, foster a sense of belonging, and confidence. Occasionally paired with this sentiment was the call for more peer-based opportunities in communities for younger people to attend.

There should also be more consideration around services that provide a sense of understanding, belonging and community for young people. A large gap in the disability space, particularly around autism, is social spaces for young people, or spaces for young people to learn about their disabilities. Peer support, social groups, and spaces for young people to interact with adults who share their disabilities could be incredibly valuable for their long-term social and mental wellbeing.

Inclusion, support in education (45)

Support in education for children and young people was noted in a considerable number of comments. Commentary focused on technology, equipment and various forms of learning support for children to foster belonging, participation and inclusion in school. A few people called for additional training for school staff, having a therapist in schools, focusing on transitions, as well as considering travel and transport to and from school.

It is important that children and young people have access to the right technology, equipment, learning support and opportunities to participate alongside their peers. They should be supported to build confidence, develop skills and be included in their communities.

Funding suggestions and concerns were also addressed in relation to inclusion and support in education for young people. Suggestions were made to expand funding to include a greater variety of support such as specialist services and assessments; funding to help with schooling fees for whānau; and overseas remote study. Others claimed that there was not enough funding in school hours and requested flexibility for this. People offered various criticisms of funding concerns relating to not receiving funding from MOE; the inflexibility between navigating funding between DSS, MOE, and MOH; and queries relating to whether

IF could be used to fund teacher aides and support in instances of ineligibility for ORS funding.

Care for children should not be limited to outside school hours, the very nature of the disability means they may not be at school.

Flexible funding should be flexible. Even if a service is available elsewhere, if it supports a person and is manageable within budget it should be allowed e.g., speech therapy/ communication services.

Transitions and milestones (40)

People tended to discuss the importance of all milestones and transitions within a young person's life, as well as a continuation of support for young adults. The most commonly discussed milestone was youth to adulthood (note that this topic is addressed in more detail in Question 7 of this report).

People wanted to see services that are more flexible and adaptable to young people's needs, services that are proactive with better transition planning at each milestone, and services with regular reviews to protect long term wellbeing. A continuation of support for young adults was also discussed, with more support being offered for finding employment, suitable housing, and transitioning into vocational or tertiary education or training.

Support should be provided early and be flexible as their needs change through different stages of life, including starting school, moving between education settings, developing independence and preparing for adulthood.

Support carers and whānau (33)

A considerable number of comments included appeals that more consideration and acknowledgement for carers of children and young people be offered, alongside more financial support. The economic consequences of not being sufficiently supported financially, as well as loss of income were common points made. Further, people made requests for a more family centred approach, with the needs and inclusion of the whole whānau (particularly other siblings) being considered when working with children and young people.

For children and young people, support is most effective when it strengthens the whole family system. Parents and caregivers often carry significant responsibility, so services should include practical support, guidance, and respite that helps sustain family wellbeing.

Listen to youth about their needs (21)

A moderate number of people were in agreement that there should be better consultation with young people regarding their needs, aspirations, wishes, and experiences and require supported decision making. A few discussed a more mindful approach for assessors is necessary when doing assessments and reviews, to build trustworthy relationships with families and capture young people's voice. A few others emphasised the importance of culturally responsive support.

ALL tamariki and rangatahi Hunga Hauā deserve the right to consult on their needs, as an adult Hunga Hauā (always, where possible otherwise - their usual whānau/ carer/ advocate should have the opportunity to do so on their behalf).

The person/people providing support would be sensitive to what is important to our culture. People would seek cultural advice when designing and developing services and resources.

Generic agreement for flexibility (20)

A moderate number of people made comments to the effect that specific considerations must apply for services for children and young people. Most of the comments were blanket

expressions of support for flexibility, consistency, attention to each young person's needs, more funding, and more services.

More respite and appropriate options (18)

A moderate number called for more respite options: age-appropriate options; the ability for parents to stay with their child; clear information regarding respite options; and more flexibility as to what services can be considered respite.

A key consideration is ensuring that young people have access to age-appropriate environments and support networks. When young disabled people require hospital-level care or residential support, being placed in combined aged care facilities can create significant barriers to wellbeing and belonging. While these settings may meet some clinical or care needs, they may not provide opportunities for young people to connect with others their own age, develop friendships, participate in age-appropriate activities, or maintain a sense of identity and independence.

Other commentary

Other unique points were raised in smaller numbers, these included:

- > Several people wanted to see specialist therapies made more available to young people to address mental health, communication and sensory needs;
- > Calls for suitably trained staff to work with children and young people;
- > Assessments and reviews to be flexible, require more information, be transparent and accessible;
- > Early intervention and proactive supports are required;
- > Clearer information for eligibility of supports, with a couple of respondents noting support for home help should not be means tested;
- > Inter-agency working between health and child education services;
- > More education on safety and safeguarding;
- > DSS to listen and collaborate with existing community groups and organisations for a more sustainable, inclusive response and supports; and
- > More support for young people who are incontinent.

24. Additional thoughts on flexibility and range of services

200+ comments

Respondents were asked: *Can you provide us with any additional thoughts you have on the questions you have just answered, or on the flexibility and range of services that DSS provides, including any services you feel should be added to help deliver better outcomes for disabled people?*

Navigating services and accessing supports (41)

The most common point made when asked about additional thoughts on flexibility and the range of services that DSS provides is that navigating the system to access those supports, no matter how flexible, is difficult. This was expressed in a range of ways.

Supports are inflexible, narrow, and inaccessible.

Families often spend significant time navigating complex systems and funding process. DSS should focus on reducing administrative burden while increasing flexibility and choice.

Overall, my biggest concern is that the disability support system remains extremely difficult to navigate... Families can find themselves moving between Disability Support Services (DSS), ACC, Health New Zealand, MSD/WINZ, education services, mental health services, and community organisations, all with different rules, eligibility criteria, forms, and assessment processes.

People also supported expanding the range of services that are available, reducing barriers to support, better inter-agency coordination, and use of connectors or navigators. All of these were described as ways that supports could be accessed more easily – in fact several comments pointed out that definitions of flexible, or what passes for flexibility in DSS services, is not as simple as it may seem.

DSS should recognise that arranging support is itself substantial work. Practical assistance with forms, meetings, recordkeeping and coordination would reduce the unpaid workload that currently falls on families. Flexibility must not mean transferring government administration and risk to disabled people and families. Nor should fixed provider services mean accepting whatever happens to be available. A better system would offer personalised choice with practical support to implement it.

Supports suggestions (34)

A wide range of additional, supplementary, or basic supports were noted by people as currently lacking or that are important to consider. These included psychologists, dieticians, transport, access to public or private spaces that are calm and/or quiet, specialist health care appointments, communication support, early intervention support, expanded in-home care, evening and weekend care, support for rare conditions and under-recognised disabilities, nursing care, peer support, more residential options, and more and better NASC representatives.

The call for “more support” was also made, both in simple terms and in specific instances such as rurally and for people with higher needs.

Increase the range and variety of services that are funded by DSS providers.

Keep it flexible but expand the reach and availability of services.

Lastly, flexibility in and of itself was supported, in ways that were not expanded on, e.g. “the strongest message I would like to leave is that flexibility matters”.

Listening to and working with disabled people, representation (29)

With respect to flexibility and the range of services DSS provides, a considerable number discussed the importance of working with disabled people around what specific support needs there are, about the importance of co-design in the systems that people interact with, and the need for genuinely understanding the needs of people accessing DSS support.

MSD staff don't have sufficient understanding of complex disabilities and as such disabled people will be at further risk if changes lead to MSD management.

Overall, DSS should continue to listen to disabled people and their whānau, reduce barriers to accessing support, and ensure services are flexible enough to respond to changing needs throughout a person's life.

People called for DSS to "LISTEN", they want to be "asked personally" about their needs, and they want to have their capacity to engage in administration acknowledged and understood. One respondent urged that decisions should be left "to the disabled person or family".

Funding (28)

Funding and having the costs of services and equipment paid for was said by a considerable number of people to be paramount to them and their ability to live life. While IF was said by one person to be "huge" (hugely beneficial), for most others who talked about funding, they stressed that funding and budgets simply need to cover the cost of what the disability requires.

Better funding to allow us to cover the cost of disability - adaptive clothing is 10x the price of 'ordinary' clothing.

Some of the toughest times can be made much worse by the gate keepers holding funds.

Allow people to adjust supports as their needs change without requiring repeated reassessments or rigid service categories.

In some cases, situations were described where funding did not adequately cover the need for specific items, clothing, occupational therapy, transport, cleaning, and medications.

Transport – without flexible funding I am stuck, with all the upheaval that's going on, nobody is getting reassessed; we need more accessibility.

Negative experiences or criticisms (22)

A moderate number of people made comments describing less than ideal situations they have experienced in accessing support to meet their own needs or the needs of those they are supporting: these included being talked down to; dismissed; being treated with little or no empathy; being given inconsistent information and advice; long waits for responses; funds being withheld in a seemingly arbitrary manner; and generally encountering a DSS support system that is more inflexible than flexible.

One revealing comment was made by a disabled adult who has experienced a degradation in quality of life from the changes in support they were eligible for.

I understand that disabled adults don't elicit the same emotional response from voters, but we actually do still need support and struggle to get it because everything is aimed at children and parents... [if support] is ripped away on the whim of an MP who is ableist ...some of us, like myself [are left] struggling with no support, [I] was in higher education, and didn't want to go to a day class on making pasta art when I was already doing a full time STEM course.

Other commentary

Several statements were made on the utility or benefits of flexible funding or IF. Similarly, a “self-managed budget” was characterised as working well, and some providers were individually named in a positive light.

I have found Individual Funding fantastic. It allows me to employ my own support workers, ensure my goals are achieved by being involved in making decisions around my annual budgets and I am well supported by a more transparent host agency.

Several others cited EGL as a useful and appropriate framework stating that its principles fit well with their household and should be embraced by DSS and its providers. Though there was criticism of the idea that family should be the first line of support, others talked about the importance of family supports, often in the context that these supports should be acknowledged, or that the labour demand on family is high and can take a toll (this is discussed in greater detail in Topic Four).

Backup and emergency support: People need a clear alternative when a support worker is unavailable, a provider closes temporarily or a primary carer becomes ill. Families should not have to create every contingency themselves.

Topic 6: Improving information and advice

DSS prompts used in engagement

Introduction to survey questions 25 – 30

We want to understand more about your experiences trying to get the information and advice you need from DSS, so we can do better.

Relevant workshop discussion point

Topic D: Information and advice, feedback and complaints: How can we improve the way information flows both ways so it works better for you – both when you're seeking advice or support, and when you want to give feedback or make a complaint?

Key findings on information and advice

Overall summary

Accessible, reliable, accurate, and high-quality information was said to be vital for accessing supports. People expressed the need for a centralised source of information provided in a variety of accessible formats that paints a complete picture of what supports are available (collated from a variety of sources), the process for accessing them, and how the system operates more broadly (such as indicating which agencies are responsible for what). Common points raised were the need for clear and simplified information as well as an easily accessible way to find information that is relevant to the person searching for it. Consistent with quantitative results, issues finding information, and the quality of that information were often related in qualitative feedback.

Survey respondent preferences

- > Respondents were most likely to get information about supports via NASC/EGL; community groups and peer networks were a close second.
- > The biggest challenge faced when accessing information about DSS – found by just over half of respondents – was that it was hard to find; a third of respondents felt information was not good quality.
- > There was majority support for all three of the options regarding the information people want from DSS – mostly so for what services DSS provides.
- > To make it easier to understand and access information about supports, over half supported both clearer simpler information, and making it easier to find.

What people said

What would make it easier to navigate support

- > Qualitative responses reiterated the quantitative findings that people desire clearly articulated and accessible information; evidence of this also came via support expressed for consolidation of services or having a (one) person as a point of contact that can navigate on behalf of the person seeking information.
- > Sources of relevant information, including DSS, government agencies, and disability support providers, were said to be 'siloed', fragmented or dispersed and

hence, the information they provide is not always consistent or well understood by other parties.

Additional thoughts on the information that DSS provides

- > In addition to repetition of the topics noted in response to the above question, people added that certain roadblocks appear to exist in the flow of information from DSS to providers, groups, and ultimately those who seek the information. This was problematic and administratively burdensome for those seeking support.

What we heard

Coordination between agencies and systems and consolidating processes and information

What improved information and advice would look like

- > An information repository, containing relevant information consolidated across a variety of sources – including a complete catalogue of the support options available (including what has worked for others), and disability-relevant information.
- > An information system that offers a clear orientation point which then branches into more specialised and relevant information.
- > Information sharing arrangements across agencies and sectors to reduce the need for people to engage in repetitive processes.
- > Better linkages between government and providers, including independent contractors for NASC, between sectors, particularly between the health system/health providers, and disability support services.

A consistent, trusted contact who can provide one-to-one guidance – a connector, navigator, case manager

What improved information and advice would look like

- > A single person that has a consistent relationship with disabled person and their family and is familiar with the specific needs and capacities of both individual and their family.
- > Someone who is highly knowledgeable about the disability support system – who know what's available (including both mainstream/non-mainstream supports), and how to access it. They can use this knowledge to provide clear, tailored information about how the system works as well as provide practical support with applications, securing funding, contacting relevant people, and acting as an inter-agency conduit.
- > Someone who is easy to contact and is attentive to the communication needs of the family unit/individual. Some people wanted this person to communicate proactively or reach out regularly, while others preferred to initiate contact on their own terms.
- > Someone who has a positive, trusting, and enabling relationship with the disabled person and whānau. Someone who seeks to understand and help people identify their needs, and work towards solutions.

25. Sources of information about disability supports

Respondents were asked: *Where do you currently get information about disability supports from?*

Respondents could select: all that apply.

- > Needs Assessment Service Coordinator (NASC) or Enabling Good Lives (EGL) site
- > Another DSS-funded provider (not a NASC or EGL)
- > A social worker
- > My school
- > My workplace
- > Friends, family or peer networks
- > A community group for people with a similar disability to me
- > Somewhere else [please write]
- > I don't know

n=285

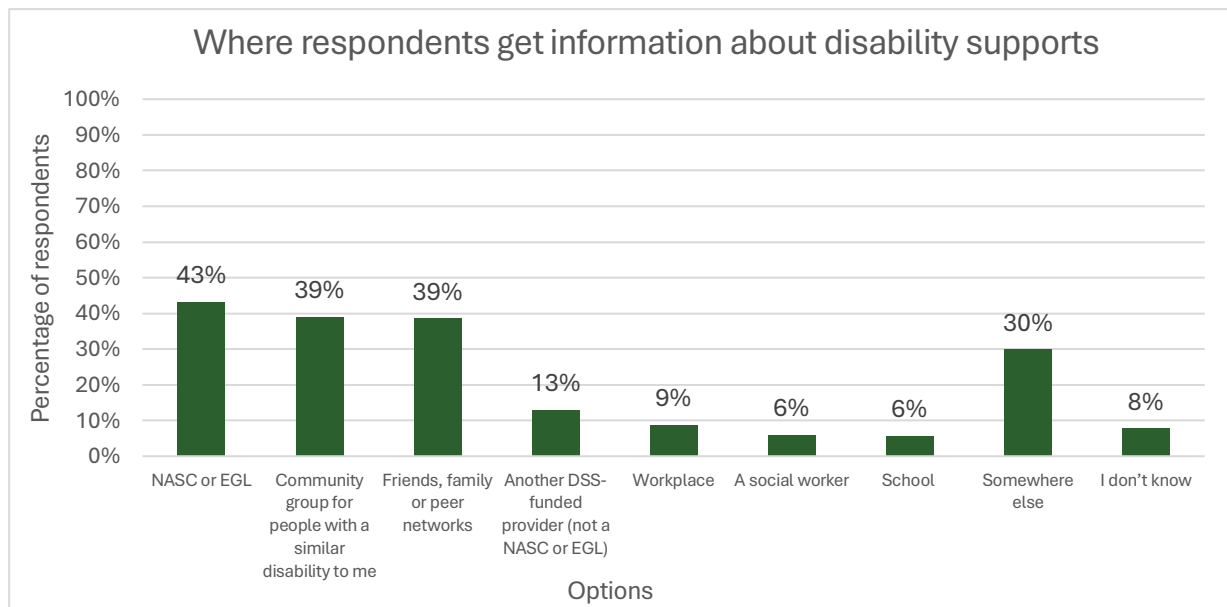


Chart 13: Where respondents get information about disability supports

Findings

- > Through *NASC or EGL sites* was the most common source of information for respondents (43%).
- > Both *community groups for specific disabilities* and *friends, family or peer networks* were selected by just over a third of respondents (39%).
- > Just over a third (34%) indicated they received information from alternative sources, with *social Worker* and *schools* both being the least common (6%) place where respondents get information about disability supports.
- > Eight percent (8%) of respondents *did not know* where to get information, and almost a third of respondents (30%) stated they get information from *another source*.

Points made by those who selected *Other*.

- o Online, internet, Google (27)
- o Community groups, networks, Disability Information Advisory Services (20)
- o Provider, agency, support person, connector, and other staff (19)
- o Social media, including community pages (18)

- I don't get information, or I rely on myself to collate information – including general criticisms of information being difficult to find (9)
- Official sources, MSD/DSS, government websites (6)
- Other word-of-mouth (5)
- Health provider or GP (4)
- Other sources of information each noted by one respondent included: education staff; 'all the above'; and news sources.

26. Biggest challenges accessing information about DSS

Respondents were asked: *What are the biggest challenges you face when trying to access information about DSS?*

Respondents could select: up to three options.

- > The information is hard to find
- > The information is not good quality (for example, it is hard to understand or is not complete)
- > The information is not in the alternate format or version you prefer (for example, NZ Sign Language, or screen reader formats)
- > The information is in the alternate format you prefer, but it comes out later than the main information it is based on
- > The information is hard to access (for example, it is hard to download or view, or comes out on a channel you can't use, like a phonenumber for a Deaf person)
- > The information only exists online, and you don't normally use online for information
- > I don't know
- > Other

n=285

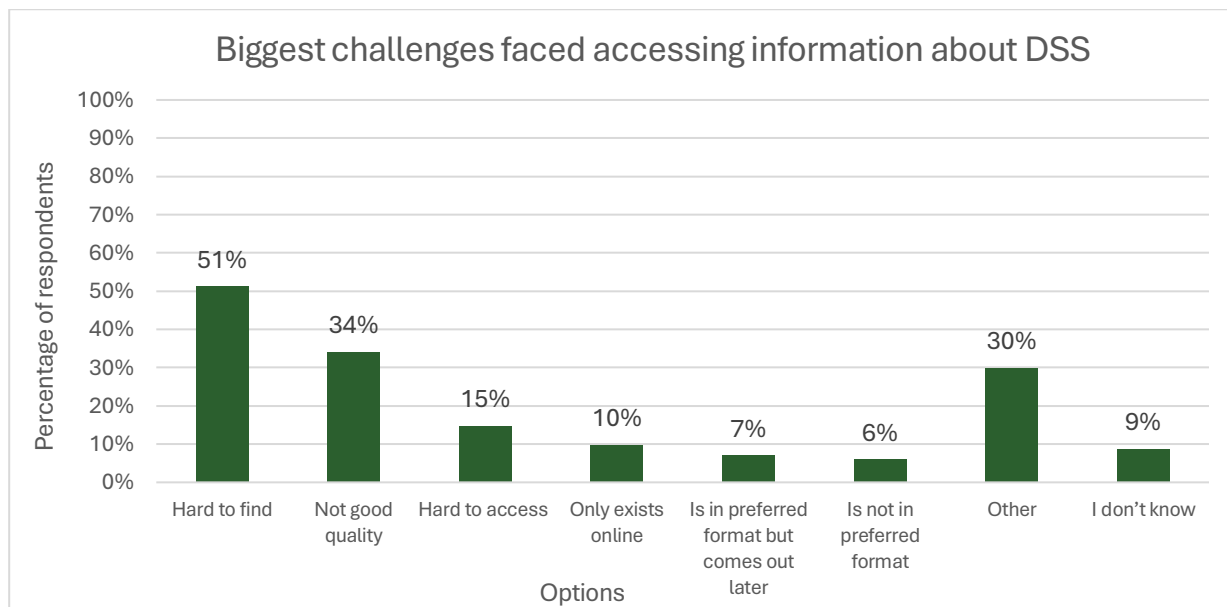


Chart 14: The biggest challenges faced when trying to access information about DSS

Findings

- > The most frequently experienced challenge to accessing information about DSS was that it is generally *hard to find*, selected by just over half (51%) of respondents.
- > Just over a third (34%) indicated that the information was of *poor quality*.
- > Fifteen percent (15%) of respondents indicated that information is *hard to access*.
- > Of the options, the least commonly selected option (6%) was that *information is not in a preferred format*.
- > Nine percent of respondents *did not know*, and just under one third of respondents (30%) selected *Other*.

Points made by those who selected *Other*.

- Information is hard to find; it is fragmented, doesn't exist, or it is hard to know where and what to look for (26)

- Existing information is not good quality; it is unclear, too wordy or uses overly complex language (15)
- It is hard to find accurate and up-to-date information; it is released too late, or it is difficult navigating and understanding what information is current due to frequent changes (14)
- General awareness of DSS is low, including respondents stating they weren't or are not aware of them (7)
- Difficult to find information relevant to personal situation (6)
- Fewer than five respondents each shared the following points: that there is a lack of communication from key channels; that they are not being listened to or helped after requesting something; that they experience no issues accessing information; and, that they prefer to talk to a real person.

27. Most important information about DSS services

Respondents were asked: What information do you want, or need, to know about the services DSS provides?

Respondents could select: up to three options.

- > *What services DSS provides*
- > *Eligibility for DSS services*
- > *About the process for accessing DSS services*
- > *I don't know*
- > *Other*

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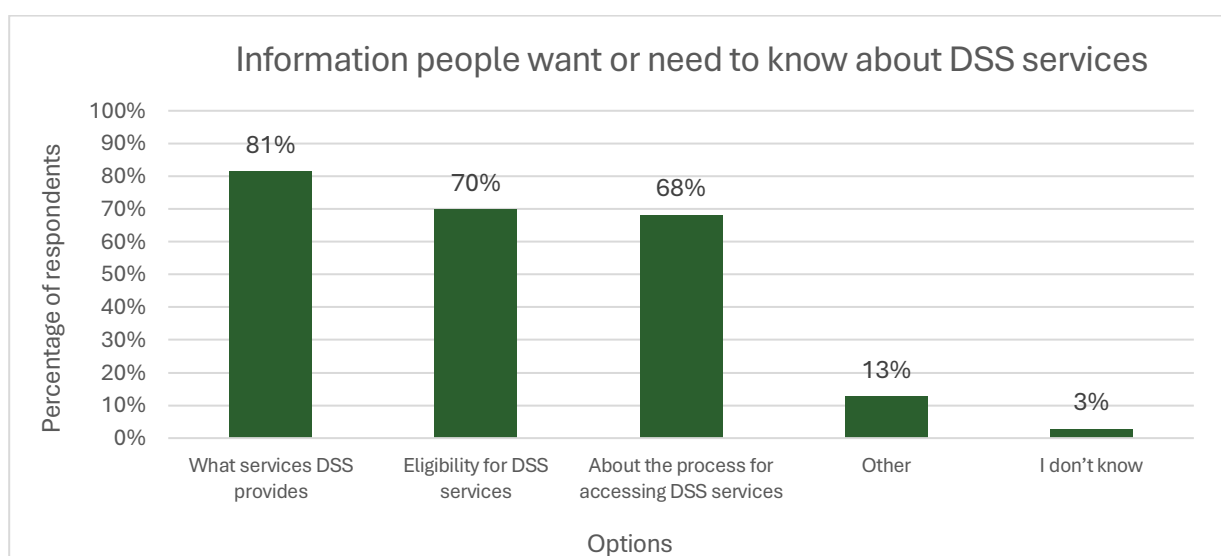


Chart 15: What information wanted or needed to know about the services DSS provides

Findings

- > Most respondents (81%) indicated that they would like information regarding the *services provided* by DSS.
- > More information regarding *eligibility for DSS services* was selected by close to three quarters of respondents (70%).
- > Information about the *processes for accessing services* was selected by just over two thirds of respondents (68%)
- > Thirteen percent (13%) indicated that they want to know information about a specific *topic outside of those listed*.

Points made by those who selected *Other*.

- Information about what support is available and where and how to access it (13)
- Proactively notifying and explaining changes or upcoming plans to the community, ensuring that this communication is timely, accurate, readily available, and that existing information is updated to reflect changes (6)
- Information about how the system works, who is responsible for what, and rationale for decisions made (5)
- Other ideas about information were shared by less than five respondents each, including the following: Being put in touch with someone who can address problems or answer questions; and presenting information better so that people can more easily find what is relevant to them.

28. Improving access to and understanding of disability support information

Respondents were asked: What else could DSS do to make it easier for you to understand and access information about disability supports?

Respondents could select: all that apply.

- > *Provide clearer, simpler information*
- > *Make information easier to find on the DSS website*
- > *Make information easier to find on DSS providers' websites*
- > *Provide information in more or different formats*
- > *Provide more community outreach or workshops*
- > *I don't know*
- > *Other*

n=285

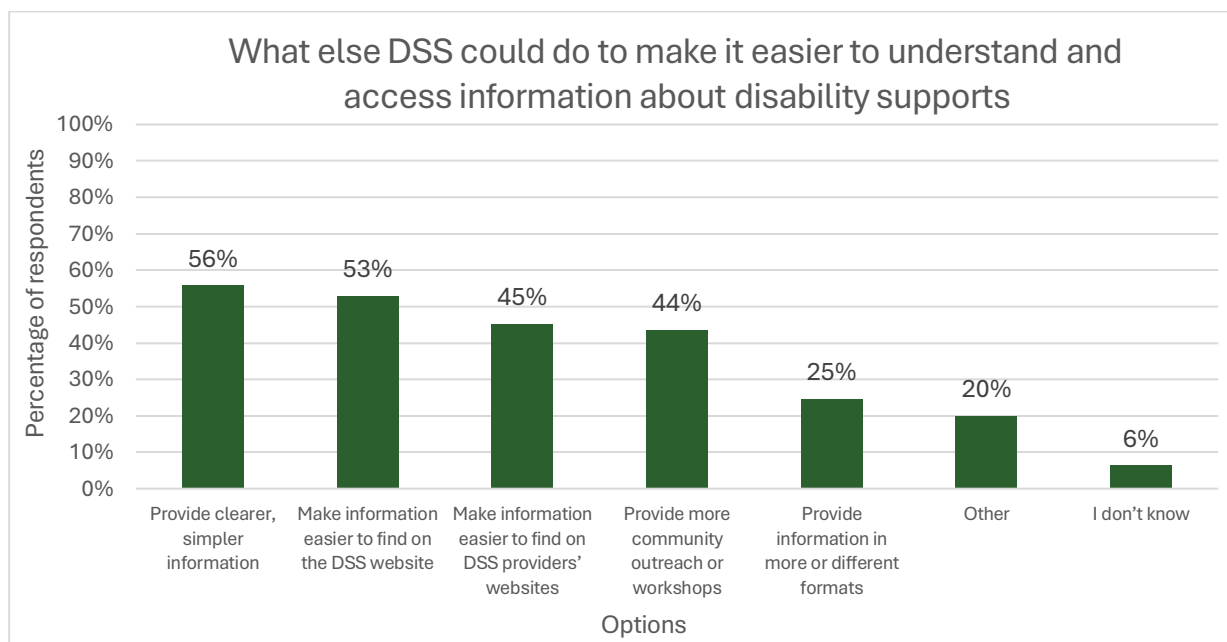


Chart 16 How could DSS make it easier to understand and access information about supports

Findings

- > *Providing clearer and simpler information* (selected by 56%) and *making information easier to find on the DSS website* (selected by 53%) were the most frequently selected ways to improve information comprehension and access, both selected by over half of respondents.
- > Similarly, *making information easier to find* and *providing more in-person community outreach opportunities* were also commonly supported by respondents (45% and 44% respectively.)
- > A quarter of respondents (25%) selected *provide information in more or different formats*.
- > One in five respondents (20%) selected *Other*.

Points made by those who selected *Other*.

- Provide a navigator role, someone to help with accessing supports, or consolidate cross-agency processes and information into a 'one stop shop' (7)
- Ensure that people are able to contact a real person directly, either via phone, email, or in-person (7)
- Ensure that all information provided is up-to-date and accurate (6)
- Inform community groups of changes or use them as a source for spreading information for better outreach (6)
- Provide more information and guidance about what is available and how to access it (5)
- Simplify and clarify information and processes (5)
- Other comments shared by less than five respondents each included the following: provide information in accessible and varied formats; stop changing things; address fragmentation and inconsistency of information across agencies; ensure that services and providers operate transparently and provide information to users.

29. Improving the experience of navigating support

650+ comments

Respondents were asked: *What would make it easier to navigate the support for disabled people provided by DSS and other government agencies or community groups?*

Clear and accessible information (145)

A large number of people stated they want to see DSS provide clear, easy to understand, easy to find information in a variety of formats and mediums that shows people how the system works, what supports are available, and how to access them. Comments generally emphasised the importance of clear, accessible information when navigating supports, as well as it being the basis for informed decision-making.

Good information is a critical part of enabling choice and control. People cannot make informed decisions about their supports if they do not understand what services are available or how to access them.

Accessible information is not simply a format. It is a way of ensuring people have the opportunity to understand their rights, explore choices and participate meaningfully in decisions about their own lives. Information should support supported decision-making by ensuring people have access to the information, time, communication supports and trusted people they need to express their views, make choices and participate in decisions that affect their lives.

People wanted greater clarity and simpler information provided about processes for accessing supports, eligibility for supports, what different agencies are responsible for, as well as a clear directory of what supports are available in different circumstances. People expressed the need for a clear, documented processes for accessing supports, including instructions or a flow chart of the steps involved and who to contact.

Clear information about: What supports are available. How to access them. Eligibility requirements. Why decisions have been made.

I have a vision impairment and prefer being emailed for information. [...] Instead of reading pages and pages, I would prefer to know up front what is required of me. I don't want the point of the communication to be dumped in the last paragraph after pages and pages of text.

Comments related a variety of issues with current information and communication processes, with people indicating that current information can be unclear, that it's difficult to keep up with changing guidelines and find up-to-date information, and that there were inconsistencies or ambiguity in the use of important terms. People also described having to read through large amounts of text to find relevant information.

Hard to find information at the DSS website, hard to search.

Better information, less use of the same terms for different things, clearer processes, better information on socials.

DSS website is bureaucratic and dry. Some social media but mainly the community. It is difficult to navigate through various websites because they constantly change. Websites have a lot of fluff – get to the point.

The other main point emphasised in comments was that information should be provided in a variety of accessible formats and use plain language to ensure all service users can access and understand it. Comments listed a variety of accessible formats to use including Easy Ready, large print, NZSL, as well as providing audio or video options. It was also noted that information files should be in a format that is compatible with adaptive technologies. People also frequently suggested that information should be provided in a variety of languages, particularly Pasifika languages, and te reo Māori.

Provide clear, plain language, Easy Read, aphasia -friendly, audio, large print, NZSL, te reo Māori and Pacific language information.

Some suggested using a variety of communication mediums or advised against relying solely on online resources to maximise the reach and access to information through the community. A moderate number of people specifically suggested in-person methods, such as workshops, or having direct contact to knowledgeable staff, with the ability to ask questions.

Information should be provided through a range of accessible formats, including face-to-face meetings, online information, email, websites, printed material, and social media. Websites and online information are useful, but they are not enough on their own. Some people need face-to-face conversations where they can ask questions, clarify what applies to their situation, and receive support to understand the process. Others may prefer email, printed information, phone support, webinars, videos, social media updates, or community meetings.

There are often expectations of digital literacy, or access to a phone/internet. This is not possible for all. Expecting digital literacy and only providing information digitally can be a barrier. It should not be assumed that all people can access all forms of technology.

People emphasised that information needs to be easy to find and that there are clear pathways for people to find information that is relevant to their situation. General suggestions included uncluttered, clear website design, and provision of clear directories or information about where to go to find specific information or who to contact for further advice.

Information that's easy to access not hidden away.

Everything has changed so much, with so many institutions. A pictorial showing who we should contact for what would be handy. Handier with the respective contact details for each institution.

Less text, use of visual literacy, modern app-like layout where it's easy to find things and click on them.

One point of contact or source of information (123)

A large number of comments were made to the effect that sourcing information could be made easier by consolidating sources into a single channel or offering a single point of contact or navigator to assist. This was viewed as a way to combat the diffusion of information and processes across a host of different agencies. This commentary largely echoed themes seen throughout consultation feedback, including the suggestion to provide a dedicated navigator role, as well as improving coordination and information sharing across government and sector 'silos'.

People used the following words and phrases that point to the difficulties in accessing information from providers and DSS: "Develop a single accessible information hub", "one person to deal with everything", and "having a central contact".

Explain eligibility, assessment, allocation, reassessment, flexible funding, carer support, complaints and review rights in one accessible pathway.

Commentary tended to either focus on consolidating information that people receive into a single authoritative source or on *combining* processes and cross sector information-sharing about an individual to reduce the need for people to "re-explain" their situation or engage in repetitive application processes. Although these were distinct suggestions, people frequently mentioned both would make it easier to navigate support.

People described difficulty knowing where to find relevant information, as well as understanding which version of information or guidelines applies to them, or which is the most current.

The information needs to be available in one central place, accurate, and kept up to date as well in alternative formats.

A single directory showing local service availability, waiting times, eligibility, costs and whether referrals are open.

Some comments combined a version of both ideas, suggesting that an online portal or in-person navigator could collate information about a person's disability support regime, including a host of relevant information about the person's circumstance, so as to provide individualised, tailored information. For instance, information relating to certain life stages, or relevant changes to guidelines.

It should be possible for a person to enter their own details – either identified or anonymised – and receive information about the funding and supports actually available to them, rather than generic information they then have to interpret for their own situation.

Reduce complexity of system, coordination of agencies (87)

A sizeable number of comments advocated for simplified systems for accessing support, for example by having better coordination of information between government-based agencies. Struggling to understand eligibility criteria and funding streams; repeating stories continuously; inconsistent and complex information; were common experiences shared, with people generally expressing that they find the system complex and tiresome. Multi agency coordination between DSS, Health NZ, MSD, ACC and other government agencies was commonly suggested.

The biggest challenge is that information is often fragmented across multiple organisations, websites, and agencies. Changes to policies, funding, and service eligibility can be difficult to track, and information is not always communicated consistently across the disability sector. This can create confusion for disabled people, families, whānau, aiga, providers, and advocates, particularly when changes affect access to supports and services.

People also generally conveyed that providing support to navigate the system would be beneficial. In a similar vein to previous topics, people supported information being organised in one central place, as well as presenting information in flow charts, to make processes clearer. Another suggestion was to allow people to submit incomplete applications or reports where there were delays in obtaining a diagnosis to make accessing support easier.

Alongside improving information, DSS should consider strengthening disability navigation services so that people are not left to navigate multiple government systems on their own. A well-informed and supported person is more likely to access the right support at the right time and achieve better long-term outcomes.

Proactive information sharing (74)

A substantial number made various points pertaining to DSS being more proactive in their sharing of information. The central idea was for DSS to clearly, concisely, and transparently provide information on full range of services and support available for people to access.

More proactive and transparent info and comms about services in all ways. Everything is behind doors and big unknown secrets as to how funding processes work etc.

Another aspect frequently noted was the lack of communication for changes and amendments implemented, supplemented by commentary in a disgruntled tone about a general lack of communication from DSS. People requested DSS proactively share information on the following: clear guidance and transparency for how DSS interacts with other agencies; providing information after a diagnosis so people know how to navigate the system; providing information before an assessment so people know how to prepare; and

clearly indicating eligibility entitlements, along with avenues to complain or provide feedback.

The pace of change within DSS, NASCs, and assessment, planning and purchasing guidelines has been significant, and it produces real change fatigue in the community. People need a clear, ongoing way to find out what has changed and what's proposed to change next.

Utilise information sources external to DSS, including community networks (70)

A substantial number provided diverse commentary for the ways in which existing DSS information could be communicated within the wider community, in addition to utilising information that already exists within community groups and organisations. People frequently wanted to see DSS providing information to other government-based agencies about existing supports and general information, with many referencing GPs and other health professionals as well as community outreach to marae and other community groups. A few called for information in the community to be shared in other formats other than writing, such as radio, TV, or at church galas.

GPs, doctors that's their role for carer wellbeing. Limited time of consultation 15 mins... Where was the suggestion from the GP for mobility parking, why did it take 5 years; where's the flyer basic stuff.

Further, people requested that DSS work closely with existing disabled-led community groups to co-design information, which would ensure accessibility, in addition to recognising the close relationships that disabled people and whānau already have with these groups. At times, people additionally requested EGL-based community groups and more pop-ups.

DSS should recognise the role of community organisations in building the capability and confidence of disabled people and whānau to understand their rights, navigate systems, develop support networks and access opportunities. Information is most effective when people are supported not only to receive information, but to understand it, use it and act on it.

Listen, understand, interact better (44)

A considerable number of people conveyed that navigating support would be easier if disabled people were listened to, respected, and understood, and more specifically, that DSS and service providers should make genuine and meaningful attempts to understand people's circumstances.

For some, this meant having people with lived experience in decision-making roles, for others it meant co-designing systems with disabled people, while others still simply wanted to see basic respect be afforded in all interactions.

We need a bigger voice and be seen and heard.

Not have people being judgemental or close minded or cross. Often they try to make out they are not these things but they are in reality.

[Name] must be involved in planning in ways she can understand and use. Information should be concrete, appropriately paced and supported by people she trusts.

People emphasised that DSS's focus should be establishing a person-centred, mana-enhancing relationship with disabled people which focuses on increasing capabilities, as opposed to enforcing compliance. Others supported DSS being more proactive in regularly checking in with people and providing reassurance when people are seeking further information.

Listening and understanding is vital to navigate support for disabled individuals. EGL treats information flow as a relationship, not a transaction. So the question becomes: How do we create communication systems that are mana-enhancing, simple, responsive, and genuinely two-way?

Right now it's a lottery and a large portion of Government Agency staff show zero empathy, care or respect to disabled people and their families.

Suggestions (29)

An array of specific suggestions were made in response to the question about what would make it easier to navigate support, each of which pointed to frustrations people have with current systems or to how improvements could ease difficulties. Suggestions included: more courses; accountability when decisions result in support not being provided; providing information about rights; DSS repeating back what was heard “after every consultation” (so that people know their points were taken on board); and, as was seen throughout consultation feedback, more funding for the provision of quality services.

Navigation should not assume that every disabled person can independently manage websites, phone calls, meetings and complex decisions.

Big space for DSS to provide knowledge and education – “train the providers”.

Other commentary

A moderate number of people made statements about inefficiencies in navigating information and support or otherwise criticised existing system. Comments noted “fragmented, inconsistent and late information”, that people are simply “unaware of their entitlements” and that policy seems made to “suit bureaucracy” rather than people’s needs. Alongside the person who couldn’t find this consultation in easy-read format, these comments reiterate others within this topic that navigating information is difficult.

An additional moderate number of comments were made in support of in-person communications (as opposed to online, email, or any other mode). These comments stated a preference for personalised information; a human being to contact that will address questions, give accurate, up-to-date information, and settle things at the time of the request rather than having to wait.

There is currently a lack of face-to-face meetings that explain what supports are available and how to access them. This is a significant gap.

A similar number of comments discussed the importance of services and service navigation being culturally grounded – a topic seen throughout the consultation feedback, and in this context the key points were that languages and cultural specificities shouldn’t exclude people from interacting with services. The phrase “culturally responsive” was used, as was “culturally appropriate”.

I want to talk with someone who knows what they are talking about, but who also understands my culture.

Lastly, another set of comments in moderate numbers specifically addressed timeframes for improving the experience of navigating support – comments called for: faster response times; contact opportunities outside of the traditional “nine to five” working week; and reducing delays overall.

30. Additional thoughts on information and advice provided by DSS

200+ comments

Respondents were asked: *Can you provide us with any additional thoughts you have on the questions you have just answered, or the information and advice that DSS provides?*

Note that the topics covered here are all covered in greater depth in response to previous questions (summarised above).

Accessibility, consistency, transparency (55)

Alongside a range of individual preferences and needs for the ways in which information could be communicated (in writing, online, email, face-to-face, in person, pamphlet, etc.), a range of comments simply argued that information be accessible, and that entitlements be proactively or transparently communicated/advertised. It was stated numerous times that “I don’t know about my entitlements” or that some go without supports simply for not having known they were available. This type of comment sometimes came with a degree of scepticism about the possibility that information is withheld or not given freely as a cost-saving measure.

The belief that information is being withheld was a source of frustration; calls were made that information “be provided”, be “passed down” and “be available to everyone that needs it”. As these comments suggest, at times it can be frustrating and difficult trying to get information about supports.

Information and advice should be treated as a core access issue. If people do not know what exists, whether they qualify, or how to apply, then the support is not genuinely accessible.

Information should explain what services exist and how to access them.

The effectiveness of DSS information should be measured by whether people obtain appropriate support with less delay, repetition and administrative effort- not by the number of webpages, factsheets, workshops or information packs produced.

When specific suggestions were made about the accessibility and flow of information in response to the question about additional thoughts, people reiterated that plain, easy-to-understand language (including avoiding jargon and acronyms) was preferred, as was the use of visual material, having multiple formats available, reducing the amount of sifting or searching through large amounts of information for what is relevant, and being aware of ‘information dumping’ particularly in the instance of a new diagnosis or change of circumstance whereby the person applying for support may be overwhelmed by the situation, let alone the need to make choices and consider options.

Life with disabilities can be very complicated and chaotic, the easier it is made to access everything the better. It almost feels like it is adding extra pressure to gain access to it currently

I think DSS provides important support, but accessing information can sometimes feel confusing and overwhelming for disabled people and their whānau. It would be helpful to have clearer guidance about what support is available, who is eligible, and who to contact for help. Information should be consistent across government agencies and community providers so people are not having to repeat their stories or search through multiple places to find answers.

A moderate number of comments urged that information be up to date, accurate, or consistently conveyed across whatever platform or provider that is publishing it.

Services, support, and navigating systems (32)

In line with the above, a considerable number of comments were made to the effect that making it simpler, easier or less complicated to navigate systems and services is vital if people are to access appropriate supports. People want to be able to easily find out how to find relevant information, who to contact, and what things need to happen/be activated for supports to be obtained.

DSS can do better by providing proactive guidance at key pressure points, offering skilled navigation.

Families and whānau also need clear and accessible information that supports them to understand systems, navigate options and support the person's aspirations without having to become experts in complex processes.

People talked about advocates or 'navigators' that could assist with this. The key concept linking comments here was the navigation aspect; that is, knowing where to go to get specific, definitive information.

People want information that helps them understand and navigate disability support processes.

Criticisms of the provision of information or advice (30)

A considerable number of comments were made in which people described difficulties or bad experiences they have had in obtaining information about services or supports. In addition to the process being described as "exhausting" and "abysmal", people went into greater detail citing having tried for years to access support, about being told 'no' multiple times only to search for and find the relevant policy that stated what was being asked for was actually an entitlement, and about 'giving up' because of difficulties in completing forms for funding for specific equipment.

There is a massive gap between support as those in policy imagine it, and what actually exists in reality. eligibility criteria is often not clear, people think support exists, but the criteria is so narrow it might as well not, or it's income tested, or the forms are too much for what is a very small amount of money/support.

Make information easier to find, both on the DSS website and other national information sources. We need clarity around eligibility and assessment and allocation processes.

Annual reviews were criticised, as was the system in general, which was said by one person to be declining in terms of its ability to assist disabled people.

I should not have to visit so many different websites to find clear eligibility criteria for DSS services, nor should some criteria be on one site and some on another.

One person shared that seeing any communication from DSS instilled fear in them that certain supports were going to be withdrawn.

Suggestions (24)

A moderate number of specific suggestions were made for as to how information, particularly about eligibility, could be presented or shared. These included having an explanatory video "on the welcome page", that DSS "work with relevant agencies to improve data management", that a "new user pathway" be made prominent on the DSS website, that more use be made of social media, providing or hosting information hubs, and hosting hui.

Initial pages on assessment and funding also helping to direct people to targeted supports and services could help, as could menus for specific disability types.

Often it can be less access for cultures that don't feel entitled or it's too hard to apply. Working with translators advise re translator service more.

Knowledge of DSS is lacking (20)

A moderate number of comments were made suggesting that DSS is a relatively unknown entity, that people are likely to get information from providers and specific disability or funding bodies or informal networks. “Other parents” or people in similar circumstances were a popular source of information; just a few stated they go directly to the DSS website.

I talk to MOH once a year and don't know much about DSS.

Other commentary

A moderate number wanted to see the disabled community actively worked with and listened to with regards to how information could be better shared – in these comments disabled people clearly articulated being in a position to know what works well.

Work with Tāngata Hunga Hauaa... NOT for us!

Several wanted to see DSS or other bodies actively reaching out in communications with disabled people and/or groups; though, a counter argument was also noted whereby communications received that suggest activities that funding could be spent on were viewed as an attempt to limit the person's choices.

[We] want them to ask “are you okay, what do you need?”.

Several people made positive comments about communications and/or information such as “I know where to go to get the information” and general appreciation for DSS operational staff, NASC coordinators, and support workers. This person acknowledged an imperfect system but that the good intent and personalities of those working in the disability sector were a valuable asset. A good portion of the positive comments praised the online survey, stating it was a valuable exercise for them and hopefully that improvements would result.

Contributor demographics

The information below includes responses from respondents to the online survey.

Demographic disclosure was not captured for submitters and was optional for those who contributed to the engagement via workshop attendance. Hence it has not been included here. However, workshops sought to capture the views of those not traditionally heard from in consultations, including Māori, Pacific people, people with intellectual disabilities, and those who otherwise require support to participate. Because of this, the findings shown below under-represent some groups.

Key findings

- > **Positionality:** Respondents were most likely to be *family/whānau member* of a disabled person (50%), or *disabled* themselves (49%), while just over a third of respondents (34%) stated they were *carers*. Under a third of respondents overall (29%) selected both *family member* and *carer* options.
- > **Ethnicity:** Most respondents (80%) were *Pākehā*, and over a tenth (14%) were *Māori*.
- > **Where respondents live:** Most respondents (70%) were from the *North Island*, while 30% indicated they live in the *South Island*. The largest proportions of respondents were from *Auckland* (27%), *Canterbury* (19%), *Waikato* (12%), and *Wellington* (12%).
- > **Current support or services received:** The most common type of support indicated was *Individualised Funding* (30%), however respondents were also likely to say that they receive *nothing* (17%), or that they receive *caregiver support* (14%).
- > **Deaf respondents:** Six percent (6%) of respondents indicated they are deaf.
- > **Respondent disabilities:** The most common types of disabilities were *physical disabilities* (selected by 30%), *neurodivergence* (selected by 28%), and *mental health conditions or mental distress* (selected by 25%).

Respondent positionality

Respondents were asked: *Are you responding to this survey as a:*

Respondents could select: all that apply.

- > Disabled person
- > Family/ whānau member
- > Carer
- > Service provider
- > NASC
- > EGL site
- > Community group
- > Other [please write]

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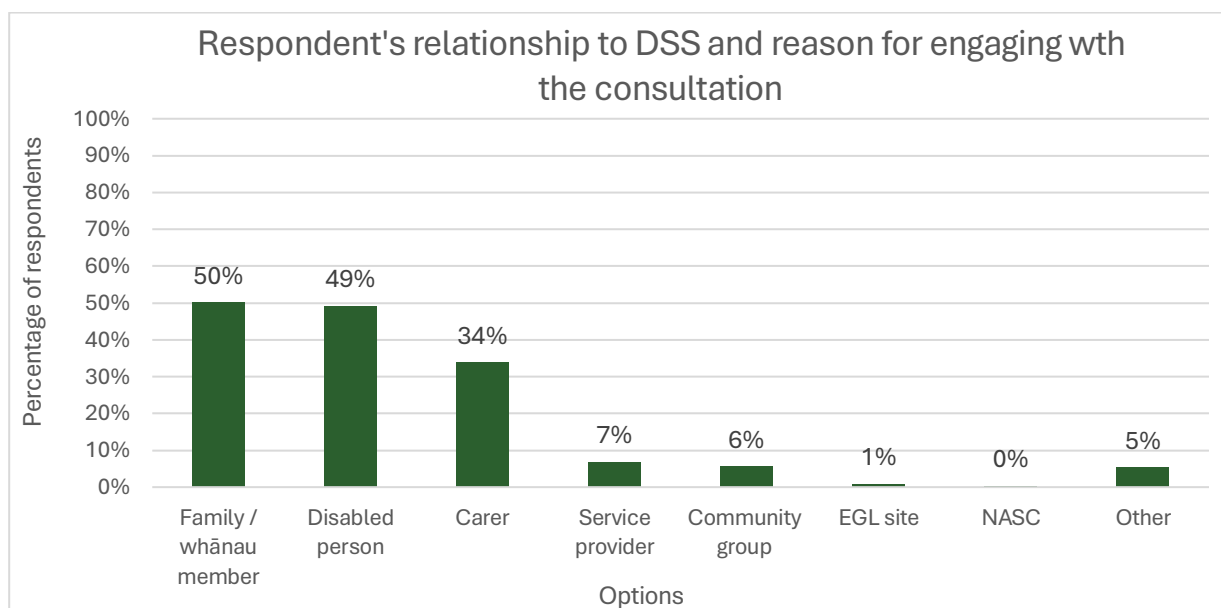


Chart 17: Demographics - Role as a survey respondent

Findings

- > Half of respondents (50%) indicated they are *family or whānau of a disabled person*. Under a third of respondents (29%) selected both *family member* and *carer* options.
- > Very close to half (49%) respondents said they are a *disabled person*.
- > *Carers* comprised of just over a third (34%) of respondents.
- > Fourteen percent (14%) of respondents either responded as a *service* (7%), or a *community group* (6%).
- > Five percent (5%) of respondents used a different descriptor, selecting *Other*.

Positionalities described by those who selected *Other*.

- o Community organisation, disability sector employee (or former employee), ally or friend, Deaf, employer, and one stated they have a hidden disability.

Ethnicity of respondents

Respondents were asked: *What is your ethnicity?*

Respondents could select: all that apply.

- > Māori
- > New Zealand European/Pākehā
- > Samoan
- > Cook Islands Māori
- > Tongan
- > Niuean
- > Fijian
- > Chinese
- > Indian
- > Other [please write]

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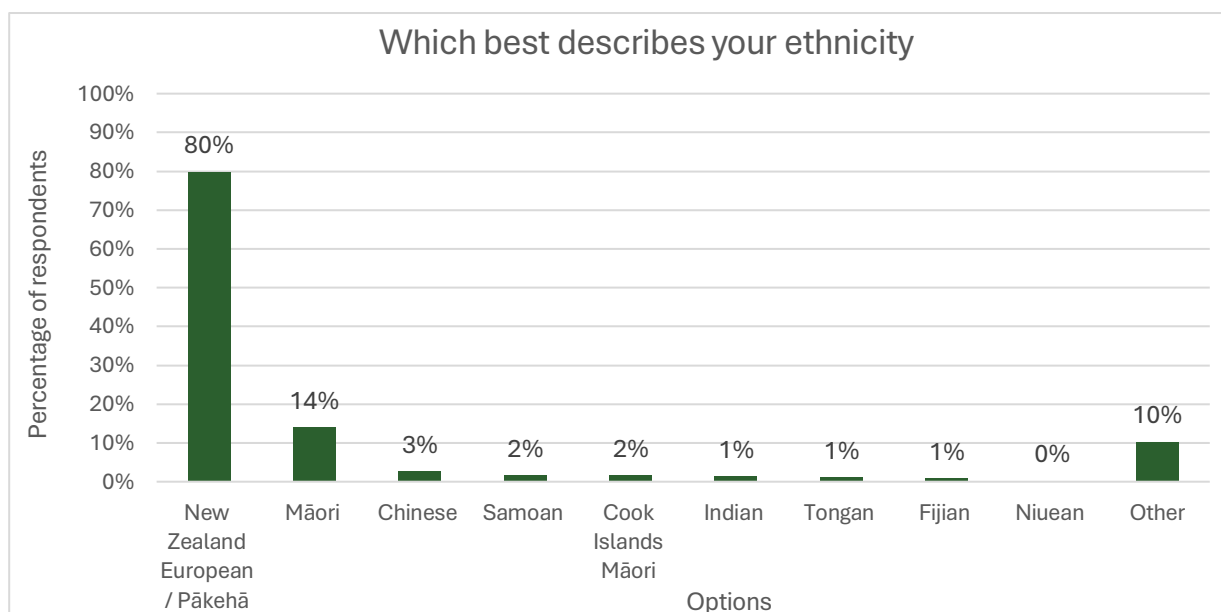


Chart 18: Demographics - Ethnicity

Findings

- > Eighty percent (80%) of respondents described their ethnicity as *New Zealand European / Pākehā*.
- > *Māori* was the second most common ethnicity, with fourteen percent (14%) of respondents selecting this option.
- > A combined ten percent (10%) of respondents indicated their ethnicity out of the remaining options (including *Chinese*, *Samoan*, *Cook Islands*, *Indian*, *Tongan*, and *Fijian*).
- > Ten percent (10%) of respondents selected '*Other*', indicating an ethnicity outside of the options provided.

Ethnicities described by those who selected *Other*.

- Other European ethnicities (14)
- Asian ethnicities (6)
- Other ethnicities noted by less than five respondent each included: Pasifika ethnicities, African, and American.

Where respondents live

Respondents were asked: *Which region do you live in most of the time?*

Respondents could select: one option.

- > Northland
- > Auckland
- > Waikato
- > Bay of Plenty
- > Taranaki
- > East Coast
- > Central
- > Wellington
- > Nelson/Marlborough/West Coast
- > Canterbury (including Chatham Islands)
- > Southern

n=369

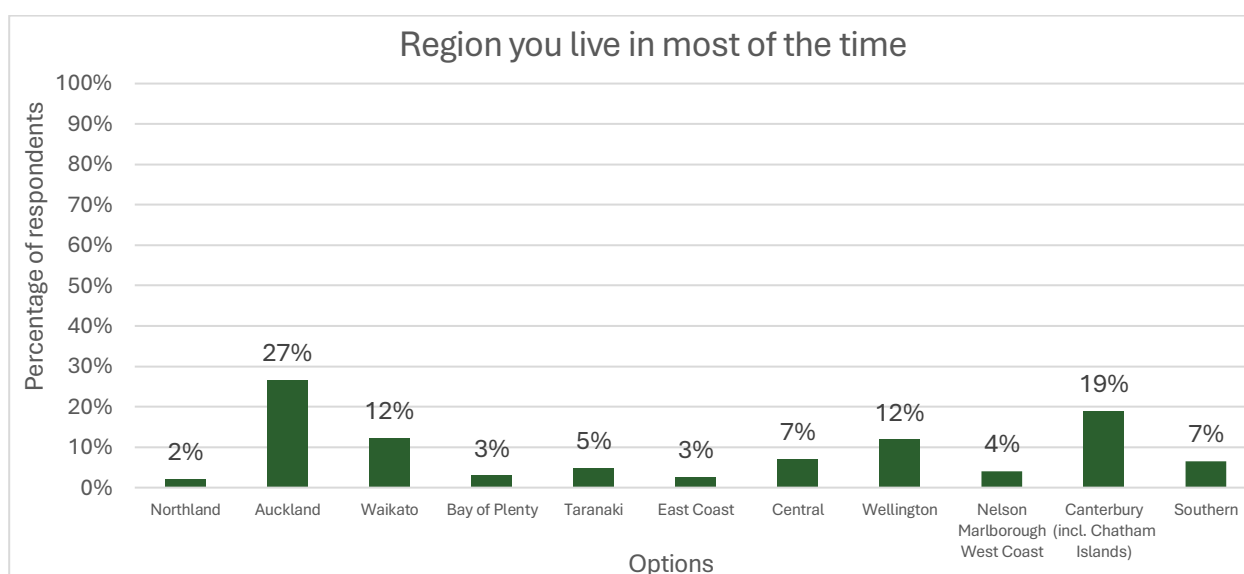


Chart 19: Demographics - Usual place of residence

Findings

- > The majority of survey participants indicated they are from the *North Island* (70%) and just under a third stated they live in the *South Island* most of the time (30%).
- > Just over a quarter of respondents (27%) stated they live in the *Auckland* region.
- > Nineteen percent (19%) of respondents indicated they live in *Canterbury (including the Chatham Islands)*.
- > Both *Waikato* and *Wellington* were regions indicated by 12% of respondents as their place of residence most of the time.
- > Remaining regions all were selected by less than 10% of respondents, with *Northland* being the least common region (2%) where respondents live most of the time.

Current support or services received

Respondents were asked: *What services and supports do you receive from DSS (or provide)?*
Respondents could: write their response

n=274

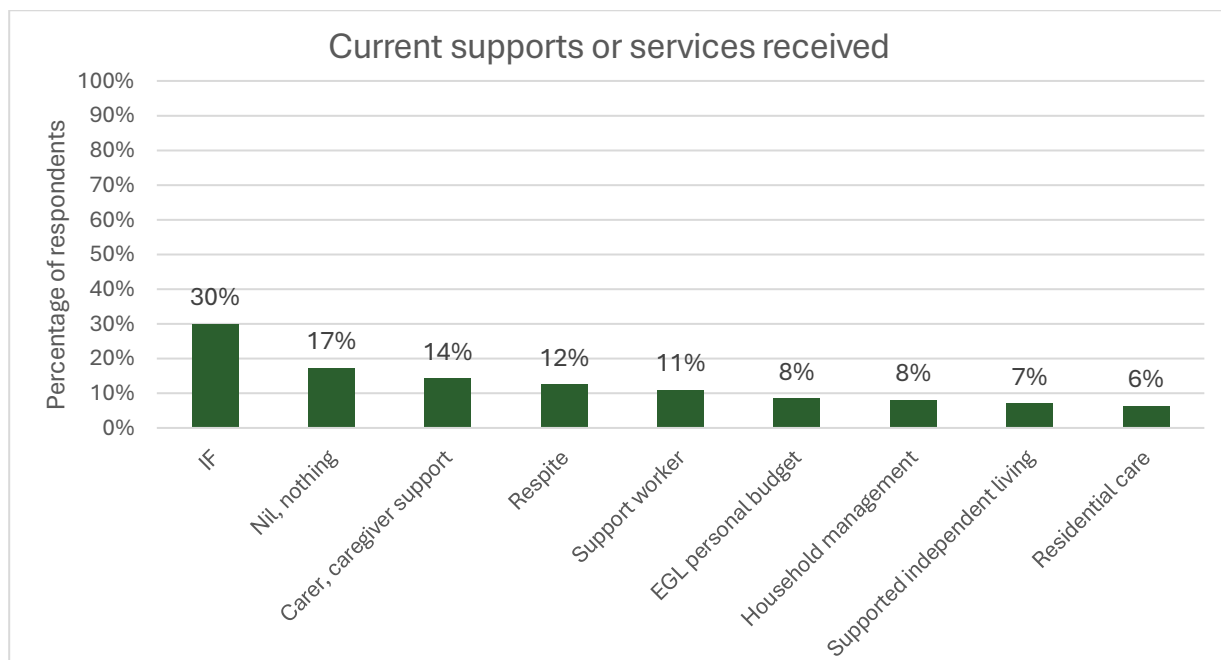


Chart 20: Demographics - Current services or supports received/provided

Findings

- > The largest proportion of respondents, constituting 30%, stated they received *individualised funding (IF)*.
- > The next largest proportion was 17% of respondent who stated they receive *no support, or nothing*.
- > *Caregiver support, or 'a carer'* was stated by 14%, while 11% stated they have a *support worker*.
- > *Respite* was accessed by 12% of those who responded to this question.
- > *EGL personal budget, household management and supported individual living* were accessed by 8%, 8%, and 7% of respondents respectively.
- > *Residential care* was accessed by 6% of respondents who answered this question.

Supports or services described by those who selected *Other*.

- o Total Mobility, community support, equipment or housing modifications, disability income support (Work and Income welfare payment), day stay programme, CCS, and Kia Roha.

Deaf respondents

Respondents were asked: *Are you Deaf?*

Respondents could select: one option.

- > Yes
- > No

n=361

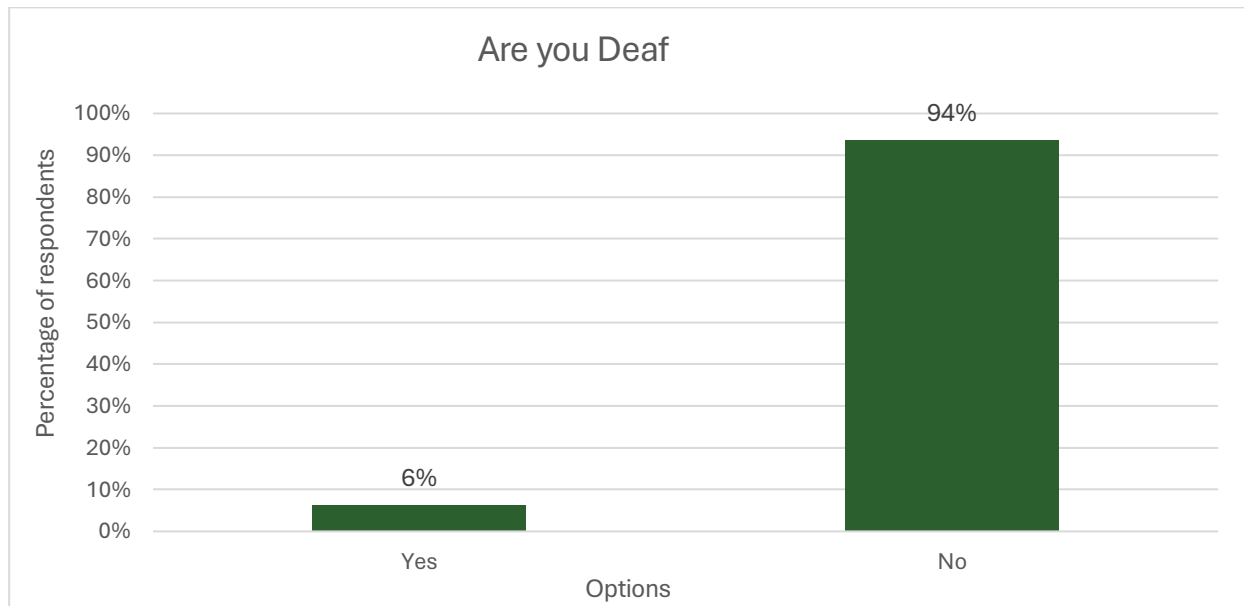


Chart 21: Demographics - Respondents who are deaf

Findings

- > Six percent (6%) of respondents indicated *they are Deaf*.
- > Ninety four percent (94%) of survey respondents stated *they are not Deaf*.

Respondent disabilities

Respondents were asked: *How would you best describe your disability?*

Respondents could select: all that apply.

- > *Physical disability, such as mobility, traumatic brain injury, or amputation*
- > *Vision impairment, such as blindness, low vision or Deafblind*
- > *Hard of Hearing or experiencing hearing loss*
- > *Neurodivergent, a non-medical umbrella term used to describe how some people's brain activity processes, interacts with or experiences the world around them differently, such as an autistic person*
- > *Learning disabilities such as Down syndrome*
- > *Experiencing mental distress or mental health conditions, such as anxiety or depression*
- > *Chronic or invisible disabilities such as endometriosis, diabetes or Tourette's syndrome*
- > *I am disabled myself and also care for or am a family / whānau member of a disabled person*
- > *I don't identify with any of the above*

n=360

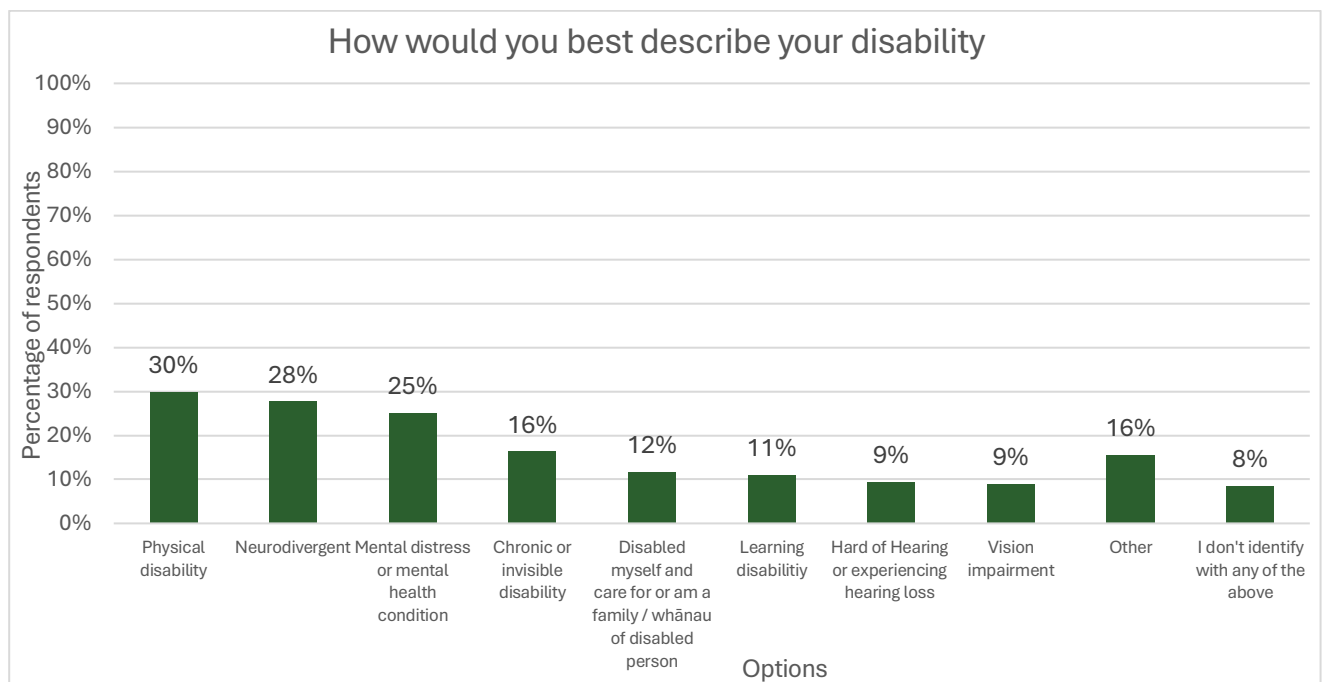


Chart 22: Demographics - Respondent disabilities

Findings

- > *Physical disability* was the most common type of disability, selected by almost a third (30%) of respondents.
- > Over a quarter (28%) of respondents indicated they are *neurodivergent*.
- > A quarter (25%) of respondents indicated they have a *mental health condition* or are *experiencing mental distress*.
- > Less than one in five (16%) indicated they have a *chronic or invisible disability*.
- > Smaller proportions indicated they are a *disabled carer* (12%), have a *learning disability* (11%), *hearing loss* (9%), or *vision impairment* (9%).

- > Under a fifth (16%) indicated they have a *disability that doesn't fit within the options provided*, while eight percent (8%) indicated that *they don't identify with any of the described categories*.

Disabilities, or other points, described by those who selected *Other*.

- People responding as a caregiver, family member, support worker of a disabled person (22)
- Intellectual disability (9)
- Autoimmune condition, such as Multiple Sclerosis (8)
- Disability, condition, or injury that impacts brain function (6)
- Critiques of the options provided and wording of survey question (6)
- Neurodivergent (5)
- Other disabilities, shared by fewer than five respondent each included: physical disabilities or mobility issues, mental health conditions, hearing issues, and communication or speech impairment.

About Global Research

Global Research is an independent New Zealand research consultancy specialising in public consultation analysis – the collection, analysis and reporting of community feedback and submissions for government organisations. Every response in this consultation was read and analysed by our researchers, and the findings reflect the community's feedback.

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