



29 September 2025

Tēnā koe

Official Information Act request

On 16 July 2025, Whaikaha – Ministry of Disabled People transferred your request for official information to the Ministry of Social Development (the Ministry) to respond to. You requested information about Enabling Good Lives (EGL) and Safeguarding Adults Framework.

I have considered your request under the Official Information Act 1982 (the Act). Please find my decision on your request set out below.

Pursuant to the OIA and point 4 of my original request, just wondering if you can send a printed copy of:

1. *Enabling Good Lives (a government strategy), and*
2. *2. Safeguarding Adults Framework work?*

Enabling Good Lives is a social movement led by the disabled people, tāngata whaikaha Māori and whānau.

The EGL approach includes commitment to a vision and eight principles that describe how disabled people can live better lives in communities that value who they are and what they have to offer.

The Government's response to the EGL Report (developed 2011) has resulted in investment in disabled people and whānau leadership (through regional leadership groups and three Enabling Good Lives 'sites' – based in Waikato, Mid Central (Mana Whaikaha) and Christchurch. In the Enabling Good Lives sites, eligible disabled people have access to a connector / kaitūhono (who assists with planning and connection) and a flexible, personalised disability support budget.

I have identified 8 documents (including any appendices) in scope of your request. I have enclosed these documents with this letter.

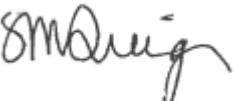
In regard to part 2 of your request about the Safeguarding Framework, please refer to the Safeguarding Framework Detailed Design enclosed with this letter.

I will be publishing this decision letter, with your personal details deleted, on the Ministry's website in due course.

If you wish to discuss this response with us, please feel free to contact OIA_Requests@msd.govt.nz.

If you are not satisfied with my decision on your request, you have the right to seek an investigation and review by the Ombudsman. Information about how to make a complaint is available at www.ombudsman.parliament.nz or 0800 802 602.

Ngā mihi nui

pp. 

Anna Graham
General Manager
Ministerial and Executive Services

Vision

In the future, disabled people and their families will have greater choice and control over their lives and supports, and make more use of natural and universally available supports.

The future disability support system

Vision

In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.

Disabled people and their families, as appropriate, will be able to say:

- I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
- I have real choices about the kind of support I receive, and where and how I receive it.
- I can make a plan based on my strengths and interests.
- I am in control of planning my support, and I have help to make informed choices if I need and want it.
- I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
- The level of support available to me is portable, following me wherever I move in the country.

- My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
- My family, whānau, and friends are recognised and valued for their support.
- I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
- I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed.

The Government will get better value for the funding it provides because:

- the new approach will generally provide better quality of life outcomes for disabled people and their families (based on international evidence)
- less money will be spent on providers premises and more on support
- government agencies will work more closely together, for example using shared way to determine support needs, integrated funding and contracts.

Like

Principles

Achieving our future vision for disability supports is complex and will take time. There will be many details to work through. A principles-based approach will ensure we stay on track to progress the vision. We will use the principles in the Enabling Good Lives report to help guide decisions on the changes.

Principles and long-term change direction

Principles to guide change

Achieving our future vision for disability supports is complex and will take time. There will be many details to work through. A principles-based approach will ensure we stay on track to progress the vision. We will use the principles in the Enabling Good Lives report to help guide decisions on the changes.

The principles are:

Self-determination

Disabled people are in control of their lives.

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

Person-centred

Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

Ordinary life outcomes

Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

Mana enhancing

The abilities and contributions of disabled people and their families are recognised and respected.

Easy to use

Disabled people have supports that are simple to use and flexible.

Relationship building

Supports build and strengthen relationships between disabled people, their whānau and community.

Long term change direction

- Significant redesign and change will be needed on multiple fronts:
- Building knowledge and skills of disabled people: to ensure disabled people understand the direction for change, and can exercise more choice and control over their supports.
- Investment in families/whānau: to assist them to support their disabled family member to have a good life and help them develop aspirations about what can be achieved.
- Investment to build inclusive communities: to ensure communities, including businesses, workplaces, schools, and cultural, sport and recreational activities, are accessible, welcoming and recognise the contribution of disabled people.
- Changing government systems and processes: to support the system redesign e.g. integrated, outcomes-focussed contracting, individualised funding, funding pooled from across Votes and involving disabled people and families in governance, system and service design and monitoring.

Changes to service provision: to align service governance, delivery models, workforce capability, accountability measures, monitoring and evaluation with the vision and principles of the transformed system.

Like

Guidance on developing EGL Regional Leadership Groups

 Posted by Jade Farrar

 29 March 2022

The EGL National Leadership Group (NEGL) supports the development of Regional Leadership Groups as a critical part of the EGL approach.

An EGL Regional Leadership Group:

- brings life to Mana, Self-determination and Voice
- is an independent[1] forum that enables disabled people and families to lead and influence development.

1. Purpose

Why an EGL Regional Leadership Group exists

The Leadership Group's purpose can be to:

- Promote and protect Enabling Good Lives' (EGL) principles and values that the evolving system change is informed by
- Contribute guidance to local initiatives and the implementation of change
- Give direction to any "EGL Entity"
- Provide feedback to the Minister
- Provide feedback to various ministries and public services regarding alignment of service delivery with EGL approach
- Provide connection between local/regional change and National EGL Leadership Group
- To ensure a clear understanding of the priorities and perspectives of disabled people, families and service providers
- To ensure the system will be accountable locally
- To create an 'honourable space' that promotes accessible and inclusive communities
- To bring key stakeholders together to discuss key issues of the community

2. Role

What an EGL Regional Leadership Group does

The Regional Leadership Group can:

- use a partnership approach to develop, implement and monitor the changes
- actively promote collaboration between the Ministries of Health, Social Development, Education and other central government agencies so that their activities and projects are aligned with the Enabling Good Lives approach
- be involved in the co-development and oversight of the change
- promote good communication with persons with disabilities, families and providers regarding the transformation in the region
- increase awareness and understanding of Enabling Good Lives approach
- link with the Enabling Good Lives National Leadership Group.

3. How Regional Leadership Groups can get set up

There will be many ways to set up a Regional Leadership Group. Each area is best to map assets (people, previous EGL aligned work) and develop in ways best suited to their community.

The successful process demonstrated in the current EGL sites has been to:

1. Hold a series of parallel open community forums about the EGL approach e.g. workshops for disabled people, families, Māori, Pacifica and providers
2. Encourage interested people in forming a Core Group
3. Core Groups then continue an in-depth look at what the EGL approach can mean
4. Core Groups select a sub-group from their membership to create the Regional Leadership Group i.e. Regional Leadership Group members are mandated by and accountable to their Core Group

External facilitators, knowledgeable in the EGL approach and community development, can assist this process.

4. Core Groups

Core groups meet prior to each Regional Leadership Group meeting and their purpose is to:

- Provide a space for specific stakeholders
- Support the people they selected to be on the Regional Leadership Group (RLG)
- Provide guidance to their members on the RLG

- Offer a space where a wider group of interested local people can discuss ideas, potential impacts and perspectives on suggested changes
- Ensure there are informed people who can step in, when required, if a member of the RLG is unable to attend a meeting i.e. “back-ups” and succession planning
- Assist with hosting community forums
- Provide a place where people with specific experiences and expertise can offer their views to the local leaders before RLG meetings

Core Group membership is typically organic and flexible. People self-select, with the understanding that consistent participation is desirable. The core groups are focused ‘working groups’ and will meet monthly for approximately 1 ½ hours each month.

- Participation in core group meetings is voluntary
- Local leaders on the RLG attend core group meetings.

5. Membership

Who is on the Regional Leadership Group

The Regional Leadership Group will ensure that there is equitable representation from disabled people, family, whanau, Mana Whenua, Pasifika and providers in the region. Group composition varies. It is typically something like: five disabled people (one seat reserved for People First), three family members, three Mana Whenua (tangata whaikaha or whanau whaikaha), two Pacific people (disabled people or families) and two providers. The aim is equity and not equality.

Officials can routinely attend all or part of each meeting. However, they are non-voting members.

Each Core Group determines a process for selecting Regional Leadership Group members and the processes they will use to gather information/opinions prior to meetings and circulate information after meetings.

Regional Leadership members must agree to become familiar with and be committed to the following:

1. The EGL vision and principles
2. Te Tiriti o Waitangi
3. The UN Convention on the Rights of Persons with Disabilities
4. Working co-operatively within the group
5. Be a local person willing to be involved in community system transformation

The group may choose to occasionally review its composition.

6. Considerations

What Regional Leadership Groups have needed to think about:

Natural justice - Transparency and fairness of procedure and freedom from bias on the part of the person making the decision/judgment [2].

Equity of voice - “speaking time should usually be shared more or less equally by the number of the people in the group, and most of our time should be spent listening.”[3]

Safety - without fear of negative consequences, feeling accepted and respected.

Honourable space - “... respect and maintain the sacred space, harmony and balance within relationships”[4]

Consensus - “a generally accepted opinion or decision among a group of people”[5] Consensus, in the group, is reached when all Leadership Group members present have the chance to give their opinions and nearly all (e.g. 80%) of the voting members agree. If people disagree, this will be recorded and their reasons briefly described.

Mandate - the authority that is given to do something

Role of Support Workers - support workers are here to ‘support’ and not participate – unless, specifically requested by the person being supported.

7. Requests from officials

Officials (and others) are requested to send papers two weeks in advance (four weeks to maximise input from networks) and to be clear about what actions they want from the group.

8. Making decisions

The decision-makers are the disabled people, families, Mana Whenua, provider representatives and Pasifika representatives. Officials present are encouraged to contribute to discussions.

The aim will be for decisions to be made by consensus. Consensus is described as an agreed position reached by the group or where the group agrees to support a decision in the interests of the whole. Consensus can be linked to the idea of mana kotahitanga (the strength and integrity of unity).

Different approaches to building consensus may be used at different times. This may depend on the importance of the decision, its possible impact, the time available and whether people need more information.

Regardless of the approach used, all perspectives will be valued and all people will have the space to put their view forward. Any meeting notes will be clear about whether a statement reflects the consensus of the group or whether it is an opinion expressed (individual views).

Typically, disabled people will speak first on an issue, then families and then others.

After initial discussion, a position will be put to the group. It is likely that discussion goes around the decision makers in the group person by person and ask them to indicate what they think. People indicate whether they agree, disagree or if they want something clarified or changed. These ideas are then considered by the whole group.

After this has happened, it is likely that members go around the decision makers in the group again, person by person, and ask them to indicate what they think now.

The aim is for everyone to have the space to have their views understood and to agree on the “next step” or position the group will express to others. It may be that an outcome of the discussion is just clearly and simply described i.e. how many people agree, disagree or are not sure.

The group may revisit any issue when it considers there is new information available.

9. Meeting Notes

Notes of the meetings, or any conversations about them, typically do not record who said what. Instead, they reflect the main themes of contributions, the outcome of the discussion and associated actions.

People attending the meeting usually have five working days to approve the notes and then they will be made publicly available to any interested party.

10. External facilitation

Meetings of Regional Leadership Groups have been externally facilitated until the group is self-sufficient. This is to ensure that the views of people with a lived experience leads discussion, to develop consensus-based processes and to equip group members with techniques related to community development.

External facilitators have generally been people who have: a good understanding of the EGL approach, community development, active facilitation techniques, constructively managing conflict and equity. Sometimes there are co-facilitators – where at least one of the facilitators are disabled people or family members.

How does this get funded/ resourced?

Ideally, NEGL would like a transparent funding source for all Regional Leadership Groups that does not compromise your autonomy, local ownership or identity.

We have not reached this point yet.

It may be that various funding sources can be considered locally or funding can be obtained through the Ministry of Health, Ministry of Social Development or the new Ministry (after 1st July 2022).

NEGL imagines that you will use funding to pay for things like:

- Venue
- Refreshments
- External facilitation
- Guest presenters
- People's time
- Running events or projects

NEGL also imagines that, at some point, you may be in a position to hold funding to commission local initiatives that enable more disabled people, families, tangata whaikaha and whanau to understand EGL, explore what a good life looks like, develop skills and build a community where all citizens are valued.

If a Regional Leadership Group chooses to do things like this, you will need to consider how you will build a legal entity, to hold/distribute funding or how you can use another organisation to do this on your behalf.

It is important to consider where funds are coming from because, even though other sources may agree to fund your work, you need to ensure that the funding is given to your group to control and does not remain in the ownership of another entity.

12. What is a “Region”

As of March 2022, there are no defined regions. As the change process continues, there will be decisions about how many regions there will be. However the regions are formed, your work assisting people to understand EGL, connect with each other and develop local leadership networks can feed into the agreed regional and national Mana, Self-determination and Voice mechanisms.

13. with the EGL National Leadership Group (NEGL)

As part of creating a cohesive national network, the Regional Leadership Group (RLG) can explore how they can feed into NEGL and how NEGL can support the RLG.

[1] Independent means the group is not managed or influenced by a direct support provider, NASC or EGL/ministry entity

[2] Glossary | New Zealand Ministry of Justice

[3] Equity of Voice and why it matters | Kate Frykberg

[4] <https://www.leva.co.nz/about>

[5] CONSENSUS | meaning in the Cambridge English Dictionary

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COMMENTS

By Saige (6 days ago)

I appreciate this thorough, principled, clear and structured guidance paper. The paper and the links to related content, provide an excellent and useful exemplar for procedures and processes.

By John Ashim (6 months ago)

Feel safe and proud to be part of such a great team.

By Thomas Kupa (14 months ago)

Just looking forward to learning more about EGL on the 17th June.

By Lorna Clowes (2 years ago)

Kia ora is there a contact please for the Northland Regional Leadership Group member who looks after educating and supporting business to understand and implement the principals of EGL? Thanks

By Michele Columbus (2 years ago)

Our location is Nelson. Nelson always seems to be low on the list for reform in the area of disability. We have lived in the Manawatu where EGL has been introduced and unfortunately

moved prior to it getting well established. I would be very happy to see EGL introduced here and wondered if it is being established and how I may be able to get involved.

By Cherie Cawdron (3 years ago)

Hi Jade Can you advise what progress has been made since March? We are based in Auckland which has no regional leadership group yet - have regions even been defined yet? Maybe a first step. Lots of family members who care for complex disabled people are eagerly waiting for news.

By June Rameka (3 years ago)

I would like to be apart of this New Group Over the Years 39 to be Exact... I have watched others control and make Decisions on behalf of mine and my Daughters Life It seems Unfair and Unjustly How Parents and Disabled People are Governed by People who know nothing of our Daily Lives Example different Regions have missed out on the EGL Model For Years O that's Right they are still Trialing it? It's not Rocket Science but simply A UNFAIR POLITICAL SHAMBLES AND SYSTEM.!! It will be Interesting who will be the next Decision Makers and Core Group.... Let's see if I get a Reply or Deleted lol

By rick (3 years ago)

how do these regional groups usually become established...are they driven by the local dhb or just created by individuals in the community? how would you know if one has been set up in your region?

[RSS feed for comments on this page](#) | [RSS feed for all comments](#)

Mana, Self-Determination & Voice PDF

Read about the Mana, Self-Determination and Voice key features developed as part of the Machinery of Government Review

Regional Leadership Group Job Description Template

Download a free job description to support the formation of a regional leadership group in your local area

1. How Enabling Good Lives started - the August 2011 report

Government has recognised the need and broad direction for change to the disability support system through the New Zealand Disability Strategy and the UN Convention on the Rights of Persons with Disabilities, and the Government response to the Social Services Select Committee inquiry into the quality of care and service provision for people with disabilities.

In 2011, the Minister for Disability Issues, Hon Tariana Turia, invited the Ministries of Social Development and Health to work with an independent working group of disability sector stakeholders to develop a "clean sheet" approach to community participation and day services for disabled people. The process of meetings and discussions over several months was facilitated by the Office for Disability Issues. The report from the independent working group was completed in August 2011. In October 2011, Minister Turia asked officials to engage with the disability sector on how to take the "Enabling Good Lives" approach further.

In 2012, the Ministries of Social Development and Health worked with disability sector organisations to test the "Enabling Good Lives" approach in Wellington, Christchurch and Hamilton in consultation

Watch NZSL video of the report <https://www.odi.govt.nz/nz-disability-strategy/other-initiatives/enabling-good-lives/egl-background-information/easyread-version-of-the-enabling-good-lives-august-2011-report/>

Download an easy read version of the report below

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ENABLING GOOD LIVES

A report to the Minister for Disability Issues

The Independent Working Group on 'Day Options'

July 2011

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Introduction

This report takes a ‘clean sheet’ view of government support for disabled people, and describes what this could look like in the future. It aims to put aside the constraints of our current service structures and models, and take a ‘first principles’ look at the types of supports government should provide so disabled people can have the life they aspire to like other New Zealanders.

This report was written for the Minister for Disability Issues by an independent working group of people who work in the disability sector. Some of the Working Group also have personal experience of disability or are family/whanau of disabled people. The Working Group was facilitated by the Office for Disability Issues, with secretariat support from the Ministries of Health and Social Development. This report presents the views of the Working Group, and does not represent Government views or policy. Further information on the Working Group and the process involved in developing the report is outlined in Appendix A.

The Working Group identified the key values and principles that should drive government support for disabled people. Although the Working Group was specifically asked to consider day services and community participation, it soon concluded that it was not possible to address one element of disability support without looking at the whole system.

The Working Group proposes that the current centre-based model for day and community participation services be incrementally replaced with a facilitation-based support model. At the heart of the proposed model is the provision of support for disabled people to achieve a ‘good life’ like other New Zealanders, which is reflected in the title of this report ***Enabling a Good Life***. The focus of facilitation-based support would be on enabling disabled people to do everyday things in everyday places’ in communities, rather than on provision of ‘special’ places or activities for disabled people. It would include support funding from across government agencies that would be individualised and flexible.

Implementation of the ideas in this report will have to take notice of what currently exists to ensure that a smooth transition to a new type of support model is achievable and affordable. This report provides options for incremental approaches to implementation. Further detail on these options will need to be developed by the government agencies involved before implementation can begin.

Government support for disabled people

As New Zealanders, we value having a society where all people are included and their human rights are promoted and protected. We expect our government to support disadvantaged people so their fundamental needs can be met and they can participate in our communities. Where people with impairments experience barriers to participation, we expect government to take some action to address these.

This report takes a closer look at why government should support disabled people, when it should, what it should be supporting them to do, and how the support should interact with supports provided by families and communities. It also proposes practical steps government could take to begin implementing a facilitation-based support model and how the model might operate.

Why: To achieve a fair and inclusive society

Government supports disabled people for the same reasons it provides services to any other disadvantaged group. Supports are based on principles of fairness, inclusion and valuing all peoples' contribution. Where disabled people are unable to meet their own needs, or exercise their rights as citizens, or when they face inequity through social or economic exclusion, government steps in to ensure they get a 'fair go'.

Government should provide support to ensure that we have a fair and inclusive society that values 'disabled people' and maximises their potential.

Social Justice	Inclusion	Economic potential
<ul style="list-style-type: none">• equal opportunities (to live an everyday life)• self determination (and choice)	<ul style="list-style-type: none">• prevent social isolation and exclusion for individuals and their families and whanau• opportunity to participate and contribute to communities	<ul style="list-style-type: none">• avoid the loss of human potential• value disabled peoples' talents, skills and contribution

The New Zealand Disability Strategy

Government is committed to the New Zealand Disability Strategy (NZDS). The vision of the NZDS is for a society that highly values the lives of disabled people and continually enhances their full participation.

The United Nations Convention on the Rights of Persons with Disabilities

New Zealand has signed and ratified the United Nations Convention on the Rights of Persons with Disabilities. The Convention aims to promote, protect and ensure full and equal rights and freedoms for all disabled people and promote respect for their inherent dignity. Its core principles include; accessibility, equality of opportunity, non-discrimination, participation and inclusion, independence and autonomy, freedom to make choices, respect for difference and acceptance of disabled people as part of human diversity.

For whom: Those in need of support

The Working Group agreed government support should be provided for people with impairments:

- who are socially isolated (don't have social connections outside the home) or whose participation in communities is limited (or are at risk of this)
- who do not have family, whanau or 'natural' supports, or
 - the family/whanau are experiencing undue stress (and the family's participation is limited or is at risk because of the stresses of caring)
 - the needs are beyond what the family/whanau is able to meet
- who are not able to exercise their rights as described in the United Nations Convention on the Rights of Persons with Disabilities (including Articles 19, 27 and 30¹).

¹ Article 19 - Living independently and being included in the community, Article 27 - Work and employment, Article 30 - Participation in cultural life, recreation, leisure and sport

When: Basic support and additional support

The Working Group identified that some disabled people require support or accommodations for essential activities of daily life such as: communicating, mobility, looking after themselves and their family, and making decisions - and that this should not be compromised. The Working Group also recognised that families/whanau and carers also need support.

Two levels of support are proposed.

1. A basic level of support is required when:

- the disabled person has essential needs they are unable to meet themselves (this support could be in various forms, eg a person, equipment, information)
- there are safety concerns around the disabled person
- whanau/family carers need support in their caring role.

2. Support for community participation (that goes beyond safety) to achieve an 'everyday life' when:

- the disabled person (or their family/whanau) does not have the skills and/or resources required to participate
- family/whanau support for the person to participate is limited (eg. there is little or no family/whanau support)
- individuals or whanau/family ask for it (ie: express readiness)
- community building is needed ie engaging and supporting communities to be more welcoming and inclusive of disabled people.

The Working Group concluded that government should provide this additional support (beyond safety) when it is essential to enable participation, equal opportunities, and in order to achieve social justice and inclusion.

Proposal: Move towards facilitation-based support

Services for disabled people have changed over time to reflect society's changing view of disabled people. Historically we have seen a shift from custodial and institutional models of service, to specialist community-based facilities, and now towards supports that focus on fully integrating people into the community.

The Working Group considered how our disability support system should evolve in response to disabled people's calls for greater participation and inclusion, and for more choice and control over the supports they receive. Two issues in the current system particularly need to be addressed. These are firstly, the way that existing centre-based services are designed and operate, and secondly, the way services and supports are divided up into many different silos which lack flexibility. See Appendix B for information on current day services and community participation services.

Day and community participation services are often based in centres and allow limited interaction with communities. Many people, including disabled people and their families,

still assume that most disabled people who do not work should be attending full-time centre-based services if they are not working. While some disabled people do need this level of care (24 hour care, or full-time support during the day), the Working Group believes there are people engaged in this level of service who may not need it. Because these services support people in groups, many miss out on an individualised approach to their support. All would benefit from opportunities to be more fully engaged in communities and to live their lives as independently as possible.

In addition, government support is provided for a myriad of different things. Disabled people often receive services and support from three or four different sources for different types of supports that each focus on only one small aspect of their lives.

A new type of support model is proposed that will facilitate access to 'everyday life in everyday places' in communities, rather than focusing on 'special' places or activities for disabled people. It would encompass a person's whole life, not only one part of it. The Working Group recognised that there will still be some centre-based services, but that future government supports should more and more be built around the individual, rather than groups of people.

Principles

The Working Group developed the following set of ten principles to underpin future disability supports. These are:

- ***Self determination - tino rangitiratanga:*** disabled people are in control of their lives, and supports are tailored around their interests, preferences and goals.
- ***Whole of life:*** supports are designed to take a whole of life approach (ie people's lives are not compartmentalised into day, night, home, community etc).
- ***Ordinary life outcomes:*** disabled people and their family/whanau are supported to imagine what a good life might look like and how this can be achieved. They have opportunities to work, contribute, learn, have relationships, have a family, have a home, take part in their culture and participate in recreation and sport - like others at similar stages of life.
- ***Mana enhancing:*** empowerment: values the contributions of disabled people and their families, and ensures support provided empowers them – ie support should be invisible, not diminishing mana.
- ***Mainstream is the default:*** community based or generic supports are made accessible and available to disabled people before separate disability supports are provided.
- ***Kotahitanga tatou – whanaungatanga:*** supports are based around relationships - a unified partnership connecting disabled people and their family and whanau with communities, building supportive relationships, and encouraging community responsibility.
- ***Manaakitanga - Community building:*** engage and support communities to be more welcoming and inclusive of disabled people – create accessible communities.
- ***Simplicity:*** supports are simple, easy to access, are the least restrictive they can be, and make things easier for the disabled person.
- ***Timatanga (beginning early):*** invest early in families and whanau to support them to be aspirational for their disabled child, to build community and natural supports and to support disabled children to become independent, skilled adults.

- **Flexibility:** supports meet the continuum of need and are responsive to people's changing needs and aspirations over time.

What facilitation-based support would look like

The facilitation-based support model would actively support disabled people to have an 'everyday life in everyday places'. It would support people to achieve desirable outcomes such as education and training, employment, being with friends, having relationships and a family, taking part in community and cultural activities.

Key differences from the current service models would be that:

- government support would facilitate participation and inclusion in mainstream community activities and social networks, rather than mainly providing centre-based activities
- people (with their family/whanau) would have more choice and control over the supports they use, rather than simply being allocated a specified service
- a person's day and week would be made up of a range of different types of activities built around their stated preferences, not a generic day programme
- natural supports and mainstream services and resources would be first choice - before specialised disability supports
- divisions between current programmes would diminish, so a single entry type of arrangement could cover supports across day and night, employment support (eg business enterprises and supported employment), home support and community participation
- funding from different agencies (in particular the Ministries of Health and Social Development) would be pooled or provided through a joint funding model.

The elements of facilitation-based support would include:

- ***Self-directed planning & facilitation:*** a skilled facilitator chosen by the disabled person would assist him or her to build and maintain relationships and support networks in the community, access mainstream community-based services and activities, and identify opportunities to contribute to the community. The facilitator would help the person to identify their aspirations and goals, and develop a plan to achieve them. The level and duration of facilitation support would vary for each person.

The facilitation role would be independent from both funding allocation and direct service provision (eg support with personal care, mobility assistance). It would be a joint agency initiative (potentially the Ministry of Health and Ministry of Social Development). There would be regular independent external evaluation to ensure that the facilitator is being responsive to the individual/families within a reasonable timeframe.

- ***Cross-government individualised/portable funding:*** an individual allocation of funding would be available to the disabled person, potentially on a self-directed basis. This would require all current disability support funding the person (and their informal carers) attracts to be identified, (eg day service, community participation, home and community support service, individualised funding, residential, supported living) and 'unpacked' where this is possible.
- ***Strengthening families/whanau:*** Families/whanau would be supported to assist the disabled person (eg by promoting family-to-family support, and family and whanau collectives. There would be separate funding support for family carers to

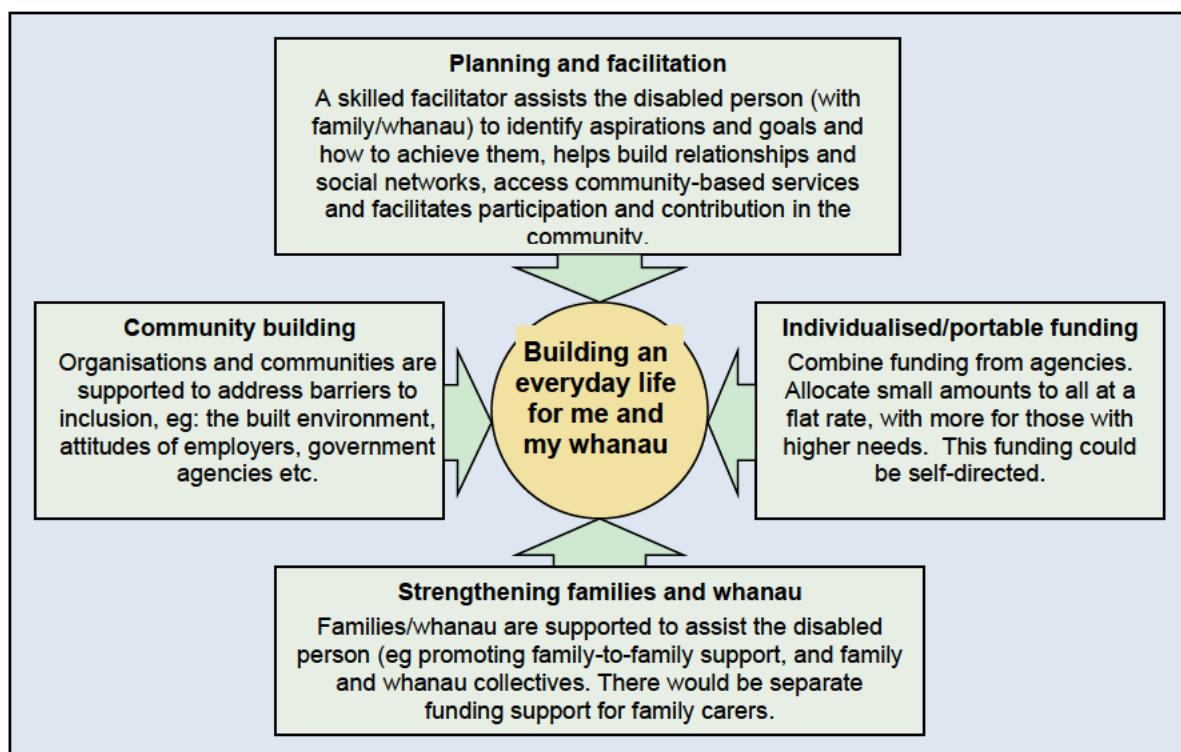
build integrity into the system, cultivate natural supports, and distinguish the legitimate (but sometime competing) needs of the individual and family.

- **Community building:** mainstream organisations would be supported to address barriers to inclusion that disabled people face, eg: the built environment and attitudes of employers, government agencies etc. Most of this work would be done by the facilitator or providers who are enabling people to participate in the community. There may also be support from general disabilities funding, specific initiatives or employing 'change agents'.

How it would work

The disabled person (and family/whanau) would choose a facilitator to support them in a self-directed planning process. (There would be some criteria to ensure that the facilitator has appropriate skills and experience). The facilitator would help the person to identify their aspirations and goals, and develop a plan to achieve them. The plan would identify available community resources and other natural supports (eg: family, friends etc) but may also suggest areas that need additional resource or funding. The facilitator would also advocate for other government-funded supports, if required.

Overview of facilitation-based support model



How funding could be structured and delivered

The Working Group proposes that resources equal to that already allocated for individuals by the Ministry of Health and the Ministry of Social Development be combined to fund eligible people. This could include the funding from day services and community participation services, as well as Ministry of Health funding for residential services,

supported living and home and community support services². The Working Group also suggests that elements of Needs Assessment and Service Co-ordination services, and Disability Information and Advice Services could be used to fund the facilitators, and that consideration should be given to including some of the funding for Disability Allowance.

People would have an individualised funding package (with self-directed funding as an option) to enable them to choose their support. This would mean identifying what is already being funded for people and pooling these resources on a case by case basis. In the short to medium term it may not be possible to unpick all the funding some individuals get. Care would need to be taken to ensure that existing bulk funded services were not compromised unless all the people using those services were catered for elsewhere.

The Working Group favours a tiered-funding model based around the person's needs or milestones identified in their plan, rather than funding being allocated to specific supports as now. This would ensure the funding was distributed more equitably (people in similar situations would receive similar levels of funding) and more flexibly (around what the person requires rather than being limited to a standard menu of supports).

Everyone who meets the general eligibility criteria would be entitled to a small amount of funding to use flexibly as they choose. People requiring more support would have a more intensive assessment to determine their level of funding.

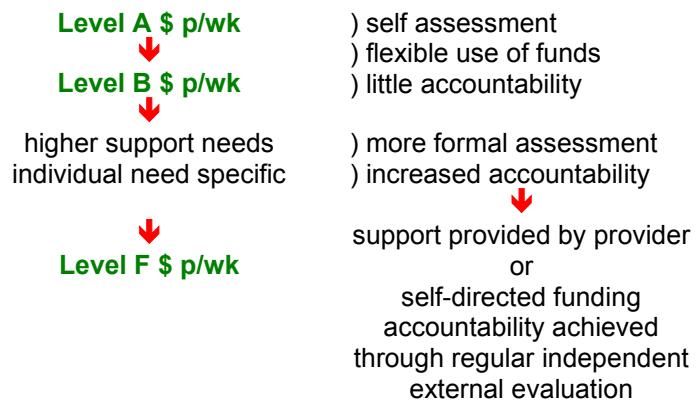
FUNDING MODEL

Base component

- The information support is available to all
- The facilitator support is available to all
- All eligible people get a small amount of funding eg \$2,000 per annum to use in a way they choose:
 - a deaf person may purchase interpreter services for 2 hours once a month
 - transport to access the community or employment
 - a person with an intellectual disability may purchase photographic prompts to assist their employment or participation at some activity
 - a person may purchase additional tickets to an event so they can invite a friend to support their attendance

Additional funded support

- Accessed via assessment with increased formality and accountability to access higher funded packages



² The Ministry of Health's New Model for Supporting Disabled People includes moving towards allocating funding rather than types of services, so these categories will become less significant over time.

Transition to facilitation-based support

Existing services would be encouraged to base their provision on the principles outlined in this report.

People in an existing service would have the choice to ‘opt in’ to facilitation-based support, and new entrants would self refer to facilitation-based support.

The Working Group agreed that there should be a simple assessment for the additional funding levels (beyond the base component) based around what the people self-identified in their plans. Further consideration is needed on whether the funding should be held and allocated through the current Needs Assessment and Service Co-ordination services (NASC), a revamped NASC service, or some other arrangement.

How facilitation-based support relates to existing initiatives

Facilitation-based support is broadly consistent with the Ministry of Health’s New Model for Supporting Disabled People, but goes further in several ways. For example, it extends the facilitation approach across government, and encompasses support funded through the Ministries of Health and Social Development, and potentially other government agencies. It is likely to require the development of cross-agency (or joint) facilitation, entry processes, funding allocation, purchasing and accountability arrangements.

Implementation approach: Where to start?

A staged implementation with targeted starting points, and regular evaluation and review would enable government, government agencies, disabled people, families/whanau, and providers to examine how the new approach is working, and modify elements when necessary. Potential places to start could include:

- young people leaving school or who have left school within a specified time period (eg the last ten years)
- identified geographic regions or specific towns
- Christchurch, as changes to the nature and delivery of supports and services have already been occurring in response to the earthquakes
- services that have demonstrated a willingness to be innovative and embark on service transformation – build on emerging ideas and good practice.

A first step would be to share the vision for a new facilitation-based support model with disabled people, families/whanau and the wider disability sector and engage them in planning and implementing the changes. This general approach was endorsed by disabled people and their families/whanau during the review of disability supports in the early/mid 2000’s.

Some service users, their family/whanau and disabled people’s organisations are ready to start making the kind of changes signalled in this report, but feel they are being held back by the inflexibility of government agencies. The recommended strategy is to start working with people and organisations who are interested in change to develop and demonstrate

an alternative approach. Others will be prepared to change when they can see how the new approach is working.

Transitions from school

Disabled young people who are transitioning out of school and into adult life, would make a good starting point, as they are already at a point of change in their lives. The questions that will be asked and plans for adult life that will be developed, as part of facilitation-based support, are the kind that would be asked by any young person at this point in their lives.

Young disabled people in New Zealand are generally distinct from older disabled people in their experiences (eg of mainstream schooling) and consequently their expectations are often different from those of earlier generations of disabled people. This means that young people typically have greater readiness for a support model that allows greater independence. Many of them are asking for these types of changes (and so have their families/whanau).

Geographic centres or regions

Implementation could begin in identified geographic regions or towns, and be expanded to other locations as capacity allowed. This would mean different ideas could be tested, and more detailed costings identified, and would be consistent with the approach used by the Ministry of Health's 'New Model for Disability Supports' in the Bay of Plenty.

The Ministry of Health is developing a proposal for new Community Living options for disabled people currently living in residential services. There may be opportunities to test the Community Living and facilitation-based support together as the people concerned will need new arrangements for all their supports in the community.

Christchurch

There may be opportunities to try some different approaches or delivery mechanisms, in Christchurch as many of the centre-based day services (funded by Ministry of Health) and vocational services (funded by Ministry of Social Development) there have been disrupted for many people.

Innovative services

A number of service providers are already developing their ideas and practices along the lines discussed in the report. Some would be very interested in participating in 'piloting' a more facilitation-based community-focused approach to delivering services.

Recommendations

The Independent Working Group on Day Options for disabled people recommend that the Minister for Disability Issues:

1. **endorse** the 10 principles set out in this report as the basis of the operating principles for all disability supports in New Zealand and share these widely with disabled people, families, providers and other funders
2. **endorse** the vision of this report to move away from centre-based daytime services for disabled people towards facilitation-based supports that enable them to engage in a range of activities that make up an everyday life for example: employment, (full-time or part-time) voluntary work, recreation, housework (eg shopping, cooking), meeting friends and spending time at home
3. **note** that the facilitation-based support model would involve:
 - 3.1. each disabled person being allocated a facilitator to support them to develop a life-plan and a small amount of funding they can use flexibly (eg up to \$2,000 per annum)
 - 3.2. each disabled person developing their own plan describing the life they want to lead, specific goals and what steps will be taken to achieve their goals
 - 3.3. individualised packages of funding to spend in accordance with the plan
 - 3.4. support for the disabled persons family/whanau if required to implement the life-plan
 - 3.5. the facilitator will help connect the disabled person, and their family/whanau, to the social networks and services in the community
 - 3.6. the facilitator will also advocate and connect to other government-funded services (eg clinical services, Work and Income etc.)
4. **engage** with the wider disability sector (disabled people, families/whanau, service providers and other funders) on the concept of facilitation-based support and how it could best be implemented
5. **fund** the facilitation-based support model by combining elements of existing funding from different agencies including the Ministry of Social Development and Ministry of Health. This could include funding for day services and community participation services, as well as Ministry of Health funding for residential services, supported living and home and community support services and possibly Needs Assessment and Service Co-ordination services, Disability Information and Advice Services, and Disability Allowance
6. **invest** in capacity building to enable existing day service and community participation providers to transition from providing centre-based activities to the facilitation-based support model, including providing workforce and organisational development resources
7. **implement** this facilitation-based support model incrementally over time, on an 'opt in' basis, starting with:
 - 7.1. providers who are already experimenting with this type of support
 - 7.2. young people transitioning out of school, or who have recently left school

- 7.3. Christchurch (where some day services are unable to operate, so action is required anyway)
8. **ensure** there is monitoring and evaluation of the facilitation-based support model as it is implemented, including the impact on families/whanau, identifying any emerging barriers to support and gaps in support provision.

Appendix A: How the report was developed

This report was developed by a working group of disability sector stakeholders facilitated by the Office for Disability Issues and supported by the Ministries of Health and Social Development. The Working Group was asked to come together to take a 'clean slate' approach to thinking about how government might be able to better support disabled people to have an everyday life within the existing resources available to it.

The Working Group came together for three one-day workshops.

Members of the Working Group are:

Lorna Sullivan (Chair): Chief Executive, Standards Plus

Anne Wilkinson: Chief Executive, Parent to Parent New Zealand, and a parent

Charmeyne Te Nana-Williams: Director, What Ever It Takes

Grant Cleland: Chief Executive, Workbridge Inc

John Taylor: Executive Director - Community Connections, and Chair – New Zealand Disability Support Network

Mark Benjamin: Chief Executive, SAMS – Standards and Monitoring Service

Tess Casey: Chief Executive, NZ Federation of Vocational and Support Services Inc (VASS)

Wendy Isaia: Parent and Evaluator of disability services (SAMS).

Appendix B: Current Community Participation and Day Services

Community Participation services

The Ministry of Social Development funds community participation services for people with all types of disability aged 16 to 65 (except people eligible for similar assistance from the Ministry of Health or ACC). These services support people with all types of impairments to access and take part in activities in the community, and to develop skills to participate in the community.

Community participation services are partially funded. The funding is paid in bulk to the service providers, with providers determining which people access their service.

The Ministry of Social Development also administers the Very High Needs School Leavers programme which provides individually-targeted funding for vocational services for school leavers classified while at school under the Ongoing and Resource scheme as having very high educational needs. The funding is mostly used to pay for Community Participation services.

Day services

The Ministry of Health funds day services for people with intellectual, sensory or physical impairments who:

- were de-institutionalised under formal de-institutionalisation plans
- are care recipients under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (ID (CC&R) Act). While not specifically responsible, the Ministry of Health also funds people with very high and complex needs similar to those accessing ID (CC&R) Act services.

The Ministry of Health also has a historic practice of funding day services in some regions. In those regions, the Ministry of Health funds people with high needs unable to be supported by the Ministry of Social Development. In most cases, the Ministry of Health funds the full service. In a small number of cases the Ministry of Health 'tops up' funding when a Ministry of Social Development -funded community participation service is not able to provide sufficient support for a person with high needs.

Ministry of Health -funded day services are primarily for people aged under 65. However they continue to be funded for existing clients once they turn 65, unless the person no longer wants the service or is assessed as requiring age-related residential care.

The following table summarises the different funding arrangements.

Ministry	MSD	MSD	MOH
Service type	Community Participation	Very high needs school leavers	Day Services
Number in service	10,000	590	2,200
Age & disability	<ul style="list-style-type: none"> • people with all types of impairment • age 16-65 	<ul style="list-style-type: none"> • people with all types of impairment • age 16-65 	<ul style="list-style-type: none"> • people with physical, sensory and intellectual disabilities. • no age limit for people who accessed day services before age 65
Funding model	<ul style="list-style-type: none"> • partial funding • bulk-fund services • providers determine access • capped funding 	<ul style="list-style-type: none"> • specified amount • funds individuals who meet eligibility criteria • demand driven 	<ul style="list-style-type: none"> • full funding • funds individuals who meet eligibility criteria • capped funding
Total funding	\$42 million p a	\$10 million p a	\$40.3 million p a ³
Amount per person	\$4,200 p a	\$17,600 p a	Range is \$28 - \$68 per half day ⁴ (approx \$12,000-\$30,000 p a) Most people receive \$33.30 to \$37.80 a half-day (approx \$15,000 p a)

³ Includes \$9.1 million which is spent on Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 clients.

⁴ Excludes Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 clients.



Briefing

Date:	24 August 2023
For:	Hon Priyanka Radhakrishnan, Minister for Disability Issues
Cc:	Hon Barbara Edmonds, Associate Minister of Finance
File Reference:	REP/23/8/750
Security Level:	Budget Secret

Disability Transformation Tagged Contingency Drawdown

Purpose

- 1 This paper seeks agreement to draw down a Budget 2022 tagged contingency for disability support system transformation.

Executive summary

- 2 The Minister of Finance and the Minister for Disability Issues have been delegated authority to approve the draw-down of a Budget 2022 contingency for disability support system transformation (with the amount of the contingency recently revised downwards (CAB-23-MIN-0344 refers)).
- 3 Drawdown of the contingency is subject to Ministers considering: a system operating framework; how the contingency will be used; an implementation plan; governance structures; risk management; and arrangements for ongoing reporting to Ministers.
- 4 We consider that the criteria for drawing down the contingency have been met, so Whaikaha now seeks your approval to draw-down the funding. More detailed implementation planning will be possible once the funding has been drawn down.
- 5 To build on work commissioned by Ministers in March 2022, officials from Whaikaha and the Treasury also recommend that you agree to establish a work programme on the fiscal sustainability of the disability support system, including the impact of the Enabling Good Lives (EGL) approach, to provide Ministers with better quality information on potential fiscal costs and risks, and the options for managing them.
- 6 The contingency funding will enable Whaikaha to deliver the following:
 - 6.1 *Improved safeguarding for people who are at risk of abuse (2,500 people will experience change over 4 years)*. This enables the development and provision of a more robust response to disabled people identified as "in harm" within current services. Improving safeguarding will help respond to the issues raised by the Royal Commission on abuse in state care.
 - 6.2 *Extending EGL to historically under-served communities (1,000 people will experience change over four years)*. This initiative will create two new EGL sites, extending transformation to historically under-served communities such

as Tairawhiti and Northland. This option will explore opportunities to integrate with Whānau Ora.

- 6.3 *Transforming existing disability support services (5,400 people will experience change over 4 years)*. This initiative will change how existing disability support services operate.
- 6.4 *Building community capability for partnership and stewardship (e.g. disability leadership groups)*. This funds the establishment of regional leadership groups and the building of their capability and capacity.
- 6.5 *System infrastructure changes*. Developing the data and payment system used in the demonstration sites into established systems. These will form the backbone of the transformed system.
- 6.6 *Transformation management*. This will establish a Transformation Management Office (TMO) within Whaikaha to plan and implement the work programme. The TMO will oversee the detailed development and implementation of the contingency funded initiatives.

7 Treasury has been consulted on the paper and their feedback incorporated into it. The proposals for spending the contingency were developed through a process involving representatives of disabled people and whānau, disability NGOs and providers.

Recommendations

We recommend that the Minister for Disability Issues:

	Minister for Disability Issues	Agree Disagree
a Refer this paper to the Associate Minister of Finance, Hon Barbara Edmonds, for her approval;		

We recommend that the Minister for Disability Issues and the Associate Minister of Finance:

	Minister for Disability Issues	Minister of Finance
b Note that, in September 2021, Cabinet agreed to implement the EGL approach to disability support nationally, subject to Budget 22 decisions (SWC-21-MIN-0146 refers);	Noted	Noted
c Note that in Budget 22, Cabinet:		
i agreed to establish a tagged operating contingency of up to the following amounts to provide for implementing the next stages of the EGL approach to disability support nationally:	Noted	Noted

	\$m – increase/(decrease)			
	2022/23	2023/24	2024/25	2025/26 & Outyears
Implementing the EGL approach to disability support nationally Tagged Operating Contingency	14.600	17.500	27.400	40.500
Total Operating	14.600	17.500	27.400	40.500

	ii authorised the Minister of Finance and the Minister for Disability Issues to draw down the tagged operating contingency funding in recommendation c (i) above;	Noted	Noted
		Noted	Noted
d Note that approval of the drawdown is subject to Ministers considering: a system operating framework; how the contingency will be used; an implementation plan; governance structures; risk management; and arrangements for ongoing reporting to Ministers;		Noted	Noted
e Note that in August 2023, Cabinet agreed to the following amended amounts for the tagged contingency (CAB-23-MIN-0344 refers):		Noted	Noted

	\$m – increase/(decrease)				
	2023/24	2024/25	2025/26	2026/27	2027/28 & Outyears
Implementing the EGL approach to disability support nationally Tagged Operating Contingency	10.600	15.600	20.600	26.900	40.500
Total Operating	10.600	15.600	20.600	26.900	40.500

	Minister for Disability Issues	Minister of Finance
<i>Meeting the agreed criteria</i>		
f Agree to the implementation approach described in paragraphs 8 to 14, and Appendix One, below;	Agree Disagree	Agree Disagree
g Agree to the governance and advisory structures described in paragraphs 15 to 17 and Diagram One below;	Agree Disagree	Agree Disagree
h Agree to the operating framework for the transformed system described in paragraphs 18 to 23 and Diagram One below;	Agree Disagree	Agree Disagree
i Note that Whaikaha is still working with the disability community to develop partnership structures, but this does not impact on the implementation of contingency funded initiatives;	Noted	Noted
j Note the risk management issues and mitigations described in paragraphs 25 and 26 and Table One below;	Noted	Noted
<i>Fiscal sustainability work programme</i>		
k Note that the Minister of Finance has requested that officials develop a work programme around the fiscal sustainability of the disability support system and the impact of the EGL approach, and this has formed part of his recent delegation to Minister Edmonds;	Noted	Noted
l Agree to establish a work programme focused on the fiscal sustainability of the disability support system, including the impact of the EGL approach, with the purpose of providing Ministers with better quality information on potential fiscal costs and risks, and the options for managing them;	Agree Disagree	Agree Disagree
m Note that it is intended that the fiscal sustainability work will be combined with work commissioned by the Ministers of Finance, Social Development and Health in 2022 on options for improving fiscal management settings for Disability Support Services expenditure;	Noted	Noted
n Invite officials from Whaikaha and the Treasury to jointly report back to you in the next three months with a fiscal sustainability work programme, including opportunities to consolidate this work with previously commissioned work;	Invite do not invite	Invite do not invite
o Note the ongoing reporting to Ministers described in paragraph 34 and Table Three below that will include updates on progress and allow them to influence the future development of the operating framework;	Noted	Noted

Financial recommendations

p **Agree** that the conditions described in recommendation d above have been met and the next stage of implementing the EGL approach to disability support nationally can now proceed;

q **Approve** the following changes to appropriations to provide for the decision in recommendation p above, with a corresponding impact on the operating balance and net debt:

Agree Disagree	Agree Disagree
Agree Disagree	Agree Disagree

Minister for Disability Issues	2023/24					2027/28 & Outyears
	2024/25	2025/26	2026/27	2027/28 & Outyears		
Multi-Category Expenses and Capital Expenditure: Supporting tāngata whaikaha Māori and disabled people						
Departmental Output Expenses:						
Connecting people with supports and communities (funded by revenue Crown)	1.660					
Stewardship of the Disability system (funded by revenue Crown)	6.700	2.770	4.500	6.470	7.480	
Non-Departmental Output Expenses:						
Community-based support services	0.740					
Connecting and strengthening disability communities		1.830	4.200	7.120	10.190	
Early intervention support services	-	2.200	3.000	4.100	6.700	
Non-Departmental Other Expenses						
Community capacity and support	1.500					
Total	10.600	2.000	2.000	2.000	2.500	
Minister for Disability Issues	2023/24	15.600	20.600	26.900	40.500	

r **Agree** that the proposed changes to appropriations for 2023/24 above be included in the 2023/24 Supplementary Estimates and that, in the interim, the increases be met from Imprest Supply;

s **Agree** that the expenses incurred under recommendation q above be charged against the *Implementing the EGL approach to Disability Support Nationally* tagged contingency described in recommendation c above;

Agree Disagree	Agree Disagree
Agree Disagree	Agree Disagree

	Minister for Disability Issues	Minister of Finance
t Note that following the drawdown of the tagged contingency agreed to in recommendation q above, the tagged contingency will be exhausted and therefore closed.	Noted	Noted

Hon Priyanka Radhakrishnan
Minister for Disability Issues

Date:

Hon Barbara Edmonds
Associate Minister of Finance

Date:

Ben O'Meara
Deputy Chief Executive, Whaikaha

Date: 24 August 2023

Action for private secretaries:

Forward the paper to Hon Barbara Edmonds, the Associate Minister of Finance.

Disability Transformation Tagged Contingency Drawdown

Background

- 1 In September 2021, Cabinet agreed to implement the Enabling Good Lives (EGL) approach to disability support nationally, subject to Budget 2022 decisions (SWC-21-MIN-0146 refers). In Budget 2022, Cabinet agreed to contingency funding of \$100 million over four years, with outyear funding of \$40.5m from 2026/27 to enable the next stage of implementation to proceed.
- 2 The Minister of Finance and the Minister for Disability Issues were delegated the authority to draw-down the contingency at any time until 30 June 2024, if two sets of criteria are met. First, Ministers must agree to:
 - 2.1 A straightforward governance structure as well as advisory and partnership functions.
 - 2.2 A clear and comprehensive operating framework for the transformed system; and
 - 2.3 A clear and appropriately detailed plan to implement the transformed system;
- 3 Second, Ministers must receive information on:
 - 3.1 How the contingency funding will be used to further the implementation and/or design of the transformed disability support system;
 - 3.2 The key risks to the implementation and ongoing functioning of the transformed system and options for mitigating them; and
 - 3.3 How Ministers will be kept up to date with progress on the roll out and be given opportunities to influence ongoing implementation of the operating framework.
- 4 In August 2023, Cabinet agreed to amend the amount of the tagged contingency to the following (CAB-23-MIN-0344 refers)

	\$m – increase/(decrease)				
	2023/24	2024/25	2025/26	2026/27	Outyears
Implementing the EGL approach to disability support nationally Tagged Operating Contingency	10.600	15.600	20.600	26.900	40.500
Total Operating	10.600	15.600	20.600	26.900	40.500

- 5 The remainder of this paper addresses the criteria that need to be met to approve the drawdown of the tagged contingency, then sets out the financial implications if the draw down is approved.

Comment

- 6 Whaikaha will use the tagged contingency to carry out the next stages of the nationwide disability support system transformation that Cabinet agreed to in 2021. Implementing the transformation involves redesigning the disability support system from a set of predetermined services to instead build good lives for disabled people, tāngata whaikaha Māori, their families and whānau (disabled people and whānau) using flexible support arrangements.

7 The transformation draws on the EGL vision and principles, with the system guided by the purpose of 'disabled people, tāngata Whaikaha Māori, and their family and whānau live the life they are seeking'. Delivering the transformation requires changes to all elements of the system (a paradigm shift), which includes the following (see Appendix One for more detail):

- 7.1 Community: investment in disability community leadership and in making the wider community more inclusive and welcoming to disabled people.
- 7.2 Family and whānau: Build up and value existing and new support networks for disabled people and tāngata whaikaha Māori.
- 7.3 Disabled people: Seen as experts and leaders in their own lives, with the support system understanding and responding to the disabled person's aspirations, will and preferences, and to their potential.
- 7.4 Delivery: The development of providers and a workforce that support disabled people to exercise agency, choice, and control.
- 7.5 Investment: Guidelines, tools, and processes for managing funding and its allocation. There is a range of options for managing personal budgets. Connectors | Kaitūhono (Connectors) work alongside people to help them plan for and build their lives. Providers and a workforce are in place to meet demand.
- 7.6 Whaikaha System: system stewardship and governance are in place, a backbone for EGL expansion is built, outcomes, equity and finances are tracked and inform investment and financial risk management. There is appropriate legal authority for the transformed system.
- 7.7 All of Government system: Leverage the investment in system transformation across the broader social sector (education, income and employment, housing, transport etc).

Implementation plan

8 The work programme required to make these system-wide changes is expected to take up to 10 years, with the actual changes made, and the speed at which they occur, being guided by ongoing Cabinet and Ministerial decision making. There are many matters in the work programme that meet the threshold for being considered by Cabinet (e.g., how to allocate funding), and additional resources will be required over time to support a full national roll out.

9 Whaikaha envisages that there will be three broad phases to implementing the required changes:

- 9.1 *Phase One (2023/24 to 2025/26): Preparing for Full Implementation.* This phase involves the work programme described in this paper in the section entitled "how the contingency funding will be used." The focus is on:
 - 9.1.1 Creating the underpinning systems and process required to effectively manage the transformed system, developing the monitoring and reporting systems, building community capacity, beginning to transform residential care ("My Home, My Choice" and "My Time, My

Choice”¹) and beginning small-scale transformation initiatives in two new regions (in addition to Christchurch, Waikato and MidCentral).

9.1.2 Providing advice to Cabinet on a range of policy issues, including how to allocate funding, the most appropriate organisational form for the regional EGL sites, and addressing the wide-ranging policy issues raised by the envisaged Disability System Bill that will provide the necessary legal foundations for the transformed system.

As soon as approval is given to draw down the contingency, Whaikaha will recruit a team to carry out in-depth planning of this Phase. At the conclusion of this Phase, Whaikaha will present a business case for funding for full implementation of system transformation.

9.2 *Phase Two: Intensive development across Whaikaha (2026/27 to 2029/30).* This phase involves embedding the EGL principles into all aspects of support funded by Whaikaha. The development of systems and processes during Phase One will allow Whaikaha to implement the core underpinnings of the transformation. The primary focus will be on the following:

9.2.1 The progressive introduction of full regional EGL sites across the country, so that all people supported by Whaikaha can benefit from person-directed support options. This process will require a lead time of about 18 months before each site can be established.

9.2.2 Continuing to transform existing supports, over and above the changes being made to residential care. This means implementing changes to other services such as Home and Community Support, Equipment and Home and Vehicle Modifications, and Child Development Services.

9.3 *Phase Three: Embedding the transformation (2030/31 onwards).* This phase shifts the focus to full implementation. This involves the roll-in of the transformed system for all people within regional sites, the continued transferral of providers of existing services to new support models and retiring existing systems and processes. This reflects a shift towards the transformed system becoming ‘business as usual.’

During this phase, everyone supported by Whaikaha will benefit from the transformed system. In addition, development work shifts to:

9.3.1 Ongoing improvements to the transformed system;

9.3.2 Making complementary changes in other government agencies; and

9.3.3 Further work to transform disability supports funded through other government agencies.

10 The maturity model in Appendix Two describes in more detail the broad-ranging changes that Whaikaha expects will be made over time.

11 More detailed implementation planning will be possible once Whaikaha has drawn down the contingency funding, a part of which will be used to enable further development of the EGL model in ways that support a nation-wide roll out.

¹ My Home, My Choice focuses on transforming, and reducing entry into and increasing exit from, residential services. My Time, My Choice complements My Home, My Choice through giving people in residential care choice and control over what they do and when.

Differences from 2021 Road Map

12 This approach to implementation differs from the three-year phased road map that Cabinet endorsed in 2021 (SWC-21-MIN-0146, Appendix 5). That road map emphasised the following elements:

12.1 Establishment of Whaikaha;

12.2 Community capability building;

12.3 Development of tools and practices to support person-directed commissioning and funding; and

12.4 Transition from NASCs to new regional EGL entities.

13 That road map was predicated on the following assumptions:

13.1 The full investment needed to transform the system being provided in Budget 22; and

13.2 An expectation that the required development work could be carried out in about 18 months.

14 Whaikaha considers that the 2021 road map does not reflect the complexity and breadth of the changes required to fully transform the existing system. For example:

14.1 It did not allow for investment in or development of Whaikaha's commissioning, funding, and data systems to enable Whaikaha to monitor and evaluate system transformation;

14.2 It did not recognise the time required to develop and test policy and operational changes before significant changes could be implemented on the ground; and

14.3 It did not recognise the lead time (at least 18 months for each region) required for regional EGL entities to begin operating, and the challenges of establishing several sites at the same time.

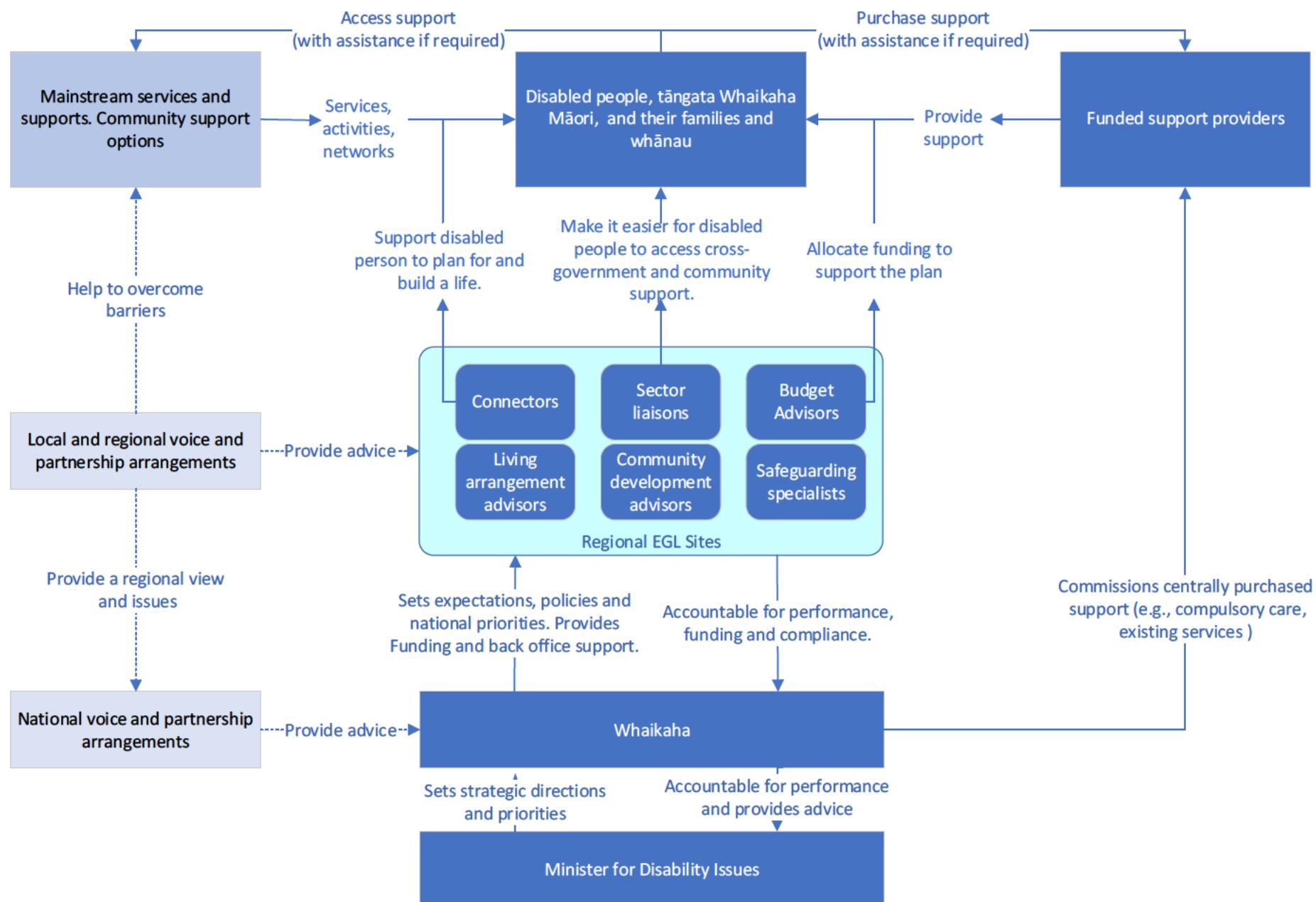
Governance, advisory and partnership arrangements

15 As shown in Diagram One on the following page, Whaikaha is accountable for the disability support system. This includes the management of the existing system, the funding allocated for it, its transformation, and the management of the transformed system.

16 Within Whaikaha, responsibility and accountability for the transformation itself will sit with a Transformation Board, chaired by the Chief Executive of Whaikaha. The Transformation Board will be supported by a Transformation Office, led by a Transformation Director.

17 These governance arrangements will be complemented by partnership arrangements with the disability community. Whaikaha is working with representatives of disabled people, tāngata whaikaha Māori, and their families and whānau to establish enduring arrangements for working in partnership with the community. These partnership arrangements will continue to develop through the early stages of implementing transformation throughout the 2023/24 financial year.

Diagram One: Governance Arrangements and Operating Framework for the Transformed Disability Support System



Operating framework

18 The operating framework for the transformed system is also summarised in Diagram One on the previous page. Key features of that framework are the following:

18.1 Whaikaha is accountable to the Minister for Disability Issues for the operation of the disability support system, including managing within the available funding and setting the framework within which other parts of the system operate.

18.2 Responsibility for the day-to-day operation of most of the disability support system will be delegated to 10 to 11 regional sites (apart from those functions which are managed nationally, such as compulsory care under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003).

18.3 National level partnership and voice mechanisms will provide advice to Whaikaha on what matters to disabled people and whānau, and how well the system is working for them. They will not, however, have decision making responsibility.

19 A Regional Director will be responsible for the operation of the transformed system within each site, including expenditure that they control. The regional sites will:

19.1 Invest in building up the capacity, capability, and confidence of disabled people and whānau to act for themselves.

19.2 Employ² Connectors who will support disabled people and whānau to plan for and build lives that are connected to their local community.

19.3 Employ Budget Advisors who will:

19.3.1 Allocate funding for personal budgets after reviewing funding proposals, with the amount of funding sought assessed against indicative ranges for the whole population in similar situations. Where necessary, indicative ranges may be adjusted to allow for early investments with a future payoff. Note that Connectors and people from the disability community are not involved in making funding allocation decisions.

19.3.2 Agree the purposes that funding can be used for, with purchasing guidelines agreed to by Cabinet³.

19.3.3 Allocate funding to enable a person to move on from a crisis. This funding is not, however, included in personal budgets, which means that it is not managed by the person themselves.

19.4 Employ sector liaisons who work behind the scenes to make it easier for disabled people and whānau to access social supports provided by other government agencies, and to access support available in the community generally (e.g., in Mana Whaikaha they are working with housing developers to create houses that can be leased to disabled people).

20 The work of Regional Directors will be supported in two important ways by the disability community:

² Note that in a small number of cases, people will be contracted to carry out roles, e.g., to avoid conflicts of interest.

³ In 2018, purchasing guidelines were agreed to by Cabinet for Mana Whaikaha (SWC-18-MIN-0108 refers). Any changes to these purchasing guidelines would need to be agreed by Cabinet.

20.1 Disabled people and whānau collectively will lead change within their community through e.g., removing barriers that disabled people and whānau face to living the life they are seeking. Removing barriers can help reduce the demand for disability support as funding is not required to overcome those barriers.

20.2 Regional Leadership Groups will advise the Regional Directors on the priorities for transformation and investment within their local communities. This can make it more likely that investments will benefit those communities. Note, however, that ultimate decision-making on funding and investment will sit with Regional Directors, under delegation from the Chief Executive of Whaikaha.

Purchasing guidelines

21 Subject to any future changes by Cabinet, Whaikaha will apply the purchasing guidelines that Cabinet has agreed for Mana Whaikaha (SWC-18-Min-0108):

21.1 A personal budget can be used to purchase goods and services that help a disabled person and their whānau to overcome barriers they face because of living in a disabling society;

21.2 A personal budget cannot be used to pay for:

21.2.1 Family carers who are not eligible to be funded under the government's funded family care policy;

21.2.2 Illegal activities, gambling, or alcohol;

21.2.3 Support for personal injuries that are covered by ACC;

21.2.4 As a general supplement to household income;

21.3 A personal budget can only be used to purchase a good or service that another government agency (other than ACC) has funding responsibility for after they have made reasonable efforts to access that support through the other government agency and the support is either not available in a timely manner or is not suitable.

22 Cabinet also agreed that a MidCentral Regional Governance Group (drawn from the Regional Leadership Group), appointed by the Minister for Disability Issues, would be responsible for decisions about whether an individual's funding can be used to pay for:

22.1 Alternative therapies that do not otherwise attract public funding; or

22.2 Goods and services that may lead to adverse public perceptions.

23 This reflected the view that the Governance Group was closest to the affected disabled person and their whānau, so had good access to the necessary information.

Risk management

24 The most significant risks to the implementation of the transformation of the disability support system are:

24.1 The possibility that transformation will exacerbate already high rates of cost growth occurring in the disability support system. There is a particular concern that the transformation might lead to an increase in the number of eligible people who seek support, over and above the increases currently occurring (which is discussed further in paragraphs 27 to 30 below).

24.2 The legal, operational, and financial risks arising from the current paid family carers litigation, with a Court of Appeal decision on some of the cases due to be released soon. Dependent on the Court's approach, the decision may make it difficult to implement central aspects of the transformed system such as a defendable funding allocation process.

25 To manage this risk, legislative change may be needed to provide a clear framework for funding allocation. Policy advice on this and other legislation needed to create the legislative framework for the disability system is being developed by Whaikaha. Cabinet approval is likely to be sought early in 2024.

26 Other risks and their mitigations are described in Table One below.

Table One: Implementation Risks and Mitigations

Risk	Mitigations
Whaikaha is not able to implement at the pace anticipated	<ul style="list-style-type: none">Whaikaha is establishing an internal Transformation Management Office to oversee the system transformation programme and has appointed a Transformation Director.Whaikaha will recruit the workforce to lead implementation as soon as the contingency draw-down is approved.
The community feels frustrated at the pace of EGL implementation	<ul style="list-style-type: none">The wider service improvement plan will begin to shift the whole system to align to EGL principles.The Regional Leadership Groups will help to prioritise who can access the EGL features in their region.
Recruiting the right workforce in regions takes longer than anticipated	<ul style="list-style-type: none">Whaikaha is undertaking workforce planning and modelling.Regional roll-out plans will be regularly reviewed based on recruitment progress, to enable different regional phasing if needed.
Personal budgets are not allocated fairly	<ul style="list-style-type: none">A budget range tool will be developed by Whaikaha to measure personal budget spend against benchmarks.Budget advisors will determine funding allocations, with scope for escalation.Separation of duties between being the disabled person's ally in planning and implementing the budget, and the person agreeing the level of funding for the budget.
Misuse of personal budgets	<ul style="list-style-type: none">Cabinet mandated purchasing guidelines will govern the use of personal budgets.Upfront support to build capability to manage a personal budget well.A stepped approach of escalating support and responses where issues emerge.
System changes don't deliver to EGL principles	<ul style="list-style-type: none">Overall roll-out will be overseen by arrangements involving Whaikaha, disabled people, tāngata whaikaha Māori, and their family and whānau.

Fiscal sustainability work programme

27 There are already high rates of cost growth in the disability support system and there are concerns around the impact that system transformation may have on the medium to long-term fiscal sustainability of disability supports. While Cabinet has taken an in-principle decision around the national roll-out, this was taken with limited visibility of the financial implications of this decision. Moreover, the current fiscal environment means there is more pressure on overall public funding.

28 The Minister of Finance requested that officials develop a work programme around the fiscal sustainability of the disability support system and the impact a shift to the EGL approach would have on this. Responsibility for this work programme has formed part of the recent Associate Finance portfolio delegation to Minister Edmonds.

29 Some of these issues are already being considered through work that the Ministers of Finance, Social Development and Health commissioned in March 2022. Those Ministers directed Whaikaha officials to investigate and report back ahead of Budget 2024 on options for improving fiscal management settings for Disability Support Services expenditure with a focus on options that:

- 29.1 Reflect the demand driven nature of the spend;
- 29.2 Increase the transparency and accountability of expenditure;
- 29.3 Provide a pathway for addressing key challenges to equitably funding clients and providers;
- 29.4 Better manage spending growth fairly and sustainably for clients, the Crown, and providers; and
- 29.5 Support strategic management of the spend.

30 We recommend that you invite Whaikaha and Treasury officials to jointly develop the details of this new work programme, including identifying opportunities to consolidate this new request with the earlier commissioning noted above. We will, along with the Treasury, provide you with advice on the detailed work programme for your agreement in the next three months. This advice will include a timeline of the proposed report backs. Indicative timing is provided in table three below, but this may be revised in the next report.

How the contingency will be used

31 The contingency will be used for the following initiatives:

- 31.1 *Initiative one: System infrastructure changes.* Developing the "boot-strap" data and payment system used in the demonstration sites into properly established systems. These will form the backbone of the transformed system. The intention is to use software-as-a-service options, rather than capital investment.
- 31.2 *Initiative two: transformation management.* This establishes a Transformation Management Office (TMO) within Whaikaha under the Director, Transformation, to plan and implement the work programme. The TMO will oversee the detailed development and implementation of the contingency funded initiatives.
- 31.3 *Initiative three: Improve safeguarding for people who are at risk of abuse (2,500 people experience change over 4 years).* This enables the development and provision of a more robust response to disabled people identified as "in harm" within current services. Improving safeguarding will help respond to the issues raised by the Royal Commission on abuse in state care.
- 31.4 *Initiative four: Extending EGL to historically under-served communities (1,000 experience change over four years).* This initiative would create two new EGL sites, extending transformation to historically under-served communities such as Tairawhiti and Northland. This option continues the expansion of EGL through enabling us to learn what it means for EGL to work for Māori and to integrate with Whānau Ora.

31.5 *Initiative five: transforming existing disability support services (5,400 people experience change over 4 years).* This initiative will change how existing disability support services operate, with a primary focus on two issues:

- 31.5.1 Reserving connector capacity to support disabled people considered "at risk" or "vulnerable". This will support, for example, outcomes under the My Home, My Choice, project.
- 31.5.2 Adding aspects of personal budgets, such as facilitation, to Individualised Funding, to improve the management of those service lines.

31.6 *Initiative six: building community capability for partnership and stewardship (e.g., disability leadership groups).* This funds the establishment of regional leadership groups and the building of their capability and capacity. Community leadership plays a central role in the transformed system, as the community collectively works to address barriers disabled people face. It also enables independent voices to provide valuable input into decision making.

Table Two: Expenditure on Contingency Funded Initiatives by year

Initiative	Intended Expenditure (\$millions)				
	2023/24	2024/25	2025/26	2026/27	Outyears
Initiative one: System infrastructure changes	\$4.0	\$4.0	\$3.6	\$3.2	\$3.2
Initiative two: Transformation management	\$2.7	\$2.8	\$2.8	\$2.8	\$2.8
Initiative three: Improve safeguarding for people who are at risk of abuse	-	\$2.2	\$3.0	\$4.1	\$6.7
Initiative four: Extending EGL to historically under-served communities	-	-	\$2.1	\$4.3	\$9.80
Initiative five: Transforming existing disability support services	\$2.4	\$4.6	\$7.1	\$10.6	\$10.7
Initiative six: build community capability for partnership and stewardship	\$1.5	\$2.0	\$2.0	\$2.0	\$2.5
Risk Pool	-	-	-	-	\$4.7
Total	\$10.6	\$15.6	\$20.6	\$26.9	\$40.5

32 Table Two on the previous page sets out contingency expenditure by component for each year. Following the decisions on the recent savings exercise:

32.1 Initiative three, Improve Safeguarding for People who are at Risk of Abuse, will now start in 2024/25.

32.2 Initiative four, Extending EGL to Historically Under-served Communities, will now start in 2025/26.

33 There is also a risk-pool in the out-years of \$4.7 million a year, which reflects the need for Whaikaha to manage the considerable uncertainty over medium term costs during transformation processes. Separating out a risk pool (rather than incorporating the risks into each line) reduces the chance that the risk reserve will not be spent on the transformation.

Ongoing reporting

34 There will be several opportunities for Cabinet to influence the design of the transformed system, how it performs, and how the next stages of the system transformation are approached. Indicative reporting dates are set out in Table Three below.

Table Three: Indicative Cabinet Reporting Dates

Date	Issues
Early 2024	Responding to the issues raised by the family carers litigation (timing is dependent on when the Court of Appeal releases its decision). Advice on a nationwide approach to funding allocation for the transformed system
Late 2024	Initial reporting to Ministers on the financial sustainability work programme.
Mid 2025	Reporting on the outcomes and costs of existing EGL demonstrations and the contingency funded changes.
September 2025	<ul style="list-style-type: none">Any changes to high-level policies, the system transformation operating model and ways of working required to reflect Whaikaha's commitment to the Treaty.The feasibility of, and requirements for implementing, an approach in which community-based entities take on more responsibility for the operation of the transformed system.How the disability support system could be integrated more closely with other social services.Reporting to Ministers at the conclusion of the financial sustainability work programme.
Budget 2026	Funding sought for the next stage of system transformation.

Te Tiriti o Waitangi Analysis

35 Articles and treaty principles are interdependent. Progressing one article or principle frequently has a positive impact on others. The system transformation work aligns well with all articles of Te Tiriti and individual Te Tiriti principles, so funding and implementing this policy should significantly improve the alignment of the disability support system with Te Tiriti o Waitangi.

36 Māori have concerns about the disability support system that are currently being heard by the Waitangi Tribunal in the ongoing Health and Disability Kaupapa Inquiry (Wai 2575). Those concerns include:

36.1 The current disability support system does not work well for tāngata whaikaha Māori me o rātou whānau, as evidenced by the disproportionately low uptake of disability support services by tāngata whaikaha Māori.

36.2 Tāngata whaikaha Māori have also expressed that their identities as both disabled people and Māori are not acknowledged by government systems.

37 The transformation of the disability support system will promote improved outcomes for tāngata whaikaha Māori me o rātou whānau and alignment with Te Tiriti o Waitangi.

37.1 **Article One - kāwanatanga:** Transforming the disability support system in line with Enabling Good Lives and Whānau Ora principles is a direct expression of both kāwanatanga and the principle of *whakamaru* (*active protection*). The

Crown has identified inequities and is developing policies to remedy them in partnership with tāngata whaikaha Māori. Through system transformation, the Crown is also acting to embed those changes into the future disability support system and will monitor the success of those investments in relation to outcomes that matter to disabled people and tāngata whaikaha Māori.

The future system transformation work aligns well with the Crown's obligation to work in *pātuitanga* (*partnership*) with Māori. To date, tāngata whaikaha Māori have actively participated in developing and making real the vision expressed in Enabling Good Lives, including through a Whānau Ora Interface Group. The next stage of transformation includes developing a partnership with Iwi and tāngata whaikaha Māori.

37.2 Article Two – *tino rangatiratanga*: The continued implementation of system transformation will enable more tāngata whaikaha Māori me o rātou whānau to have a greater degree of choice and control over their supports and broader lives. This shift helps to support *tino rangatiratanga* as it enables tāngata whaikaha Māori to determine for themselves what a good life looks like for them in the context of their communities and to receive support on their journey to achieve it.

By growing choice and control, more tāngata whaikaha Māori me o rātou whānau will be able to allocate their resources towards supports that respond to what is important to them, including more culturally appropriate supports. This will create the space necessary for communities to promote more community-led, culturally appropriate supports and thus effective *kōwhiringa*.

37.3 Article Three - *ōritetanga*: Māori experience higher levels of disablement than non-Māori in Aotearoa and the rebalancing of current inequities in access to support promotes *ōritetanga* (*equity*). It is anticipated that implementing EGL within Tairāwhiti and Northland provides opportunities to develop and implement a Te Ao Māori approach to system transformation, which will help to improve equity.

Engagement

38 The approach to system transformation forming the core of this paper was developed through a process involving representatives of disabled people and whānau, disability NGOs and providers.

39 Treasury has been consulted on the paper and their feedback incorporated into it.

Financial Implications

40 Following Cabinet's decision in August 2023, the tagged contingency, which expires on 30 June 2024, is for up to the following amounts:

	\$m – increase/(decrease)				
	2023/24	2024/25	2025/26	2026/27	Outyears
Implementing the EGL approach to disability support nationally Tagged Operating Contingency	10.600	15.600	20.600	26.900	40.500
Total Operating	10.600	15.600	20.600	26.900	40.500

41 The plans described in this paper for implementing the next stages of system transformation require the following changes to appropriations, with a corresponding impact on the operating balance and net core Crown debt:

Vote Social Development	\$m – increase/(decrease)				
Minister for Disability Issues	2023/24	2024/25	2025/26	2026/27	Outyears
Multi-Category Expenses: Supporting tāngata whaikaha Māori and disabled people					
Departmental Output Expenses:					
Connecting people with supports and communities	1.660	2.770	4.500	6.470	7.480
Stewardship of the Disability system	6.700	6.800	6.410	6.030	10.760
Non-Departmental Output Expenses:					
Community-based support services	0.740	1.830	4.200	7.120	10.190
Connecting and strengthening disability communities		2.200	3.000	4.100	6.700
Early intervention support services	0.000	0.000	0.490	1.180	2.870
Non-Departmental Other Expenses					
Community capacity and support	1.500	2.000	2.000	2.000	2.500
Total	10.600	15.600	20.600	26.900	40.500

42 The expenses described in paragraph 41 above will be charged against the *Implementing the EGL approach to Disability Support Nationally* tagged operating contingency. The proposed increases to appropriations for 2023/24 will be included in the 2023/24 Supplementary Estimates and, in the interim, will be met from Imprest Supply.

43 Funding for future tranches of implementation will be sought in the usual way through future budget processes. The plans for using the tagged contingency set the system up for further system transformation but allow Cabinet to determine when the next stages of the national roll-in will be funded.

Next steps

44 Once the contingency draw down is approved, Whaikaha will finalise its detailed planning for, and commence implementing, the contingency funded initiatives, as well as continuing the fiscal sustainability work programme.

Ends.

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Appendix One: Transforming the system so disabled people have agency and an eco-system of safeguards

	Current state	Future state: Disabled people have agency, and an eco-system of safeguards	Actions needed to transform the system
Community disability-focused and wider	Ad hoc processes for hearing and responding to the voices of disabled people and tāngata whaikaha Māori Low investment in disabled people and tāngata whaikaha Māori community leadership capacity, capability, and confidence.	Effective, representative national partnerships, to guide Whaikaha's strategic priorities. Networks of people invested in for the wellbeing of disabled people and their whānau. Community safeguards: build the capacity, capability, and confidence of the community to create and maintain inclusive and welcoming places and spaces.	Investment in community leadership, regional leadership groups, Disabled People and tāngata whaikaha Māori Organisations to create a 'network of networks' Investment in mainstream community, so it develops more inclusive and welcoming places and spaces.
Disabled person's whānau	Existing networks are expected to continue supporting disabled people. This can lead to feeling unsupported and stretched to beyond coping.	Have sustainable expectations of what family and whanau members can provide. Relationship safeguards strengthen relationships between disabled people and their whānau, expand their networks and increase their community connections (both for disabled people and for whānau).	Existing networks built up and valued, and new networks developed. Resources to support family/ whānau, education, tools, and options on how supports and funding can be used to maximum effect. Investment in intentional networks / circles of support.
Disabled people	Often the focus is on what disabled people can't do (deficit and needs-based) Funding is siloed, with low flexibility. Mainly get a set of services based on 'need', (and what the system has already contracted) Often seen as passive recipients of services. Enabling Good Lives approach in 3 locations (only one - Mana Whaikaha- reaches the whole eligible population).	Supported to build a life they are seeking across the full range of disability and mainstream supports. Have genuine options, including where they live, who they live with, and what they do each day. Able to access a flexible personal budget. Have the skills, agency, confidence, and support to form, express, test and enact their will and preference. Access to a peer-to-peer advocate supporting them to express their voice. Are supported in gaining foundational skills: <ul style="list-style-type: none">self-regulation and attachment (communication, behaviour, consequences, choice)forming boundaries (e.g., bodily consent) and other decision-making habitsre-negotiating boundaries in adolescence and adulthood (identity, sexuality, perspectives, contributions)creating a strong set of life-skills to exercise practical agency (e.g., financial literacy). Personal safeguarding through: <ul style="list-style-type: none">building disabled people and tāngata whaikaha Māori capability to make informed choices about their lives, including the dignity of taking everyday life riskssupported decision-making is widely used in all contexts to enable agency, choice, will and preferenceensuring strong, healthy relationships and community connections are seen as foundational, and are invested in and strengthenedensuring every person's rights to be free from abuse and violence.	Disabled people and tāngata whaikaha Māori are seen, and treated as, experts and leaders in their own lives Self-directed planning and facilitation, to reflect the disabled person's aspirations, will and preferences, progress, and possibilities Build independent voice and feedback mechanisms into decision-making Kaitūhono workforce and peer-to-peer workforce are available (and are skilled and representative) Disabled person is seen in their wider context, not in their 'funded support' context Flexible personal funding options in place Investment in supported decision making (+ contractual expectations that all involved in 'the system' keep the disabled person's will and preference at the forefront of decision making).
Delivery	Funding approach tends to be siloed, and focuses on 'needs', 'crises,' and escalated situations Focus predominately on social services, and often misses broader life outcomes and contexts	Supporting disabled people to exercise will and preference Ensure planning is person-directed, and supports ordinary life outcomes, with a tailored mix of equipment, technology, accommodation, capability building and support (from family, peers, community, support workers, facilitators, Kaitūhono and professionals if needed). Disability and community services safeguards: mechanisms to protect and promote people's rights against the risks that arise within the disability support system and wider community.	The development of a workforce that can enable disabled people and tāngata whaikaha Māori to exercise agency, choice, and control. Greater investment in Kaitūhono (connectors) with parallel investments in communities, to: <ul style="list-style-type: none">ensure they become more inclusive and welcomingassist with self-directed planning and flexible use of funding.
Investment	Decisions on funding are made by a third party (NASC, Individualised Funding host, service provider), often initiated in response to a crisis. Funding reflects contract lines rather than what is important to the person	Allow for flexible investments, supported by parameters for allocation and prioritisation. Broaden investment from social services to capability building (people, peers, community) and broader life outcomes (e.g., education, employment, enterprise, home ownership etc) Investment safeguards: build funding, prioritisation and allocation approaches that allow for flexible responses to disabled people's will and preferences and needs.	Guidelines, tools, and processes are in place for funding, allocation, and prioritisation. Range of options for managing personal budgets. Connectors work alongside people to help them plan for and build their lives Workforce planning (including pay equity), diversity and development is in place to meet current and forecast demand
System: Whaikaha	Focus on a sub-set of disabled people Challenge in tracking or matching investments to outcomes (personal and population level) Some funding decisions have been successfully challenged in court.	EGL principles are increasingly visible in funding, support and services across all agencies who support disabled people. Enable disabled people the dignity of 'everyday' risks, while ensuring they are not placed in situations where they are at risk of abuse (financial, physical, emotional etc) Understand population-level demand, and key transition points. Whaikaha system safeguard: in collaboration with disabled and whanau experts, monitor and review strategies, policy, and practice to ensure they work to increase agency, choice and control, safety, and wellbeing for disabled people and their whānau.	Stewardship and governance for system transformation is in place. Backbone for EGL expansion is built. Options to improve cross-government funding and build EGL principles into all forms of disability support are developed Outcomes and equity are tracked, and inform investment, and fiscal risks are managed through fit-for-purpose financial tracking mechanisms. There is legal authority to support flexible funding approaches and decisions.
System: All of Government	Lack of data, data consistency and data sharing on the issues faced by disabled people Low awareness of responsibilities to the UNCRDP including work to eliminate poverty and inequality for disabled people Centrally-set barriers to person and whānau-centred ways of working, investing, and assessing outcomes.	Better alignment across disability and mainstream services and supports, and EGL principles are applied by all government agencies supporting disabled people. Government agencies take responsibility for improving outcomes for disabled people, their whānau and communities. Potential changes are made to the broader social support system. This includes responsibility for mainstream family violence responses that are safe and accessible Population outcomes and public value is improved through earlier, more holistic support and investment, for disabled people, family/ whānau and communities. All of government systems approach to safeguarding: to promote disabled people's rights, wellbeing and safety through legislation, regulations, policy, and other mechanisms that have a broader focus than disability support.	Leverage policy and investment across the broader social sector (education, income and employment, housing, transport etc) Leverage enablers (e.g., IT and workforce development in health and MSD, improved legislative underpinning across Employment, Health and Safety, Adult Decision-making Acts, and possible amendments to other acts, as well as improving outcome measurement to support investment decisions, including early investment and capability development (people, whānau, communities, community leaders, peer workforce etc).

Appendix Two: Maturity model - what the transformed disability system looks like over time

Time	Current state	1-2 years	3-5 years	10 years	
Te Tiriti o Waitangi	<p>Tino rangatiratanga (self-determination) requires Māori self-determination and mana Motuhake in design, delivery and monitoring of services and systems. Ōritetanga (equity) requires the Crown to commit to achieving equitable wellbeing outcomes for Māori. Whakamaru (active protection) requires the Crown and its agents to work towards equitable wellbeing outcomes for Māori, including across broader psychosocial and environmental determinants of wellbeing. Kōwhiringa (options): requires properly resourcing kaupapa Māori services, support for Māori models of care and ensuring all services are culturally safe. Pātuitanga (partnership) requires the Crown and Māori to work in partnership in the governance, design, delivery and monitoring of services and systems.</p>	<p>Commitment to building strong partnerships with tāngata whaikaha Māori and developing mechanisms to apply Te Tiriti o Waitangi to policy and service delivery design.</p>	<p>Growing application of Te Tiriti o Waitangi principles in policies, strategies, tools, processes, and monitoring. Building mechanisms for whānau voice.</p>	<p>Te Tiriti o Waitangi principles are embedded into core organisational policies and practices.</p>	<p>Te Tiriti o Waitangi principles are embedded into all organisation policies and practices.</p>
Community disability-focused and wider	<p>Ad hoc approach to disabled people's – and their communities' – voice.</p> <p>Low investment in community leadership</p> <p>Communities can be inaccessible or unwelcoming to disabled people.</p>	<p>Mechanisms are in place to capture the voice of disabled people and their communities, and the 'network of networks' begins to grow</p> <p>Resources are directed to supporting community and regional leadership (led by the disability community), DPOs and helping the wider community to become more accessible and welcoming.</p>	<p>Disabled leaders and partnerships are more visible at the national, regional, and local levels, for disability and broader wellbeing issues (social, economic, education, housing etc).</p> <p>Communities are more accessible and welcoming.</p>	<p>Disabled leaders and partnerships are influential at all levels, and across all sectors, and shape strategic priorities.</p> <p>Communities are inclusive and welcoming places and spaces for disabled people.</p>	
Disabled person's whānau	<p>Expectation of continued support, even when stretched</p> <p>Low investment in networks of support</p>	<p>Resources are in place to support family/ whānau: education, tools, and options on how supports and funding can be used to maximum effect</p>	<p>Networks of support are becoming established.</p>	<p>Strong support networks in place.</p> <p>Family/ whānau feel valued.</p>	
Disabled people	<p>Often seen through a deficit and needs-based mindset, and as passive recipients of services.</p> <p>Funding is siloed, with low flexibility.</p> <p>Get what the system thinks they need.</p> <p>Safeguarding focuses on protection from abuse and harm.</p>	<p>Strengths-based and holistic, with a focus on building skills, agency, and confidence to form, express, test and enact their will and preference.</p> <p>Flexible funding options are available to more disabled people.</p> <p>Safeguarding broadens from protection from harm to building healthy relationships and community connection.</p> <p>Build independent voice and feedback mechanisms into decision-making.</p>	<p>Self-directed planning and facilitation, to reflect the disabled person's aspirations, will and preferences, progress, and possibilities.</p> <p>Funding is flexible and seamless.</p> <p>Safeguarding occurs across many levels.</p>	<p>Disabled people are experts and leaders in their own lives, and are supported to build a life they are seeking (across the full range of disability and mainstream supports)</p> <p>Have genuine options, including where they live, who they live with, and what they do each day.</p> <p>An 'eco-system' of safeguarding exists (across community, relationship, personal levels, services, the disability, and wider government system). Disabled people are at no greater (or less) risk than other New Zealanders.</p>	
Delivery	<p>Focus on services to address needs</p> <p>Third parties make funding decisions.</p> <p>The workforce has a primary focus on 'doing things to' disabled people.</p> <p>EGL principles applied in specific locations, and to parts of disability support.</p>	<p>Greater investment in Kaitūhono (connectors).</p> <p>Development of the peer-to-peer workforce</p> <p>Increased support for disabled people to exercise will and preference.</p> <p>Services and other supports are more holistic, and strengths-focused.</p> <p>Application of EGL principles evident in more locations, and across more disability supports (e.g., residential) and specialist services</p>	<p>Connector and peer-to-peer workforce become more skilled and representative.</p> <p>Planning becomes more person-directed.</p> <p>Increased options in the range of supports available, providers and workforce (e.g., peer support).</p> <p>EGL principles continue to expand across all parts of the disability support system.</p>	<p>Connector and peer-to-peer workforce are skilled and representative.</p> <p>Planning is person-directed and supports ordinary life outcomes.</p> <p>EGL principles evident in all parts of Whaikaha's disability support system and are also increasingly shaping other forms of disability support across government.</p>	
Investment	<p>Focus is on social services.</p> <p>Funding is siloed, focused on services, 'crises and escalated situations.</p> <p>EGL sites operate as extended pilots.</p>	<p>Investment to understand how to embed EGL approach at scale (what are core elements, and parameters of flexibility, for processes and priorities).</p> <p>Tools and processes are in place for funding, allocation, and prioritisation.</p> <p>Develop the EGL backbone, to support expansion.</p> <p>EGL not yet the norm across the disability system.</p>	<p>Investment has expanded from social services to capability building (people, peers, community) and broader life outcomes (e.g., education, enterprise)</p> <p>EGL is increasingly becoming the norm across the disability support system.</p>	<p>Allow for flexible investments, supported by parameters for allocation and prioritisation.</p> <p>EGL is the norm across the disability support system.</p> <p>Increasing devolution of funding to disabled people and partnerships, recognising their leadership role.</p>	
System: Whaikaha	<p>Transformation activity is subsumed by everyday delivery requirements.</p> <p>Focus on a sub-set of disabled people.</p> <p>Tracking is output focused.</p> <p>Some funding decisions have been successfully challenged in court.</p>	<p>Effective governance drives the transformation work programme</p> <p>EGL is increasingly shaping how Whaikaha operates</p> <p>Options to improve cross-government funding and build EGL principles into all forms of disability support are identified.</p> <p>Information management system developed.</p> <p>Legal authority for funding decisions in place</p> <p>Workforce planning is underway.</p>	<p>Transformation stewardship, governance and results help inform organisational practices and investments.</p> <p>EGL shapes how Whaikaha operates.</p> <p>EGL principles are increasingly visible in funding, support and services across all agencies who support disabled people.</p> <p>Fiscal risks are managed through fit-for-purpose financial tracking mechanisms</p> <p>Workforce development is underway.</p>	<p>Transformation mindset is embedded into everyday practice</p> <p>EGL principles are enacted by all agencies who support disabled people</p> <p>Outcomes and equity are tracked and inform investment.</p> <p>Workforce dynamics across sectors are well managed</p>	
System: All of government	<p>Limited data and awareness of shared UNCRPD responsibilities.</p> <p>Barriers to person and whānau-centred ways of working and investing.</p>	<p>Growing understanding of disability issues and shared responsibilities across all of government.</p> <p>Re-shaping ways of working and investing to become more person and whānau-centred</p>	<p>Government agencies take responsibility for improving outcomes for disabled people, their whānau and communities.</p> <p>Potential changes to the broader social support system.</p>	<p>Population outcomes and public value is improved through earlier, more holistic support and investment, for disabled people, their whānau and communities.</p>	
Māori-Crown relationship	<p>Tāngata whaikaha Māori were key partners in the work to establish Whaikaha. Whaikaha has an ongoing tripartite partnership with the disability community and Māori.</p>	<p>Work to build capacity and capability in te ao Māori within Whaikaha and across the wider disability sector, including meaningful outcome measures.</p> <p>Working with Te Ao Mārama, tāngata whaikaha and whānau on next steps for Whāia Te Ao Mārama (Māori Disability Action Plan).</p>	<p>Ongoing work with whānau, hapū and iwi so tāngata whaikaha Māori and their whānau realise their aspirations across all domains; disability and wider wairua, social, cultural, economic, education and general wellbeing domains.</p>	<p>Increasing leadership and decision-making from tāngata whaikaha Māori in shaping Whaikaha's priorities and investments. Outcome reporting is now meaningful for tāngata whaikaha Māori and other disabled people.</p>	

Budget Sensitive

Office of the Minister for Disability Issues

Office of the Minister of Health

Chair

Cabinet Social Wellbeing Committee

Disability System Transformation: establishing a Ministry for Disabled People and national implementation of the Enabling Good Lives approach

Proposal

1 This paper seeks:

- 1.1 Cabinet agreement to establish a Ministry for Disabled People, as a departmental agency hosted by the Ministry of Social Development, responsible for driving better outcomes for all disabled people, leading cross-government strategic disability policy, delivering and transforming Disability Support Services, and progressing Disability System Transformation
- 1.2 Cabinet agreement to implement the Enabling Good Lives approach to Disability Support Services on a national scale, subject to Budget 2022 decisions
- 1.3 approval for additional funding to cover costs associated with establishing the new Ministry to be charged against the Between-Budget Contingency established as part of Budget 2021.

Relation to government priorities

- 2 Disability System Transformation is a programme of work under the Disability Action Plan 2019-2023. It aligns with the Government's priority to support healthier, safer, and more connected communities and is consistent with the Labour Party's 2020 election manifesto commitment of strengthening the mandate and resourcing of public leadership for the disability community.
- 3 This work also supports the health and disability system reforms, including the goal to build a stronger health and disability system that delivers for all New Zealanders, including disabled people.

Executive Summary

- 4 Achieving better outcomes for disabled people (including disabled tamariki and rangatahi), tāngata whaikaha Māori and whānau (including parents, caregivers, and guardians) depends on transforming how government works with them. The call for "nothing about us without us" is central both to Te Tiriti o Waitangi and to New Zealand's commitments under the United Nations Convention on the Rights of

Persons with Disabilities (UNCRPD) and Declaration on the Rights of Indigenous Peoples (UNDRIP).

- 5 The current cross-government disability system presents barriers for many disabled people and whānau in achieving ordinary life outcomes. Supports and services are fragmented across multiple agencies with no single agency responsible for system leadership or for driving improved overall outcomes for disabled people. Barriers to accessibility also make it harder for disabled people to navigate the system and to participate in everyday life.
- 6 Work on Disability System Transformation has been ongoing for more than a decade and is underpinned by the Enabling Good Lives (EGL) vision that all disabled people and their families have greater choice and control over their supports and lives. To date, the main focus of Disability System Transformation has been on transforming Disability Support Services (DSS) funded by the Ministry of Health (MOH).
- 7 The Government's current health and disability system reforms provide a strong impetus for transformation of the disability system. New structural arrangements for the health system will come into effect from July 2022. Disability and DSS were specifically excluded from the scope of the health and disability system reform decisions. However, Cabinet noted in March 2021 that we would bring advice on the future model and governance of Disability Support Services to Cabinet in September 2021 [CAB-21-MIN-0092 refers].
- 8 In June 2021, we provided an Oral Item to the Cabinet Social Wellbeing Committee, updating you on Disability System Transformation and outlining the key decisions we intended to seek in September 2021 [SWC-21-MIN-0076 refers]. This paper seeks those decisions.
- 9 The disability community has challenged government to be aspirational in transforming the disability system. We now have the opportunity to take a bold and truly transformative approach to how government supports disabled people and whānau. Ensuring that the right organisational arrangements are in place to support transformational change across the disability system is critical.
- 10 A Machinery of Government working group, comprised of officials and disability community representatives, has developed advice in partnership on proposed new organisational arrangements. Their advice is that a new Ministry, in the form of a departmental agency hosted by the Ministry of Social Development (MSD), is the best organisational structure to lead the realisation of a true partnership between the disability community and government to achieve ongoing transformation of the disability system.
- 11 Therefore, we seek your agreement to establish a new Ministry for Disabled People as a departmental agency hosted by MSD. A dedicated disability Ministry will enable a holistic whole-of-life, whole-of-whānau approach to addressing inequities and realising aspirations and opportunities for disabled people and whānau. MSD as the host department provides a strong base to support an EGL approach to disability and creates opportunities for closer alignment with MSD's leadership role in social sector commissioning.

12 The Ministry for Disabled People (the Ministry) will provide strong and focused leadership of the disability system across government. It will be responsible for leading strategic disability policy development, delivering and transforming DSS and progressing ongoing work on Disability System Transformation. The Ministry will ensure continuity of existing services as well as lead ongoing improvements and better co-ordination of disability supports and services across government. In addition, a new disability Ministry will raise the profile of disability in government and demonstrate the Government’s commitment to working in partnership with the disability community to drive better outcomes for all disabled people.

13 The Ministry’s ongoing work will include looking at what other government-funded services could be in scope for future transformation, such as learning support funding provided by the Ministry of Education and employment supports provided by MSD. Any new statutory functions resulting from Cabinet decisions on Accelerating Accessibility could potentially also sit within the Ministry.

14 We propose the new Ministry come into existence from 1 July 2022. This will align with the establishment of Health New Zealand and the Māori Health Authority. The new Ministry will work closely with the reformed health system agencies to ensure that disabled people continue to access the health services they are entitled to and to ensure that a disability perspective continues to inform the ongoing changes to the health system. However, it will take longer for the Ministry to be fully operational with existing DSS-related functions from MOH transferred and new functions, including strengthened strategic policy capacity, established.

15 We seek agreement to set up a dedicated Transition Team, located within MSD, to support the establishment of the new Ministry and the transition of DSS-related functions to it. A key focus will be ensuring no disabled people are worse off during the transition and that there is appropriate engagement with disabled people, whānau and Māori (including iwi leaders) during the establishment and ongoing operation of the Ministry. Appropriate due diligence to establish a departmental agency hosted by MSD will also need to be carried out.

16 A responsibility of the new Ministry will be delivering DSS, including transforming DSS in line with the EGL approach. We seek Cabinet agreement to implement the EGL approach nationally, subject to Budget 2022 decisions. Cabinet agreement is also sought to a number of technical elements including the scope of national implementation and the proposed funding in scope.

17 New funding is required to establish the Ministry and implement the EGL approach nationally, and a Budget 2022 bid is being prepared. However, establishing the Ministry by 1 July 2022 will require out of cycle funding. Therefore, we seek funding for the Transition Team and initial establishment costs of \$5.0 million in 2021/22 to be charged against the Between-Budget Contingency established as part of Budget 2021. Remaining funding for the new Ministry, estimated at a further \$80.0 million over the forecast period, will be sought through Budget 2022.

18 Subject to Cabinet agreement to the recommendations in this paper, the Transition Team will be set up, and processes will begin to appoint a chief executive and legally establish the new Ministry from 1 July 2022 (through an Order in Council).

19 We intend to report back to the Social Wellbeing Committee in early 2022 with further detail on establishing the new Ministry and next steps for Disability System Transformation.

20 This paper is divided into three parts:

20.1 **Part One** – Machinery of Government

20.2 **Part Two** – National implementation of the Enabling Good Lives approach

20.3 **Part Three** – Opportunities for further disability system transformation.

Context: A new approach to disability is needed for disabled people and whānau to experience ordinary life outcomes

21 One in four New Zealanders self-identify as having a disability based on data from the 2013 Disability Survey. Disabled people face significant barriers to experiencing positive wellbeing – including disproportionate representation in poverty statistics and experiences of inaccessibility and discrimination. Māori and Pacific people are more likely to be disabled than other population groups.

22 Historically, disability has been considered through a ‘medicalised model’, which focuses on disability as a health problem and something to be ‘fixed’. However, disability is now increasingly seen as a social construct that emphasises the right of individuals to choose how they live. This ‘social model’ of disability is reflected in the New Zealand Disability Strategy which has a vision that New Zealand is a “non-disabling society...where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen”.

23 The current cross-government disability system presents barriers for many disabled people and whānau in achieving ordinary life outcomes, as functions and responsibilities are spread across multiple agencies. This includes disability supports and services provided by a number of agencies such as MOH (e.g. Disability Support Services), MSD (e.g. income and employment supports, and Community Participation), the Ministry of Education (e.g. learning support for disabled learners), and the Ministry of Transport (e.g. Total Mobility Scheme) among others. Other disability-related functions include disability policy provided by MSD, and disability advocacy and advice provided by the Office for Disability Issues (ODI).

24 An overall lack of coordination and system stewardship limits government’s ability to achieve more equitable outcomes for disabled people. The different processes and requirements for different services, including inconsistent eligibility criteria, make it difficult for disabled people to know what services are available to them and how to access these services. Supports have tended to focus on impairments or diagnoses rather than taking a strengths-based approach to support disabled people to achieve their aspirations and live their best lives. Barriers to accessibility also make it harder for disabled people to navigate the system and to participate in everyday life.

25 In 2011, an independent working group of disabled people, their families and whānau, advocates and allies developed the EGL vision and principles (collectively the EGL approach) to be the foundation for transformative change to the disability system. The

EGL vision and principles are outlined in Appendix One. In a system based on the EGL approach, disabled people:

- 25.1 determine what type of assistance they require from whom and when to achieve the outcomes that they have chosen for their own lives
- 25.2 are provided with support based on a ‘whole-of-life’ approach that focuses on strengths and interests rather than being based on their impairment
- 25.3 are assessed through one centralised process (rather than multiple assessments and applications, each with different criteria)
- 25.4 are welcomed into the system in multiple ways and have access to a Connector/Tūhono who assists them in navigating the system
- 25.5 have access to a personal budget that can be used flexibly with the aim of seamless access to government funded disability services.

26 Over the last decade, successive governments have made a series of key decisions to progress Disability System Transformation. Appendix Two provides an overview of work and key decisions so far. To date, the main focus has been on transforming the operating model for DSS, currently provided by MOH, to align better with the EGL approach. Appendix Three provides further information on DSS.

27 The Government’s current health and disability system reforms are creating new structural arrangements from July 2022. As MOH will no longer deliver operational functions, DSS cannot stay in its current location in MOH, so a location for DSS within government is now needed. DSS was specifically excluded from the scope of the health and disability system reform programme and deferred to decisions on Disability System Transformation. To support the shift towards a social model of disability, we consider DSS should sit outside the health system and be delivered by an agency whose primary focus is driving improved outcomes for disabled people through a cohesive and whole-of-life disability framework.

28 Achieving true transformation will require strong and focused system leadership across government. Currently multiple government agencies have disability-related functions and responsibilities. While all agencies would retain their responsibilities to disabled people, a new dedicated disability agency would be able to provide a strong disability leadership role across government and be responsible for driving the above transformation.

Part One – Machinery of Government

We propose establishing a dedicated disability Ministry responsible for driving improved outcomes for disabled people, leading cross-government strategic policy advice, and delivering and transforming Disability Support Services

29 In 2018, as part of decisions on Disability System Transformation, Cabinet initiated a Machinery of Government review to identify different options, including potential structural changes, for involving disabled people and whānau in the governance of the disability support system [SWC-18-MIN-0029 refers]. The Machinery of Government

review is led by MSD, in partnership with a Working Group comprised of disabled people and officials from MOH and the Public Service Commission (PSC).

- 30 Establishing a dedicated disability Ministry would demonstrate this Government’s commitment to long-term transformative change to achieve equitable outcomes for disabled people across all domains of their lives, including education, employment, transportation, and community participation. It would also lift the profile of disability across government and enable the co-creation of new structures and ways of working to meet the Government’s longstanding commitment to partnership with disabled people, families, and whānau.
- 31 A disability-focused Ministry would enable a shift away from a medicalised and deficit-based model of disability towards a framework that encompasses and enables a whole-of-life and strengths-based approach. This would strongly support an EGL approach across a range of supports and services for all disabled people and embed the principles of self-determination and choice and control.
- 32 A new Ministry would be directly accountable to a Minister or Ministers for driving a whole-of-government effort on Disability System Transformation. In addition, it would take a leadership role as the primary provider of disability-related policy advice to government as well as a role in delivering and transforming DSS. Its chief executive would have the leverage to engage with other agencies at a high level to ensure the interests of disabled people are well represented in all government policy.
- 33 A disability Ministry would also provide disabled people with the same cross-government visibility as other population groups with dedicated Ministries (for example, Māori, Pacific peoples, women and ethnic communities). However, the Ministry will also deliver a transformed DSS and so will have a broader mandate than other population Ministries across government.
- 34 The name of any new Ministry needs careful consideration. We tentatively refer to a ‘Ministry for Disabled People’, but collaboration with the disability community will be required to identify an appropriate name.

The new Ministry will have a range of functions that will expand in the future as Disability System Transformation progresses

- 35 The new Ministry will take on most functions currently delivered by the Disability Directorate in the MOH, as well as new responsibilities.
- 36 In line with a strengthened specific focus for MOH on policy, strategy, and regulation for the health system, responsibility for DSS will move from MOH to the new Ministry. The immediate priority for the new Ministry will be to lead a coherent and consistent national roll out of the EGL approach to disability services. Over time, consideration will be given to extending disabled people’s personal budgets to include other government funding, such as from MSD (employment supports), the Ministry of Education, (individualised learning support), and the Ministry of Transport (Total Mobility Scheme).
- 37 However, the ambition for the new Ministry is much more aspirational. To truly transform the way government serves disabled people, tāngata whaikaha Māori,

families and whānau, we need to look beyond disability supports to examine and strengthen the cross-government disability system. We consider the new organisation should be given a mandate to lead a future-focused and whole-of-government approach to disability. This would mean:

- 37.1 promoting the EGL vision and principles as the basis on which government supports disabled people across their lives
- 37.2 working in partnership with disabled people and ensuring a high level of trust and transparency
- 37.3 lifting the profile and visibility of disability across government
- 37.4 ensuring the system:
 - 37.4.1 gives full effect to the voice of disabled people, families, and whānau, and to Te Tiriti o Waitangi
 - 37.4.2 is consistent with the UNCRPD and the UNDRIP
 - 37.4.3 aligns with the principles and approaches of Whānau Ora
- 37.5 strengthening disability rights approaches across government strategies, including the Child and Youth Wellbeing Strategy, Better Later Life – He Oranga Kaumātua, the New Zealand Disability Strategy, and Mahi Aroha – the New Zealand Carers’ Strategy
- 37.6 improving cross-government disability data and information
- 37.7 developing a disability-focused research and evaluation strategy.

38 The new agency could also be mandated to monitor, support, and hold other government agencies to account for the outcomes they deliver for disabled people, including how well they are contributing to achieving equitable outcomes.

39 In order to fulfil this mandate, we propose the functions of the new Ministry would include:

- 39.1 **Policy** – leading and providing strategic policy advice on the wider disability system and across government as well as policy on DSS.
- 39.2 **Leadership/stewardship** – providing leadership and stewardship of the cross-government disability system.
- 39.3 **Legislation** – developing and providing stewardship of any relevant legislation.
- 39.4 **Commissioning** – commissioning and procuring disability supports in line with the EGL approach and advising on how supports are delivered.
- 39.5 **Assurance, monitoring, evaluation and reporting** – overseeing performance and operation of the Ministry.
- 39.6 **Market stewardship** – identifying and prioritising market need, as required.

39.7 **Workforce planning** – ensuring an adequate, skilled, and culturally-competent workforce is in place to deliver disability supports in line with the EGL approach.

39.8 **Capacity and capability building** – recognising, enabling, and developing the capacity and capability of disabled people, families and whānau to make decisions for themselves, make use of available resources, partner with government, and advocate for themselves and their communities.

40 The new Ministry will work closely with MOH, Health New Zealand, and the Māori Health Authority to ensure the health system is responsive to disabled people and whānau. Key relationships, such as the interface between the disability system and the Māori Health Authority, will need careful consideration in partnership with tāngata whaikaha Māori.

41 We will provide you with more information on how the new disability Ministry and broader disability system will align with the new health agencies and reformed health system in our intended Cabinet report-back in early 2022.

We have considered a number of organisational forms for the new Ministry

42 The Public Service Act 2020 enables a Ministry to take a number of different organisational forms. We have considered detailed advice on four organisational options for the new Ministry:

42.1 **Ministry as a branded business unit in MSD.** Most DSS functions would be integrated into a business unit with corporate and back-office services provided by MSD. The business unit could be led by a functional chief executive, who would be accountable for the particular functions of the business unit and would report directly to the responsible Minister. The location within MSD would enable the Ministry to leverage off MSD resources and support, but its position as a business unit would mean limited ability to incorporate broader disability functions in the future.

42.2 **Ministry as a departmental agency hosted by MOH.** Functions, including most DSS functions, are established within a functionally autonomous agency with its own chief executive reporting directly to the responsible Minister. Relevant corporate and back-office services would be shared with MOH and Health NZ. This option would strengthen the profile and status of disability through the appointment of a dedicated public service chief executive for the portfolio and would provide visible functional autonomy. However, it would be unlikely to meet the expectations of the disability community who have indicated they want disability to be separate from the health system.

42.3 **Ministry as a departmental agency hosted by MSD.** This is structurally similar to the departmental agency hosted by MOH but with MSD as the host. Corporate and back-office services would be accessed from MSD. Links with the Social Development portfolio provide a strong base to support the whole-of-life EGL approach and opportunities for closer alignment with MSD's leadership role in social sector commissioning. This is the preferred option of the disability community.

42.4 **Ministry as a new standalone department.** This would involve establishing a disability Ministry as a new and wholly independent organisation within the public service. As well as its own chief executive, the Ministry would need its own corporate and back-office services, property and other assets. This option would send a strong message of our commitment to transformative change but would also be the most costly option and take the longest to establish.

43 We also considered advice on disability supports being delivered through an existing or new Crown entity. While a Crown entity may have a role in delivering disability supports in future, we consider this structure is not appropriate at this time as Disability System Transformation is ongoing, and a new disability agency will likely evolve to take on new functions, roles and responsibilities over time. The arms-length governance by a Crown entity board is less suited to changing roles and responsibilities.

Our preferred option is to establish the new Ministry as a departmental agency hosted by MSD

44 Our preferred option is to establish the new Ministry as a departmental agency hosted by MSD because:

- 44.1 It is the preferred option of the disability community because it brings together key functions (including strategic policy), it provides disabled people with a dedicated and functionally autonomous agency, and the location within MSD provides a strong base to support a whole-of-life approach to disability.
- 44.2 It provides the scope and flexibility to bring together cross-government disability functions to drive better outcomes for disabled people, while also being well placed to meet the immediate requirements of Disability System Transformation.
- 44.3 Functional and operational autonomy will support our ambition for a more dedicated focus on disability to help drive improved and equitable outcomes.
- 44.4 The chief executive of the departmental agency would have direct accountability to the responsible Minister and the status to engage with other agencies at the chief executive level.
- 44.5 It can provide strong operational autonomy and strengthen the focus on outcomes for disabled people, families, and whānau without having to create a standalone department or Crown entity.

45 We propose MSD as the host department because we consider it would provide a greater opportunity for broader system transformation and recognise disability as a social and whole-of-life issue. The link with the Social Development portfolio provides a strong base to support the whole-of-life EGL approach and creates opportunities for closer alignment not only with MSD disability supports, but also with MSD's leadership role in social sector commissioning.

46 MSD is well placed to act as a host department for a departmental agency and is experienced in hosting a range of independent or semi-independent entities, such as the interim Independent Children's Monitor. While transferring responsibilities from

MOH to the new Ministry will add cost and complexity in the near term, MSD has the operational and implementation experience to manage this effectively. MSD also has a widespread regional presence that can provide premises for the new Ministry outside Wellington as required.

47 While the departmental agency will ultimately be functionally and operationally autonomous from MSD, it will need to work closely with MSD to ensure it has the necessary support to carry out its functions and mandate. The specifics of the relationship between the departmental agency and MSD will need to be worked through by the chief executives of the two agencies.

The future of the Office for Disability Issues will need further consideration

48 As the new Ministry will have a disability system leadership role, the future role and position of the existing Office for Disability Issues (ODI) will need to be considered. Part of ODI's existing role is to provide advice to Ministers and government agencies on disability issues, as well as coordinating implementation of the UNCRPD and the New Zealand Disability Strategy.

49 We do not seek Cabinet decisions on the future of ODI at this stage. The question of whether ODI should be brought into the new Ministry is not straightforward. Historically, government Ministries have not always adequately incorporated the perspectives and needs of disabled people into their work. ODI currently holds an important independent advisory and advocacy role in government. The question about whether it is appropriate for ODI to be moved into the new Ministry requires careful consideration and full consultation with the disability community stakeholders familiar with ODI's work.

50 Subject to Cabinet decisions on the establishment of the new Ministry, targeted consultation will be carried out on where ODI should sit within government to enable it to best perform and further enhance its role. We will provide advice to Cabinet in early 2022 on the outcomes of this consultation and recommendations on the future location of ODI.

Implementation: establishing the new Ministry and the transfer of functions from the Ministry of Health will require transitional arrangements

We propose to set up a dedicated 'Transition Team' to support the establishment of the new agency and the transition of DSS functions to it

51 We propose the new Ministry be established from 1 July 2022 to align with the start of the new financial year. Timeframes for establishment and the transition of functions are short. Subject to Cabinet agreement, the first step in establishing the new Ministry will be to set up a dedicated Transition Team to support the establishment and the transition of MOH functions. MSD and MOH will work with the PSC, the Treasury and the Health Transition Unit, as appropriate, to establish a team with the necessary expertise and set up the relevant governance arrangements. MSD, as the host department for the new Ministry, will have overall responsibility for the team.

52 The Transition Team will be led by a dedicated programme director and will include resources from relevant areas, such as policy, operations, legal, finance, information technology (IT), human resources (HR), communications and engagement, and procurement and commissioning. The Team will build on insights from the establishment of new Ministries, such as Oranga Tamariki and the Ministry of Housing and Urban Development. A key focus will be ensuring disabled people continue to receive support over the transition.

53 The Transition Team will work with established community groups, including the Machinery of Government Working Group, the Whānau Ora Interface Group and the National Enabling Good Lives Leadership Group (the National EGL Leadership Group) to ensure that the voices of disabled people and whānau shape this work. The expertise and lived experience of disabled people will be particularly important in shaping the work of the Transition Team.

54 As Budget 2022 decisions will not be made until shortly before the proposed establishment date for the new Ministry, we seek additional funding for the establishment phase in the 2021/22 financial year from the Between-Budget Contingency established through Budget 2021.

It will take time for the new Ministry to be fully established with all relevant functions and this will not be achievable by 1 July 2022

55 While we intend the new Ministry be legally established by 1 July 2022, it will take longer for the Ministry to be fully operational with all its relevant functions. This is because some new functions, such as strategic policy and monitoring and evaluation, will take time to establish.

56 The transition of DSS functions will also take time, as they will need to be separated from MOH and established within the new Ministry. This will be a complex process. It is important to note the new Ministry will continue to be reliant on some Health NZ and MOH infrastructure for a period of time, as DSS is dependent on health system IT and business processes to contract and pay disability supports. The Transition Team will work with MOH and MSD on the transition of DSS functions to the Ministry.

57 Our proposed Cabinet report back in early 2022 will provide more detail on establishment and the transition of functions, including proposed timeframes for full establishment.

A new chief executive will be appointed for the Ministry and relevant arrangements with the host department (MSD) will need to be worked through

58 Several implementation components need to be worked through for the new departmental agency including engaging with current staff, appointing a chief executive, preparation of an agreement between the chief executives of the departmental agency and host department (required by legislation), confirmation of physical workspace arrangements, and preparation of shared service agreements.

59 Subject to Cabinet agreement, the Public Service Commissioner will appoint the chief executive of the new Ministry. An acting chief executive could be appointed for an interim period if required. The chief executive/acting chief executive of the Ministry will be responsible for working with the chief executive of MSD to arrange financial

delegations to the new Ministry and establishing a working relationship with MSD, MOH and Health NZ (including shared services arrangements and a departmental agency agreement).

As part of the establishment, the Transition Team will work with disability community representatives to establish new partnership processes and to ensure the voice of disabled people is reflected in the work of the Ministry

60 We have heard from disabled people and tāngata whaikaha Māori that it is key that they and their families and whānau are involved in the governance of the new system and that their voices are embedded at all levels of decision-making.

61 Establishing a new Ministry will not in itself give disabled people, tāngata whaikaha Māori, and whānau a role in governance. However, it will provide an opportunity for shifting the relationship between them and government:

- 61.1 Partnership with disabled people and whānau would be a ‘top table’ issue for the new Ministry, a key priority for its leadership team, and a key criterion for assessing its success. The new Ministry will look to establish a disabled person and whānau-led governance structure.
- 61.2 As a functionally autonomous organisation, there is an opportunity for the new Ministry to foster a distinct workplace culture and policies that support partnership with and employment of disabled people, families and whānau using a strengths-based approach.

62 Making the most of this opportunity will require appropriate mechanisms and processes on the part of both the Ministry and the community. The mechanisms that have developed around EGL (such as national and regional leadership and governance groups and the Whānau Ora Interface Group) offer a solid basis for future partnership. However, we need to ensure that they continue to succeed and that the Ministry engages with them on its broader strategic work. This will need to include the development of regional leadership around the country and ensuring that there are the appropriate mechanisms to enable a broad range of voices to be heard.

63 There are a number of key matters that government will work on with the community in the lead up to establishing the new Ministry and beyond:

- 63.1 **Formalising the status of partnership mechanisms:** The roles, functions, authority and relationships of existing voice and partnership mechanisms will be more clearly defined. This could include mechanisms to establish a Ministerial advisory group or formal agreements between the Crown or the Ministry and particular groups, such as the National EGL Leadership Group.
- 63.2 **The accountabilities of the Ministry:** There are several other possible mechanisms for setting expectations for how the Ministry will work with disabled people, whānau, and tāngata whaikaha Māori. These include setting standards around partnership in future legislation, performance standards for appropriations, and performance expectations for the chief executive.
- 63.3 **Resourcing:** Voice and partnership mechanisms will need to be better resourced to account for a national scale and broader scope. Understanding

and coordinating insights and voices from local voice and partnership mechanisms will be challenging and will require appropriate support once these are established across the country.

63.4 **Independence:** To be trusted by disabled people and whānau, it will be key that voice and partnership mechanisms are independent. This may be more challenging with more formalised mechanisms and greater government funding.

Engagement with Māori during the establishment and ongoing direction of the new Ministry will be key

64 To date, officials have engaged with the Te Ao Mārama and the Whānau Ora Interface Group on Disability System Transformation proposals, including the proposal to establish a new Ministry. These groups are broadly supportive of the proposal. The Whānau Ora Interface Group has set out how they consider Te Tiriti provides the korowai for system transformation through the principles of kāwanatanga (partnership and shared decision-making), rangatiratanga (protection, revitalisation and development of taonga), and rite tahi (equity, participation, and equality and non-discrimination).

65 However, we recognise that more extensive engagement with Māori will be required in the establishment of the Ministry, its governance arrangements, and ongoing work. Future work on Disability System Transformation will encompass broader elements of the disability system such as the development of policy and legislation, data and information gathering, and monitoring and evaluation. It will be key that Māori are part of this broader work and appropriate engagement is undertaken. As Treaty partners, engagement with tāngata whaikaha and with Māori, iwi and hapū will also occur. It is our expectation that officials will also work closely with iwi leaders as well as the Māori Health Authority Steering Group.

There are risks associated with establishing the new Ministry

66 We recognise that a risk of establishing a specific disability-focused Ministry is that other agencies could interpret this as releasing them from their responsibilities to disabled people. While we envisage the new Ministry will take on a leadership, coordination and stewardship role for disability across government, all government agencies must deliver on their obligations to the disabled communities they serve.

67 MSD as the host for the departmental agency is also not without risk. MSD has many competing claims for its resources and a number of ambitious work programmes to deliver on, such as welfare overhaul. Supporting the new Ministry to deliver Disability System Transformation will need to be considered against other Ministerial and organisational priorities, which may affect the speed and scope of transformation. MSD's own IT systems are ageing and previous shared services arrangements, such as with Oranga Tamariki, have not been without challenges.

68 This Ministry will be the fifth new entity emerging from reform to the health and disability system. Managing the complexities and inter-dependencies of the other new entities with the establishment of the Ministry creates the risk of blurred accountability lines and potential for service disruption. Transition planning will include coordination and risk mitigation with a focus on ensuring service continuity.

69 The above risks will need to be carefully managed as the new Ministry is established. MSD will carry out extensive due diligence required to establish a departmental agency, including the support the agency will require from MSD and the expertise necessary for establishment, and the transition of functions.

Part Two – National implementation of the Enabling Good Lives approach

We seek Cabinet agreement to implement the EGL approach nationally, subject to Budget 2022 decisions

70 For many years, the disability community has expressed concerns about disability supports not working well for disabled people and whānau. These concerns centre on the lack of choice and control disabled people have over the support they receive.

71 The Enabling Good Lives vision and principles were developed in 2011 by the disability community to underpin a new approach to disability support. The EGL vision is that in the future, disabled children and adults and their families will have greater choice and control over their supports and lives and make more use of natural and universally available supports.

72 The EGL approach to DSS has been tested and evaluated through three demonstration projects since 2013 - in Christchurch, Waikato and the MidCentral DHB (Mana Whaikaha). Evidence from these projects confirms improved outcomes when disabled people, families and whānau have choice and control over the supports and services they access. The EGL approach has been well received by both users and providers, and the community has consistently pushed for a national rollout. End users report more satisfaction with their lives and a broader range of disability support services accessed.

73 Positive outcomes for disabled people, families and whānau from the EGL approach include increased autonomy and social connectedness, improved quality of life, and better access to education and employment opportunities.

74 The demonstration projects also achieved higher engagement and take-up of disability services from marginalised groups, including tāngata whaikaha Māori and Pacific peoples, in comparison with the current disability support system. Engagement with the system by tāngata whaikaha Māori and Pacific disabled people increased by 60 percent in Mana Whaikaha and 33 percent overall.

75 National implementation of an EGL approach to DSS will fundamentally change disability support services for disabled people, their families, whānau and communities, driving better life outcomes for disabled people at both the local and national level. More flexible funding options have led to the development of a greater range of services that better meet people's needs, and early engagement may divert some people from accessing funded support that would otherwise have been provided.

What does an EGL approach look like in practice?

76 The key features of a transformed disability system based on the EGL approach are:

- 76.1 **people are welcomed into the system** in multiple ways, and can then be provided with information, linked with a Connector, peer network, government agency or disability organisation
- 76.2 **access to Connectors** who can walk alongside disabled people and whānau if they choose, to help them identify what they want in their life, how to build their life, and the range of supports available to live their life
- 76.3 **easy to use information and processes** that meet the diverse needs of disabled people and their whānau
- 76.4 **seamless support across government**, with Government Liaisons supporting people in the background to access other government services (for example, benefit applications), and to build positive relationships with other parts of government (for example, learning support in school)
- 76.5 **a straightforward process for accessing funding**, with flexibility about what can be purchased and how it can be administered, and easy reporting
- 76.6 **capability funding** for disabled people and whānau
- 76.7 **outcomes-based commissioning and contracting models**
- 76.8 **greater system accountability to disabled people and their whānau** so that disabled people and whānau are involved in monitoring and evaluating the system and making recommendations to Ministers about changes to the system.

The EGL approach will be implemented nationally through an implementation plan proposed to take place through three phases over a four-year period

- 77 MOH has developed a plan for the national implementation of an EGL approach, in partnership with disabled people, families and whānau. Implementation is proposed to take place over three phases with an emphasis on design and development in Phase One, staged transition in Phase Two and stabilisation in Phase Three. Evaluations of the EGL demonstrations and key insights (outlined in Appendix Four) have informed the development of the implementation plan. Once the new disability Ministry is established and operational, it will take on responsibility for progressing the national EGL implementation.
- 78 The national implementation of the EGL approach will occur over three levels:
 - 78.1 **Governance**: System roles, responsibilities, and governance ensuring that system settings are consistent with and support the transformed system.
 - 78.2 **Operating model**: A new operating model, with person-directed models of support, easy access to information and guidance, access to Connectors/ Tūhono, authority over personal budgets and commissioning and contracting models based around achieving outcomes.
 - 78.3 **Disabled people and whānau capability**: Building the capacity and capability of disabled people and whānau, so that their voices are central to decision-making, they are able to engage in and lead the system, be valued as leaders and have authority over their own lives.

What is required to implement the EGL approach nationally?

79 The roadmap for the national implementation of an EGL approach from 2021 to 2024 is summarised below and is outlined in further detail in Appendix Five. We seek Cabinet endorsement of the implementation plan noting that it is contingent on Budget 2022 investment.

80 **Phase 1 – July 2021 – June 2022:**

- 80.1 partnership approach established with community
- 80.2 investment strategy, development of person-directed funding approaches
- 80.3 proposed transition pathway to new regional EGL entities for local service commissioning (to replace the current Needs Assessment and Service Coordination (NASC) role)
- 80.4 workforce and monitoring/evaluation strategies developed
- 80.5 disabled people and whānau capability strategy in places.

81 **Phase 2 – July 2022 – June 2023:**

- 81.1 new Ministry established
- 81.2 change process and procurement approach to regional governance initiated.

82 **Phase 3 – July 2023 – June 2024:**

- 82.1 whānau networks in place at the national and local levels, disabled people and whānau-led leadership and governance are central to decision-making
- 82.2 full transition underway, including new regional EGL entities.

How much will a national implementation of the EGL approach cost?

83 Funding was received through Budget 2021 to undertake Phase One, which is currently underway. Additional investment is required to implement the change (Phases Two and Three). The plan assumes implementation over a period of four years, but the scale and pace of change will be determined by funding availability.

84 A Budget 2022 bid seeking investment for Phases Two and Three of implementation is being prepared. Initial estimates are that the cost of national implementation of the EGL approach to DSS will be approximately \$160m - \$180m per annum. This funding would cover:

- 84.1 Early intervention initiatives (including increased funding for specialist services, personal budget administration and additional community participation).
- 84.2 Transforming the operating model (including funding for Connectors/Tūhono and service allies, independent advocacy services, provider and workforce development and effective system administration).

84.3 Capability building for disabled people, tāngata whaikaha Māori, family and whānau to support them to engage and lead across the system, ensuring disabled people are valued as leaders in their own lives and have authority over their own lives. Critical elements of this work include safeguarding and supporting decision making tools, leadership networks, tools for disabled people to articulate their aspirations and plan for achieving these and tools for disabled people as purchasers and employers.

85 The above estimate is in addition to the costs associated with establishing the new Ministry, transitional costs for organisational and governance changes, IT system requirements and costs of eligible people accessing support for the first time.

How does the national implementation align with the health system reforms?

86 The direction of travel proposed for national implementation aligns with the wider health system reforms, including:

- 86.1 locality-based commissioning functions which are closer to home
- 86.2 person and whānau-centred support with control over supports
- 86.3 a partnership-based approach to designing and delivering services
- 86.4 recognition that disability support is not solely a health issue.

87 The transformed disability support system will work closely with the health system at the national, regional, and local levels. For example, the shift to person-directed disability support provision will require new ways of thinking about workforce development. Where there is cross-over with the health workforce, this would require coordination at the local level, such as the care and support workforce which supports disabled people as well as those with aged care and other needs.

88 The reformed health system, including MOH, Health New Zealand and the Māori Health Authority, will continue to have responsibility for improving health outcomes for disabled people, supported by the appropriate capability and resourcing.

National implementation will be supported by a focus on developing the capacity and capability of disabled people

89 The EGL pilots and prototype have demonstrated that developing the capacity and capability of disabled people is critical to maximising the benefits of the EGL approach. This is reflected in the new Ministry's mandate to work in partnership with disabled people and its function building the capacity and capability of disabled people.

90 The National EGL Leadership Group has articulated three key elements of this:

- 90.1 building leadership of disabled people at local and national levels
- 90.2 increasing awareness of the EGL approach
- 90.3 equipping disabled people, families, and whānau to understand and exercise their natural authority in their own lives and communities.

91 The National EGL Leadership Group has been clear that disabled people must lead this work for disabled people, families for families and whānau for whānau. MOH is supporting the progression of this work in partnership with community groups.

A new monitoring and evaluation approach will be co-designed with disabled people

92 Officials are working in partnership with disabled people to co-develop a new approach to monitoring and evaluation which will be one of the proposed functions of the new Ministry. Current monitoring and evaluation practices and approaches across the disability support system are inadequate to provide system level insight, to capture learnings as the system transforms, or to involve people most impacted by the system.

93 The new approach aims to address these gaps, and to ensure that future monitoring and evaluation is person-centred and directed, embedded at every level of the system, and fully aligned with the EGL vision and principles. Monitoring and evaluation will recognise and build on the capacity of disabled people as commissioners and designers of monitoring and evaluation, rather than just participants.

Cabinet agreement is sought to a number of technical elements of national implementation

The scope of national implementation of an EGL approach should initially be broadly the same as was agreed for the MidCentral prototype, Mana Whaikaha, in 2018

94 The current eligibility criteria for DSS apply to people who present before the age of 65, who have a physical, sensory, or intellectual disability, or a combination of these, which is likely to remain after the provision of equipment or treatment, continue for at least six months and result in a need for ongoing support. This includes people with autism spectrum disorder.

95 To be consistent with 2018 decisions on Mana Whaikaha [SWC-18-MIN-0108 refers], we seek agreement that in the initial phase of national implementation of an EGL approach:

- 95.1 the eligibility criteria should be the same as the current eligible population for DSS with the clarification that all children with significant developmental delay but no confirmed diagnosis, regardless of age, are eligible for early intervention support¹
- 95.2 means testing for household management should not apply to people who have a flexible personal budget
- 95.3 means testing for household management should continue to apply while people continue to receive a NASC allocated package during the transition period.

96 Early access to support can have a significant positive impact on future outcomes for disabled children, including a reduced need for disabled tamariki needing out-of-home care. The current system recognises that those positive impacts can occur if support for children with significant developmental delay but no confirmed diagnosis,

¹ Outside Mana Whaikaha eligibility is contingent on when children with significant developmental delay, but no confirmed diagnosis, are identified.

can begin even before a diagnosis is made. There is, however, a cut-off for this support when children turn eight, meaning some children do not receive support, or stop receiving support, at a younger age than is desirable. To address this, the eligibility criteria for DSS will be clarified so that all children with significant developmental delay but no confirmed diagnosis, regardless of age, are eligible for intensive early intervention support.

97 Rationing through means testing is inconsistent with an EGL approach and not practical to apply to people who have a flexible personal budget. However, removing all means testing can increase costs and so should continue to apply for people continuing to receive their NASC allocated package (rather than a personal budget).

98 Disabled people and whānau will be able to find government-funded support they may be eligible for when they engage with a Tūhono/Connector. A Tūhono may assist disabled people and whānau to access other government support or support them to build relationships with key contacts in other agencies (for example, learning support). Government agencies will work in the background to better coordinate support (for example, equipment or assistive technology) and joint funding arrangements.

Funding in scope for the national implementation of an EGL approach should be similar to that in scope for Mana Whaikaha, with some minor differences

99 We seek your agreement that the following existing funding streams be available as part of personal budgets in the initial phase of implementation:

- 99.1 all Vote Health disability support funding for people who are eligible for support funded through the Vote Health: National Disability Support Services appropriation
- 99.2 the ‘Very High Needs’, ‘Community Participation’, and ‘Transition from School’ funding streams from the Vote Social Development: Community Participation appropriation.

100 Mana Whaikaha has shown some adjustments will be needed to the way some funding is integrated. In particular, it has been challenging to include community participation funding fairly in a flexible personal budget given not all people who use this funding are currently eligible for DSS.

101 Additionally, we seek agreement that the Business Enterprise and Support Funds paid on behalf of disabled people, which were in scope for Mana Whaikaha, are not included in the national implementation. This is because:

- 101.1 Business Enterprise funding² was not included in Mana Whaikaha as there are no Business Enterprises in the MidCentral region. This funding is not recommended for inclusion in the national implementation because the Government has already committed to a fundamental change to the Business

² Business Enterprises are organisations that receive a funding contribution from MSD and whose primary purpose is to provide employment opportunities to disabled people. A number of people employed by Business Enterprises hold a Minimum Wage Exemption permit which means they are paid less than minimum wage.

Enterprise model. Disabled people with a Minimum Wage Exemption permit will be paid at least minimum wage and supported by a wage supplement.

- 101.2 Support Funds paid on behalf of disabled people were included in Mana Whaikaha; however, management of the Support Funds funding was returned to MSD by mutual agreement. This was because many people who access Support Funds do not access any other government support and most are not eligible for DSS.

Part Three – Opportunities for further disability system transformation

The new Ministry will lead ongoing work on Disability System Transformation including identifying and progressing further transformation opportunities

- 102 While the focus of Disability System Transformation to date has largely been on testing the EGL approach, the opportunities, and our aspirations, are much broader. True change requires transforming the disability system from one that focuses on service provision and needs-based assessment, to a model that takes a whole-of-life approach, emphasises strengths, and enables disabled people and tāngata whaikaha Māori to make decisions to live their best lives. In particular, a transformed system will:
 - 102.1 build the knowledge and skills of disabled people and their families and whānau, so they have the opportunities to increase their choice and control
 - 102.2 change how services are provided including aligning organisational roles and functions, delivery models, accountability measures, monitoring and evaluation with the EGL approach
 - 102.3 create an enabling environment where communities are accessible, and they welcome and recognise the contribution that disabled people make to enhance community cohesion and wellbeing.

Other government funding may be included in flexible, personal budgets

- 103 Transforming DSS in line with the EGL approach is just the first stage towards realising the EGL vision. Over time, the transformation of disability supports and services could extend to include other government funding in personal budgets. This could potentially include funding provided by MSD (Disability Allowance (DA), Child Disability Allowance (CDA) and employment supports), the Ministry of Education (some individualised learning support for disabled learners), and the Ministry of Transport (Total Mobility Scheme).
- 104 MSD's DA and CDA funding are not considered in scope for national implementation at this point because MSD is in the early stages of considering DA and CDA as part of work on welfare reform. The new Ministry will work with MSD to explore how application and renewal processes for DA and CDA can be streamlined.
- 105 Similarly, the learning support funding from Vote Education is not in scope at this time. This is because further work, including meaningful engagement with disabled

children and young people, is required to identify the desirability, feasibility, and implications of bringing any Vote Education funding in scope.

- 106 Individualised learning support is currently also being reviewed as part of the Review of Interventions for Students with the Highest Level of Learning Support Needs (the Review) [CBC-21-SUB-0082 refers]. Including learning support funding in the EGL national implementation at this stage could pre-empt the results of the Review, the final report back of which is due in October 2022.
- 107 The Review will consider how supports and services are accessed from a child and young person perspective and provides a key opportunity for increased collaboration, connectedness and cohesion across services and supports funded by different government agencies. Key areas where significant improvements could be made include support in the early years (through better aligning the Early Intervention Service and Child Development Service), and support for successful transitions to life beyond school (building on the EGL Christchurch demonstration and Employment Services in Schools pilot).
- 108 The new Ministry will work with the Ministry of Education to identify any opportunities to include Vote Education funding in personal budgets.

There are also other opportunities for wider change

- 109 Future transformation opportunities are not limited to extending government disability supports and services. For example, the implementation of the broader Learning Support Action Plan 2019-2025 is a key opportunity to apply EGL principles to improve the experiences of disabled children and young people, regardless of any transfers in functions and funding.
- 110 As part of ongoing work on Disability System Transformation, we envision the Ministry will be responsible for leading a future-focused strategic policy work programme that examines core issues related to Disability System Transformation, such as removing barriers to accessibility, and considering how to drive a holistic and whole-of-life approach to disability.
- 111 The Disability Strategy 2016-2026 and implementation of the UNCRPD will be key in guiding the new Ministry’s work programme. The Ministry will have the mandate, visibility, and ability to accelerate the realisation of the Strategy and implementation of the UNCRPD in partnership with disabled people, tāngata whaikaha Māori and whānau.
- 112 We note Cabinet decisions are also being sought on Accelerating Accessibility including the proposal for a new regulatory system to remove barriers that prevent disabled people from fully participating in society. Future work on Disability System Transformation will align with ongoing work on Accelerating Accessibility. Any new statutory functions or institutional arrangements resulting from Cabinet decisions on Accelerating Accessibility could also potentially be housed within the new Ministry.
- 113 There will also be the opportunity to progress a strategic and cross-government policy work programme to tackle key disability issues affecting whānau wellbeing. For example, the disability community has called for eligibility to be based on the

functional impact of disability rather than on impairment. Once structures are in place, the new Ministry will be well placed to consider these eligibility issues, including what is needed to better support groups of people, such as those with fetal alcohol spectrum disorder (FASD), whose support and services requirements fall across multiple agencies.

- 114 As a first step, the Ministry of Health is undertaking work to explore what more can be done to improve access to Child Development Services, service delivery and early intervention support for those with FASD and suspected FASD. This work is within current funding constraints. An update on this work will be provided to the Minister of Health at the end of November 2021.
- 115 It will be key that change to the wider disability system is progressed alongside, and in collaboration with, disabled people and whānau. Work on Disability System Transformation to date has progressed in collaboration with established disability community groups, and it is fully our intention that this approach will continue as transformation work progresses.
- 116 We intend to provide you with further detail on broader system transformation opportunities, and how this will inform the transition and establishment process for the new Ministry, in our proposed Cabinet report back in early 2022.

We intend to report back to Cabinet in early 2022

- 117 We intend to report back to Cabinet in early 2022 with:
 - 117.1 further detail on establishing the new Ministry including:
 - 117.1.1 detail on the role, responsibilities, functions, mandate, and initial priorities of the new Ministry
 - 117.1.2 the transition of functions, staff, and funding to the new Ministry
 - 117.1.3 the establishment of a new appropriation for the Ministry
 - 117.2 further detail on implementing the EGL approach on a national scale
 - 117.3 future opportunities for further transformation once the new Ministry is established and fully operational
 - 117.4 advice and recommendations on the future location of the Office for Disability Issues.

Financial Implications

Funding for the new Ministry

- 118 The costs associated with establishing a new disability Ministry and the ongoing additional operating costs are estimated at \$85.0 million over the forecast period. These are made up of:
 - 118.1 Transition Team, setup costs and establishment costs of \$28.4 million over the forecast period comprised of \$5.0 million in the 2021/2022 financial year, \$16.1 million in 2022/23 and \$7.3 million in 2023/24.

118.2 Additional ongoing operating costs of \$56.6 million over the forecast period, comprised of \$11.5 million in the 2022/2023 financial year, \$13.1 million in 2023/24, and \$16.0 million per annum from 2024/25 onwards. This will be in addition to the approximately \$21.0 million per annum in Direct Expenditure that currently funds the operation of the Disability Directorate (includes funding for Mana Whaikaha and EGL Christchurch).

119 MOH and MSD are unable to fund the costs associated with the new Ministry from existing baselines and so a Budget 2022 bid is being prepared. Costs for funding sought through Budget 2022 will be refined further through the Budget process.

120 However, funding for the Transition Team and for the establishment of the new Ministry must be secured now so the establishment of the Ministry can proceed, and it is sufficiently resourced to achieve the desired outcomes. Deferring all funding decisions until Budget 2022 would effectively defer the establishment decision and its announcement until that time.

121 We, therefore, seek agreement to establish a new appropriation in Vote Social Development and increase funding in that appropriation by \$5.0 million in 2021/22 to fund the Transition Team and initial establishment costs for this financial year. We seek this funding from the Between-Budget Contingency established as part of Budget 2021.

Funding for the national implementation of the EGL approach

122 The costs of the national implementation of the EGL approach will also require new investment in addition to the costs of the new Ministry. A Budget 2022 bid seeking funding for national implementation is being prepared for an additional estimated \$160.0 million – \$180.0 million per annum which would cover:

- 122.1 \$75.0 - \$80.0 million early for investment funding, including personal budget administration
- 122.2 \$65.0 - \$75.0 million for a national network of Connectors/Tūhono
- 122.3 \$5.0 - \$10.0 million for capability building
- 122.4 \$15.0 - \$20.0 million for change management costs.

123 We note that while we might expect to see some value for money savings from improved co-ordination across government, person-centred services and increased take up is likely to result in higher cost to government over time. Consequently, additional funding may be required in the future to support responsive disability services.

124 We may propose a multi-category and/or multi-year appropriation in the future to provide sufficient flexibility for spending under the EGL approach.

Legislative Implications

125 The establishment of a departmental agency does not require new legislation but requires an Order in Council which will:

125.1 bring the new departmental agency into legal existence on a specified date by naming it in Part 2 of Schedule 2 of the Public Service Act 2020 (the departmental agency will come into legal existence when it appears on the Schedule)

125.2 provide for a transitional period relating to any transfer of functions from other agencies (if applicable) as well as any change in responsibility for functions from the chief executives of the Ministries of Health and Social Development to the chief executive of the departmental agency.

126 Subject to Cabinet agreement, the Minister for the Public Service will be responsible for issuing drafting instructions to establish a new departmental agency with a final name to be determined, and with a commencement date of 1 July 2022. MSD will be named as the host department.

Impact Analysis

Regulatory Impact Statement

127 As there are no regulatory proposals in this Cabinet paper, Cabinet's Impact Analysis requirements do not apply.

Climate Implications of Policy Assessment

128 A climate implication assessment is not required.

Population Implications

129 There are a number of population implications associated with this proposal.

Population group	How this proposal may affect this group
Disabled people	The proposals in this paper seek to improve the lives of all disabled people, families and whānau through enabling greater choice, control and self-determination and achieving equitable outcomes. These proposals will help reduce barriers that impede a large group of New Zealanders from achieving their full potential and fully participating in society on an equal basis to others. Establishment of true partnership between disabled people and government will ensure disabled peoples' voices are embedded at all levels. The disability sector is strongly supportive of this work. At least 43,000 disabled people will benefit from the national implementation of the EGL approach for DSS.
Māori	Twenty-six percent of the Māori population identify as disabled. Tāngata whaikaha Māori tend to have poorer material well-being and quality of life outcomes than non-disabled Māori and the disability population as a whole. Māori are also less likely to know about and access DSS (around 21 percent of DSS clients are Māori). The proposals in this paper will contribute towards improving key life outcomes for tāngata whaikaha Māori and whānau. They will likely result in more tāngata whaikaha Māori accessing DSS, including choosing what supports work best for them and their whānau.
Pacific peoples	Nineteen percent of the Pacific population identify as disabled. Pacific people are also less likely to know about and access DSS (around 7 percent of DSS clients are Pacific). The proposals in this paper will contribute towards improving key

	life outcomes for disabled Pacific people. At least 3,000 disabled Pacific people will benefit directly from the national implementation of the EGL approach which will likely also support more Pacific peoples to access DSS and other disability supports.
Gender	Men and women are equally likely to be disabled. Women are more likely to access disability support, however, more men access DSS specifically. Women make up the majority of carers for disabled people who depend on family and whānau for support. The disability support workforce is also largely female. The proposals in this paper aim to improve outcomes for disabled women accessing government supports and services, including DSS. They will also benefit women who are carers for a disabled family or whānau member.
Children and young people	Disabled children, and children with a parent who has a disability, are more likely to experience poverty and poorer outcomes. ³ Almost 50 percent of those accessing DSS are aged below 25. The proposals in this paper will potentially benefit all disabled children and young people and contribute towards improved outcomes and material wellbeing. National implementation of the EGL approach will directly benefit the many children and young people accessing DSS.
Older people	Older people experience high rates of disability (59 percent of New Zealanders aged 65 and over have a disability). New Zealand's population is also ageing. Around 2,300 DSS clients are aged 65 and over and will benefit directly from the national implementation of the EGL approach for DSS. As ongoing work on Disability System Transformation progresses, many more older people will also potentially benefit.

Human Rights

130 This proposal is consistent with the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993. It is also consistent with the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Declaration on the Rights of Indigenous Peoples.

Consultation

131 This paper was jointly drafted by the Ministry of Social Development and the Ministry of Health. The following agencies have been consulted: the Accident Compensation Corporation, the Ministry of Business Innovation and Employment, the Ministry of Education, the Ministry for Pacific Peoples, the Ministry of Transport, Oranga Tamariki, Te Puni Kōkiri, the Office for Disability Issues, the Treasury, the Public Service Commission, the Human Rights Commission, the Health Transition Unit and the Department of the Prime Minister and Cabinet. Their views have been incorporated.

132 The Enabling Good Lives Governance Group, the Whānau Ora Interface Group, the National Enabling Good Lives Leadership Group, the Disabled Peoples Organisation Coalition and I.Lead have also been engaged on this paper and their views have been reflected.

³ Sixty-three percent of New Zealand households with disabled children earn just enough or not enough money to meet basic needs. Of the 95,000 disabled children aged 0-14 years, 15 percent live in households with incomes under \$30,000 (compared to 10 percent of all 0-14-year olds).

133 The Whānau Ora Interface Group and the National Enabling Good Lives Leadership Group have each drafted a statement and these are attached as Appendix Six.

Communications

134 The Minister for Disability Issues and Minister of Health will liaise with the Prime Minister on the responsibility for, and the timing of, public announcements regarding the establishment of the new Ministry.

Proactive Release

135 This paper will be proactively released in accordance with Cabinet Office Circular CO (18), subject to any redactions as appropriate under the Official Information Act 1982.

Recommendations

We recommend that the Cabinet Social Wellbeing Committee:

Machinery of government

- 1 **note** that, in March 2021, Cabinet noted that the Minister of Health and Minister for Disability Issues would bring advice on the future model and governance of Disability Support Services to Cabinet in September 2021 [CAB-21-MIN-0092 refers]
- 2 **agree** to establish a new Ministry, provisionally named the Ministry for Disabled People, in the form of a departmental agency hosted by the Ministry of Social Development
- 3 **authorise** the Minister for the Public Service, the Minister for Disability Issues and the Minister of Health to determine the final name of the new Ministry, in consultation with the disability community and key stakeholders
- 4 **note** the intention that the new Ministry will be established by 1 July 2022 but that it will take longer for the new agency to be fully operational
- 5 **agree** relevant Disability Support Services functions, including responsibility for the national implementation of the Enabling Good Lives approach, will transition from the Ministry of Health to the new Ministry
- 6 **agree** the new Ministry will be responsible for driving improved outcomes for disabled people across government, which requires an expanded mandate and new disability-related responsibilities and functions, including a strategic policy function
- 7 **note** that any functions resulting from Cabinet decisions on the Accelerating Accessibility work programme will be considered as part of decisions on the new Ministry's future work programme
- 8 **note** due diligence will need to be undertaken to establish the new Ministry as a departmental agency hosted by the Ministry of Social Development

9 **invite** the Minister for the Public Service to issue drafting instructions to the Parliamentary Counsel Office for an Order in Council to establish the departmental agency by adding it to Part 2 of Schedule 2 of the Public Service Act 2020

10 **note** the chief executive for the new departmental agency (or acting chief executive if appointed) will work with the Ministries of Health and Social Development to implement the transition to the new Ministry

11 **agree** to set up a dedicated Transition Team within the Ministry of Social Development to support the establishment of the new Ministry

12 **note** that the Transition Team will work with established disability community groups to ensure that the voices of disabled people and whānau shape the establishment of the new Ministry, including the work of the Transition Team

13 **note** the costs associated with establishing the new Ministry and the ongoing additional operating costs are estimated at \$85.0 million over the forecast period comprised of:

- 13.1 Transition Team and establishment costs of \$28.4 million
- 13.2 ongoing operating costs of \$56.6 million

14 **note** funding for the 2021/2022 financial year for the Transition Team and initial establishment costs is sought now, with remaining funding to be sought through Budget 2022

15 **agree** to establish the following new appropriation within Vote Social Development:

Appropriation Minister	Appropriation Type	Title	Scope
Minister for Disability Issues	Departmental Output Expense	Establishing a Ministry for Disabled People	This appropriation is limited to establishing, and managing the transition to, a Ministry for Disabled People

16 **approve** the following changes to appropriations to give effect to the policy decision in recommendation 11 above, with a corresponding impact on operating balance and net core Crown debt:

Vote Social Development Minister for Disability Issues	\$m – increase/(decrease)				
	2021/22	2022/23	2023/24	2024/25	2025/26 & Outyears
Departmental Output Expense: Establishing a Ministry for Disabled People (funded by revenue Crown)	5.000	-	-	-	-
Grand Total	5.000	-	-	-	-

17 **agree** that the proposed change to appropriations for 2021/22 above be included in the 2021/22 Supplementary Estimates and that, in the interim, the increase be met from Imprest Supply

- 18 **agree** that the expenses incurred under recommendation 16 above be charged against the Between-Budget Contingency established as part of Budget 2021
- 19 **agree** that any underspends in the Departmental Output Expense, Establishing a Ministry for Disabled People, for the year ending 30 June 2022, be transferred to the following financial year to ensure that funding is available for any remaining transitional activities
- 20 **authorise** the Minister of Finance and the Minister for Disability Issues to jointly agree the final amount to be transferred as per recommendation 19, following completion of the 2021/22 audited financial statements of the Ministry of Social Development (or sooner if necessary), with no impact on the operating balance across the forecast period

National implementation of the Enabling Good Lives approach

- 21 **agree** to implement the Enabling Good Lives approach to Disability Support Services nationally, subject to Budget 2022 decisions
- 22 **agree** to endorse the implementation plan (attached as Appendix Five) to implement the Enabling Good Lives approach to Disability Support Services on a national scale
- 23 **agree** that in the initial phase of national implementation of the Enabling Good Lives approach:
 - 23.1 the eligibility criteria should be the same as the current eligible population for Disability Support Services (with the clarification that all children with significant developmental delay but no confirmed diagnosis, regardless of age, are eligible for early intervention support)
 - 23.2 means testing should not apply to people who have a flexible personal budget
 - 23.3 means testing on household management should continue to apply while people continue to receive a Needs Assessment and Service Coordination allocated package during the transition period
- 24 **agree** that the following funding streams be included in personal budgets for eligible people in the initial phase of national implementation:
 - 24.1 Vote Health: National Disability Support Services appropriation
 - 24.2 the ‘Very High Needs’, ‘Community Participation’, and ‘Transition from School’ funding streams from the Vote Social Development: Community Participation appropriation
- 25 **agree** that the following funding streams from Vote Social Development are not included:
 - 25.1 Business Enterprise funding
 - 25.2 Support Funds paid on behalf of disabled people

Next steps

- 26 **note** the Ministry of Health will report back to the Minister of Health in November 2021 with an update on the work to improve support for people with fetal alcohol spectrum disorder
- 27 **invite** the Minister for Disability Issues and Minister of Health to report back to the Cabinet Social Wellbeing Committee in early 2022 with further detail on:
 - 27.1 establishing the new Ministry, including relevant transitional arrangements
 - 27.2 implementing the Enabling Good Lives approach on a national scale
 - 27.3 future opportunities for further disability system transformation once the new Ministry is established and fully operational
 - 27.4 the future of the Office for Disability Issues, including recommendations on its future location within government.

Authorised for lodgement

Hon Carmel Sepuloni
Minister for Disability Issues

Hon Andrew Little
Minister of Health

Appendices

Appendix One: Enabling Good Lives (EGL) Vision and Principles

Appendix Two: background on Disability System Transformation and key decisions to date

Appendix Three: Disability Support Services (DSS)

Appendix Four: evaluation of EGL demonstration sites to inform the national implementation of the EGL approach

Appendix Five: phased roadmap for national implementation of the EGL approach 2021 – 2024

Appendix Six: statements from the Whānau Ora Interface Group and the National Enabling Good Lives Leadership Group

Appendix One – Enabling Good Lives (EGL) Vision and Principles

EGL VISION

In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.

EGL PRINCIPLES

Self-determination

Disabled people are in control of their lives.

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

Person-centred

Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

Ordinary life outcomes

Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stage of life.

Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

Mana enhancing

The abilities and contributions of disabled people and their families and whānau are recognised and respected.

Easy to use

Disabled people have supports that are simple to use and flexible.

Relationship building

Supports build and strengthen relationships between disabled people, their whānau and community

Appendix Two – background on Disability System Transformation and key decisions to date

Work on Disability System Transformation has been ongoing for more than a decade led by MOH with support from other agencies, including MSD. Successive governments have made a number of key decisions to advance this work.

In 2011, an independent working group of disabled people, their families and whānau, advocates and allies developed the Enabling Good Lives (EGL) vision and principles (outlined in Appendix One) to be the foundation for a transformative change to disability support. The EGL vision and principles (collectively the EGL approach) are consistent with the principles of Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disabilities, and the New Zealand Disability Strategy.

In September 2012, the Ministerial Committee on Disability Issues agreed to the EGL vision and principles as the basis for Disability System Transformation.

Since 2012, the main focus of Disability System Transformation has been to trial the EGL approach in a number of regions across New Zealand. Between 2013 and 2016, there was a demonstration in Christchurch for all school leavers with high or very high needs. A smaller scale initiative has continued since 2016. Since 2015, there has been a demonstration in Waikato for disabled people who opt into the new system.

In 2017, Cabinet directed MOH and MSD to work alongside the community to co-design a process for a nationwide transformation of the disability support system. It was agreed the first region to be transformed would be the MidCentral District Health Board region. Cabinet also agreed that the initial focus for Disability System Transformation should be people eligible for Disability Support Services (DSS) funded by MOH [SOC-17-MIN-0007 refers].

In 2018, Cabinet endorsed the EGL vision and principles for transforming DSS and agreed to the implementation of a prototype (Mana Whaikaha) in MidCentral which began operating in October 2018. Cabinet also agreed to initiate the Machinery of Government Review to identify options, including possible structural changes, for involving disabled people and whānau in the governance of the disability system [SWC-18-MIN-0029 refers].

Appendix Three – Disability Support Services (DSS)

What is DSS?

DSS is an appropriation managed by the Disability Directorate in the Ministry of Health (MOH). It generally supports people for whom onset of disability is prior to age 65, with more than half of clients aged under 25. Around 43,300 people who are disabled due to a physical, sensory, or intellectual neurological or developmental condition, access ongoing supports funded by DSS and allocated through Needs Assessment and Service Coordination services (NASCs).

DSS also supports over 100,000 other people, for example, through equipment and modifications and provision of hearing aids. People with ‘age-related’ or injury-related conditions are supported through services provided or funded through other government agencies including DHBs (soon to be Health NZ) and ACC.

DSS has a total budget of \$1.83 billion for the 2021/22 financial year. In 2020/21, services were delivered through approximately 975 service providers under about 1,500 contracts.

Current funding arrangements for DSS

Seventy-five percent of DSS expenditure is based on claims under a fee-for-service model. Receipt, processing, and paying of these claims is a substantial task, currently undertaken by the MOH Sector Operations Team (90,000 – 100,000 claim items are processed each month). The other 25 percent of the expenditure is mostly paid for through bulk-funded or capacity contracts.

MOH currently funds disability support services for:

- 43,300 people with long-term supports which allows:
 - 8,000 people to have help with cleaning and laundry so they can remain in their own home for longer
 - 11,000 people to be supported with daily activities such as getting up in the morning and going to bed at night
 - 7,500 people to receive 24/7 support to live in their community
 - 2,000 people to access a clinical behaviour support service
 - 500 resident family members to be paid to provide some hands-on care to their disabled family member
 - around 7,000 disabled people manage their support through ‘individualised funding’ arrangements under which disabled people, through a host agency, manage the purchasing of support themselves.
 - 23,000 caregivers to be able to take a break from their caring responsibilities
 - 2,000 patients to access inpatient rehabilitation beds and outpatient rehabilitation services following a stroke (or other illness)
- 85,000 people to get the equipment and modification services they need to retain/achieve independence, including hearing and vision services
- 22,000 people to access the hearing aid funding and subsidy schemes

86 adults and children to receive cochlear implants each year.

Appendix Four – evaluation of EGL demonstration sites to inform the national implementation of the EGL approach

Implementation of the demonstration sites, and work with national and regional EGL leadership and governance groups, has continued to build the case for change, including providing more in-depth knowledge to inform decisions on how the EGL approach can be implemented nationally.

Evaluations of the demonstration sites in Waikato and Christchurch, and the Mana Whaikaha prototype have shown positive experiences and provided many insights.

- Most participants report **positive experiences and improved outcomes** such as increased independence, personal development, and social networks.
- Families and whānau report feeling supported and **improved family dynamics**.
- Understanding context is important in determining funding allocations. This means that **decisions may differ depending on the person's circumstances**.
- Decisions on **individual support packages need to be decentralised** (for example, through devolved decision making to potential local EGL entities).
- Participants have **different capacities and skillsets to take up funding** and to manage it – a wide range of options are required to ensure this.
- Strengthening networks amongst disabled people, families and communities has the **potential to spark locally led innovation** outside of government funding.
- **EGL requires a different approach to workforce**, as disabled people are in control of their supports and who provides them. It has also showed that in most cases, **disabled people and whānau can be trusted** to manage their own personal budgets and support.

Mana Whaikaha has also provided insight on what needs to be in place to support a national implementation. This includes having established disabled people and whānau leadership in place, having the Connector capability and capacity well developed, having providers and wider community support prepared for change and having robust business processes in place to effectively manage demand and ensure continuity of supports.

The co-design work as part of Mana Whaikaha was clear that the goal would be to move operations closer to the disability community and away from government agencies and, specifically, that Mana Whaikaha should move out of the Ministry of Health (MOH) and into the community. Currently all three demonstrations are operated by central government and with staff employed either by MOH or MSD.

Based on evaluation to date, MOH has identified a number of critical features for transforming the system nationally:

- **Point of entry** – triage and ability to connect to a wide range of cross-government services. More people engaged with the system (both eligible for DSS and outside the current entry criteria).
- **Role of Connectors** – an ecosystem approach where people can access support that best suits them, including Kaupapa Māori, peer to peer, and crisis support.

Lead in time is required to ensure a strong Connector and provider workforce and grow EGL capable leaders from the disability community.

- **Early intervention** – the ability to invest immediately to support people with immediate needs is key, to ensure that good life planning can commence from a stable place.
- **Personal budgets** – the ability to easily assess personal budgets and align with good life plans, pooled funding from cross-government to allow flexibility, capability of the system to support people so that they are equipped to manage their budgets.
- **Management structure** – a single unifying culture and supporting structure based on EGL principles, accountability and delegations of decisions at an individual level.
- **Disabled people and whānau leadership** – strong and influential voices of disabled people is crucial at all decision-making levels, strong partnership across the sector including officials, providers, and the local community.
- **Robust safeguarding arrangements** – disabled people want to experience the ‘dignity of risk’; to face (and manage) the same level of risks as other people. They want to recognise, identify, and report neglect or abuse and to be able to effectively safeguard themselves.
- **Technology and data** – ability to identify and disaggregate individual level data, performance and outcome reporting based on people (not service lines), and robust financial management systems.

Appendix Five – phased roadmap for national implementation of the EGL approach 2021 – 2024

Phase 1	Description
July 2021 to June 2022	<p>Establish, implement, and refine a partnership approach, grounded in Te Tiriti o Waitangi, to ensure that community voice is embedded in the design, planning and implementation of all activities in the plan.</p> <p>Work to establish new Ministry for Disabled People and transition of relevant functions to it from MOH.</p> <p>Undertake detailed service design and specifications including:</p> <ul style="list-style-type: none"> • a person and whānau-centred approach to service design in partnership with disabled people and whānau • operational policy changes • workforce capability strategy • Connector/Tūhono eco-system design • person-directed funding and allocation tools • personalised commissioning model • performance monitoring and data requirements • financial management and reporting requirements. <p>An investment strategy, business case and Budget bid that sets out the additional, costs, benefits and risks associated with a national implementation, and informs decisions about the scale and pace of change.</p> <p>New person-directed commissioning and funding approaches to enable the move to personalised funding and support services. These have been tested through EGL pilots, and work is underway on a phased approach to scale and administer these nationally. The focus of this work in the immediate term includes:</p> <ul style="list-style-type: none"> • establishing a policy framework for funding decisions that enhances the control that disabled people have in the process, whilst working within the constraints of our current legal framework • developing outcomes-based (rather than impairment-based) allocation tools and practices • ensuring equitable and consistent funding allocation • undertaking performance measurement that links to and builds on the initial outcomes-based information informing allocation • implementing an initial expansion of flexible instruments to address known service gaps. <p>Detail a transition pathway for new regional entities that covers the process to undertake:</p> <ul style="list-style-type: none"> • market analysis to understand which organisations have the capability and capacity to meet the new requirements, who is best aligned to the EGL vision and principles, what level of market shaping may be required and what regional coverage would be optimal • market engagement to identify those organisations who best align and commence further design work to understand transition requirements and any organisational development that may be required • a procurement plan that details service specifications, funding levels, performance measurement and partnership agreements • a transition plan that progressively shifts functions and services from existing organisations to new organisations, ensuring continuity of supports. <p>A workforce strategy that includes:</p> <ul style="list-style-type: none"> • the establishment of a new Connector/ Tūhono workforce with required practice framework and competencies • capability building of the existing disability support workforce in the EGL model of support. <p>A monitoring and evaluation strategy that ensures we are learning and adapting through the change process and that the changes are meeting the intended outcomes.</p> <p>A change management, communications and engagement strategy that ensures disabled people, their families and whānau, and sector stakeholders including providers and NASCs, understand and are well prepared for changes as they happen.</p> <p>A disabled person, family and whānau capability building strategy to surface or enable local and national leadership capability. This will ensure disabled people, family and whānau are empowered to lead and influence the system at each level. This is a critical element due to:</p> <ul style="list-style-type: none"> • the need for information, tools and resources to enable person-directed supports and system settings • an EGL approach requires strong leadership by disabled people and whānau so that the system is responsive and guided by their voices. <p>EGL also shifts the balance from a siloed disability support model towards community inclusion and participation; this requires partnership with the wider community aligned with Te Tiriti to achieve success.</p>

Phase 2	Description
July 2022 to June 2023	<p>The investment and approach are confirmed through Budget 22 which will set the amount and timing of funding that will enable a national implementation to take effect. This will essentially set the timeline for implementing operating model changes.</p> <p>Machinery of Government changes will be in place and there will be a new disability Ministry established with the mandate and resource to drive the implementation programme.</p> <p>Implementation of the procurement plan to initiate the change process from current NASC based services to new EGL driven entities. During this period, we would expect to:</p> <ul style="list-style-type: none"> • identify the group of organisations to partner with • undertake further design on how the entities will operate in practice and what additional development will be required to be fully operational • detail the transition plan for moving from current support models into new models and through new entities. <p>Implementation at a national level of new person directed funding and commissioning tools, including a complete change in the way in which services are commissioned, impacting 1000 providers and 1500 different contracts.</p> <p>National and local disabled people and whānau networks are in place to advise the new agency, provide leadership and guidance for new EGL entities, and to prepare the wider community for change.</p>

Phase 3	Description
July 2023 to June 2024	<p>The procurement plan is agreed, and a full transition is underway. Key activities will include:</p> <ul style="list-style-type: none"> • commencement of new regional entities, with funding, delegations and performance measures all in place • transition of support agreements from existing to new, and for new clients entering the system • disabled people and whānau led governance and leadership models are in place to oversee and guide operations.

Disability Support System Transformation: Overall Approach

Proposal

1. This paper proposes an overall approach, based on the Enabling Good Lives (EGL) vision and principles, to transforming the cross-government disability support system. The transformation seeks to improve the lives of disabled people and their families and whānau, and create a more cost-effective disability support system.

Executive Summary

2. For some years, disabled people and their families have been raising concerns about the disability support system. They feel that there is a lack of choice and control over the support they receive and their lives as a result of:
 - 2.1. multiple eligibility, assessment and planning processes for accessing different types of support from several government agencies resulting in duplication of processes for disabled people;
 - 2.2. being allocated existing contracted services, not necessarily what works best for them which means the funding is not being used as effectively as it could be; and
 - 2.3. disability services becoming the 'hub' of their lives and placing restrictions on people, rather than helping them to connect to support available to everyone in the community and enabling them to access greater opportunities.
3. The government has worked with the sector to respond to these concerns through a range of relatively small scale initiatives that have increased disabled people's choice and control. These include several New Model demonstrations, including Enhanced Individualised Funding and Choice in Community Living, and two EGL demonstrations in Christchurch and Waikato.
4. These initiatives have been well received, and several evaluations show that they have led to improvements in people's lives enabling them to achieve better outcomes. There is mixed evidence on the impact that the initiatives have had on costs, however even if a transformation of the disability support system does not succeed in delivering significant cost savings, there is still value in the improved outcomes in terms of the effectiveness of this spend.
5. During this time, there have been ongoing increases of about 4% a year in government funded disability support across the Ministries of Health, Education and Social Development. These are driven by a mixture of volume and price increases.
6. During 2016, a small group of Ministers held several strategic discussions about the future direction for disability support. Those discussions showed that disabled people generally have worse life outcomes than New Zealanders, with the 32,000 people supported by Disability Support Services (DSS) in the Ministry of Health (the Ministry) having particularly poor life outcomes, leading to many receiving considerable disability support funding from across government.
7. Based on what we have learnt, proposals were developed for transforming the wider disability support system so that it improved outcomes for disabled people and their families and whānau, and improved cost-effectiveness. That transformation will:

- 7.1. incorporate the EGL vision and principles which have been shown to improve the lives of disabled people;
- 7.2. build on the success of individualised funding; and
- 7.3. be underpinned by a social investment approach that seeks to improve quality of life and the cost-effectiveness of cross-government disability support funding.

8. The transformation will honour and build on the commitments that this Government has made to the disability community. One dedicated agency will lead the changes. Rather than a localised demonstration that is layered on top of existing systems and structures, this transformation will apply to the whole system and be rolled out nationally.
9. The transformation will:
 - 9.1. initially be rolled out to people in mid-Central (based around Palmerston North) who are eligible for DSS funded support
 - 9.2. build on the Needs and Assessment Service Coordination (NASC) infrastructure but will require a significant change to their culture, systems, processes and brand based on the EGL principles and a social investment approach
 - 9.3. be led by the Ministry of Health, which will work with the disability community and other officials to design the initial transformation. This reflects the disability community's wish for a single agency to be responsible for the transformation.
10. Cabinet decisions on the design, the implementation timetable, and the high-level process for national roll-out will be sought in mid-2017.
11. Funding of \$1.8 million for the co-design process between March and June 2017 is sought from a \$3 million EGL contingency set aside in Budget 2016. Additional funding of \$27 million over four years for the mid-Central transformation is being sought through Budget 2017. Further funding for rolling out the transformation to other regions may be sought in subsequent budgets. A cost-benefit analysis to support the Budget 2017 bid suggests that the additional funding is likely to yield good returns through improving people's lives and reducing costs. It may potentially slow the rate of cost growth in the longer-term.

Background

12. For some years, the disability community has expressed concern that the current disability support system unnecessarily limits disabled people's choice and control over their support and their lives. These concerns were reflected in the 2008 Report of the Social Services Select Committee on its 'Inquiry into the Quality of Care and Services Provision for Disabled People'. They were also acknowledged in the Government response to the Select Committee's report.
13. Central concerns of the disability community have been:
 - 13.1. multiple eligibility, assessment and planning processes for accessing different types of support from several government agencies;
 - 13.2. being allocated existing contracted services, not necessarily what works best for them; and
 - 13.3. disability services becoming the 'hub' of their lives, rather than helping them to connect to support available to everyone in the community.
14. A range of government initiatives have been developed with input from disabled people and their families to respond to these concerns:

- 14.1. DSS has developed alternative services within the constraints of its existing system. For example, in the mid-2000s, it introduced an individualised funding scheme that allowed disabled people to use their Home and Community Support Services more flexibly without using contracted providers.
- 14.2. The Ministry's New Model for Supporting Disabled People (New Model) [CAB Min (10) 23/4A], which pre-dated EGL. There were several demonstrations under the New Model, with the most significant being in the Bay of Plenty from 2011 to 2014.
- 14.3. Two EGL demonstrations [SOC Min (13) 15/5 and SOC Min (14) 19/2 refer]. These have been in Christchurch (2013 to 2016, but with similar arrangements continuing in place after the end of the demonstration) and Waikato (beginning in 2015). Approximately 250 people have been involved in each demonstration.
- 15. While these initiatives have been generally well received and have shown some evidence of improved outcomes for disabled people, they have not involved the full system transformation that the disability community is seeking. The length of time since the demonstrations began means that there is now considerable pressure from the disability community to introduce a national approach – and a lack of confidence that it will occur.

Fiscal concerns with the current system

- 16. For some time, Ministers have also expressed concern about the ongoing high rate of increases in the cost of disability support across government. DSS' appropriation has had average increases of more than 4% a year between 2006/07 and 2016/17 (to \$1.2 billion in 2016/17). The increase in DSS' appropriation has primarily resulted from cost pressures (with a significant proportion of the increase in recent years arising from Court decisions such as the sleepovers case and paid family carers).
- 17. The Ministry of Education's Ongoing Resourcing Scheme [ORS] has increased by almost 4% a year over the same period (to \$228 million in 2016/17). The increase in the cost of the ORS scheme has primarily resulted from increases in the number of children supported.
- 18. Funding for the Ministry of Social Development's (MSD's) Community Participation appropriation (\$61 million in 2016/17) has increased by about 1.2% a year. These increases primarily result from increase in the number of people with very high needs who are supported. There have been no price increases for the partially funded services for other groups. This has created challenges for providers, dissatisfaction within the disability community, and placed pressure on DSS' costs.
- 19. There is mixed evidence to date of the impact that initiatives aimed at increasing people's choice and control have had on fiscal costs. The international evidence is that costs under the new approaches tend to be no higher – and, in some cases, may be lower – than under approaches similar to the DSS framework. The New Zealand demonstrations have not, however, consistently supported the international findings for a range of reasons:
 - 19.1. They have been small without the opportunity for economies of scale and have had to use/adapt existing disability system infrastructure, which is based on different models for supporting disabled people.
 - 19.2. Costs have not distinguished between early investments and longer term ongoing support costs, and have not operated for sufficient time to realise the benefits from early investments.
 - 19.3. The demonstrations were implemented in ways that added costs (eg., the independent facilitators, who are the heart of EGL), without simultaneously seeking to reduce other costs.

19.4. In most of the demonstrations, people self-selected whether they would participate, so may not be a representative group.

20. The varying results from the differing demonstrations suggest that actual costs are affected by the detailed design and operation of the system.

Strategic discussions by Ministers

21. In November 2015, Cabinet Social Policy Committee requested a report back on options for applying the lessons from the EGL approach to disability support [SOC-15-Min-0036 refers]. As part of the preparation for that report back, stakeholder Ministers met for a series of strategic discussions regarding disabled people and disability support to understand who receives government funded disability support, what types of support they receive, and the outcomes being achieved. Those discussions benefited from cross-government data relating to disabled people being included within the Integrated Data Infrastructure for the first time.

22. Those discussions revealed that the 24% of New Zealanders who have a disability¹ experience poorer life outcomes than New Zealanders generally. The group of 32,000 disabled people who receive ongoing support funded through DSS in the Ministry - with long-term physical, intellectual and sensory disabilities that arise before they turn 65 - have some significantly worse life outcomes than disabled people generally. An indication of these poor life outcomes is set out in Table One below.

TABLE ONE: INDICATORS OF DIFFERENCES IN LIFE OUTCOMES²

Indicator	All New Zealanders	All people with disabilities	DSS Clients
Employment of working age people	72%	45%	10% ³
Proportion with incomes below \$30,000	45%	65%	n/a
Proportion with school or tertiary qualifications	85%	67%	18%
CYF findings of abuse or neglect before age 17	8%	n/a	19%

23. These relatively poor life outcomes lead to a high level of support for DSS clients being provided from across government. For example:

23.1. They receive an average of about \$30,000 a year of ongoing support from DSS' \$1.2 billion appropriation, 94% of which is focused on 21,500 people with high and very high support needs, about 7,500 of who are in residential care. About 85% of people in residential care are expected to remain there for life, with lifetime DSS costs considerably in excess of \$1 million for some people. The 15% who leave residential care before they die, have generally been in residential care for more than 10 years, and have intellectual disabilities. They may also be part of the group of clients who have been impacted by deinstitutionalisation.

There is good evidence that increasing early investments in support have the potential to reduce long-term residential costs, as well as improving outcomes for disabled people.

23.2. About 77% of those who are aged 16 to 64 access working age income support that is managed by MSD, with 96% of this group receiving a Supported Living

¹ Source: New Zealand Disability Survey 2013

² This material is drawn from the Disability Survey and data within the Integrated Data Infrastructure.

³ This figure is the proportion of working age DSS clients who receive part or full-time income from work.

Payment (SLP). Most SLP clients will continue to receive this support until they die or become eligible for NZ Superannuation.

Proposed transformation

24. Ministers considered what a transformed disability support system might look like. The outcome of those discussions is summarised in the A3 diagrams that are attached as Appendix One. Those discussions were based on the view that there should be a single, consistent and nationwide system with the disabled person firmly at the centre and that the rate of fiscal growth must be more effectively managed than at present, especially when the increasing expenditure is not associated with improvements in the quality of disabled people's lives.
25. The transformed system would, therefore, have two high level goals:
 - 25.1. improving outcomes for disabled people and their families and whānau; and
 - 25.2. more cost-effective government disability support expenditure.
26. To achieve those goals, the transformation would be:
 - 26.1. **Based on, and reflect, the EGL vision and principles** (see Appendix Two), and what we have learned about the core elements of a system based on them (see Appendix Three which gives a review of the evidence). This approach would be strongly supported by the disability community.
 - 26.2. **Underpinned by a social investment approach.** This involves putting in place measures that are expected to improve outcomes for disabled people and families and whānau but are also expected to reduce lifetime cross-government costs.
27. A new design is required to underpin the transformation with a social investment approach and to build on and transform the existing infrastructure (NASCs). It is not possible to simply adopt the design of any of the current demonstrations. Consistent with the EGL principles, the transformed system would be co-designed by the disability community and officials. Cabinet approval of the co-designed transformation would be sought before it is implemented.
28. Appendix Four discusses the possible design of the transformed system, and what its different features are likely to build on. The building blocks include international evidence, the existing demonstrations, and the developing understanding across government of what it means to adopt a social investment approach.

Impacts

29. Table Two shows the tangible impact that the changes envisaged as part of the transformation can have on disabled people.

TABLE TWO: IMPACT FOR THE DISABLED PERSON OF IMPLEMENTING NEW APPROACHES

Part of system	Current approach	New approach
Life planning	NASCs and providers each produce plans that affect my life.	I plan what I want my life to look like and work on my goals in life (with help from an independent facilitator, if I choose).
Assessment	I go to the NASC and they assess some of my support needs. I may be assessed by other agencies for other support needs.	I complete a single supported self-assessment for all my support.

Part of system	Current approach	New approach
Support allocated	I am allocated specific types and levels of services (eg, to get ready in the morning).	I receive a single personal budget for all my support.
Purchasing options	I can choose between several DSS contracted providers of the services I have been allocated.	I can choose how I buy my support (eg, existing services, flexible provider contracts, hosted individualised funding, flexible disability services, or I can manage it myself and buy services from anyone I want).
Who supports me	The agency sends me people – I don't get to choose who supports me or when they come.	I can choose how to employ my staff. I can choose where I live and who I want to support me (eg, people my own age) and when they come.
Attitude towards family and other natural support	Funded support complements my existing natural support.	My existing natural supports are valued and nourished. There is strong emphasis on developing new natural networks.
Time horizon	Services focus on my immediate situation and needs	Support responds to my immediate situation. In addition, early investments and innovative approaches are possible which will improve my life in the future.

30. Incorporating a social investment approach alongside the EGL vision and principles will encourage a strong focus on prudent fiscal management during the design, implementation, ongoing management, and monitoring and evaluation of the transformation. There are a range of ways in which the cost-effectiveness of the government's substantial investment in disability support could be enhanced. Examples include:

- 30.1. Developing a better understanding of likely future costs based on current service delivery approaches will encourage thinking about lower cost alternatives. For example, when the intensive wraparound service for children was introduced, 16 children and young people who were at risk of entering residential care (quoted cost, \$4 million a year) were supported to remain with their families, and reported improvements in their lives – and costs were only \$1.4 million a year.
- 30.2. Investing in early supports that reduce long-term costs will reduce cost-pressures over time. For example, investing in proven early supports, such as child development services, can improve outcomes for children and lower the risk of family breakdown that precedes costly, long-term residential care. Investing in supporting someone on Support Living Payment into employment would also improve their outcomes and reduce long-term welfare spending.

31. Cost-benefit analyses prepared for Budget 2017 suggest that the additional funding required for the costs of designing and implementing the transformation is likely to yield good returns. This includes a positive return from the mid-Central transformation and recognises that there may be a positive impact on government finances over the medium to long-term.

Implementing the transformation

32. It is proposed that transformation will begin in a relatively contained way and expand in scope and across regions as we learn more about the transformed system. The initial transformation would:

- 32.1. Be for DSS' usual client group (people with intellectual, physical and sensory disabilities that arise before people turn 65) and incorporate all support funded by DSS as well as MSD's community participation services.
- 32.2. Occur in mid-Central (approximately 1,500 disabled people receiving \$50 million expenditure). The transformation timetable will be determined during an initial co-design process. While there will be benefits immediately, it is anticipated that the changes in the attitudes, capability, and culture of service providers, and disabled people building different lives, that are needed to fully realise the benefits of the transformation will unfold over several years.

This region offers a diverse mixture of rural and urban areas, has a strong Māori presence, a disability community that is keen to support change and offers 'clean' baseline data as it has not had any transformation initiatives to date. A clean baseline means that the impacts of the transformation on people lives, fiscal costs and system infrastructure will be easier to determine – something which has not happened to date.

- 32.3. Require significant process and culture change by, and a re-branding of, NASCs. The transformation will build on the long-standing investment in the existing NASC infrastructure in the regions. However, it will require a significant change to culture, systems, and processes based on EGL principles and a social investment approach. This would include the adoption of new assessment tools (for example, supported self-assessment, which would be based on learning from New Zealand and overseas), a new independent facilitation function, and spending more time with disabled people and their families to understand their circumstances.
- 32.4. Be led by the Ministry of Health, who will work with the disability community and other officials to design the initial transformation. This reflects the disability community's wish for a single agency to be responsible for the transformation.

33. Once the initial transformation in mid-Central has been implemented, it would be rolled out to other regions over a period of 10 years. The next regions to be transformed would be Waikato, Christchurch and Bay of Plenty. Key steps in the transformation process are set out in Table Three.

TABLE THREE: INDICATIVE IMPLEMENTATION TIMELINE

Early to mid-2017	Co-design of the mid-Central transformation by local and national disability community representatives and officials
Early to mid-2017	Gather baseline information to enable future monitoring and implementation
June/July 2017	Cabinet decisions on the high level prototype design, implementation timetable for mid-Central, and the approach to implementation for other regions
October 2017 to 2018	Cabinet consideration of detailed policy and financial issues raised by the transformation
Date to be determined through the design process	Go-live for the mid-Central transformation
2019/ early 2020	Initial evaluation report on mid-Central

2020	Cabinet decisions relating to the transformation in Waikato, Christchurch, and the Bay of Plenty, and any amendments to the mid-Central transformation
2020 to 2022	Possible timetable for transforming Waikato, Christchurch and the Bay of Plenty
Late 2020/ early 2021	Second evaluation report on mid-Central and initial evaluation report on Waikato, Christchurch and the Bay of Plenty

- 34. In addition to the national roll out, there will be opportunities to consider expanding the transformation to other groups of disabled people, and/ or extended to a wider range of services. Ongoing monitoring and evaluation will support the transformation by enabling refinements as the system is rolled out.
- 35. Decisions on the possible extensions and any high level changes to the system design will be made by Cabinet. In effect, this means that the transformation will include a series of decision points which will enable Ministers to decide whether they are comfortable with the way that transitional issues are being managed, or whether changes are required.
- 36. The proposed timetable reflects lessons from the demonstrations and international evidence that investing time prior to the roll-out of change process within each region results in better outcomes and lower risks than making changes quickly. For example:
 - 36.1. Taking the time to effectively involve the disability community in a region in the design and testing process leads to strong ownership of, and ongoing support for, the transformation.
 - 36.2. Rushing implementation without adequate time for design has ongoing adverse consequences for the operation of the system.
 - 36.3. Investing in disabled people, family and provider development means these groups are better placed to take advantage of the changes.

TRANSITIONAL RISKS AND ISSUES

- 37. There will be a strong focus on prudent fiscal management during the transition to the new system. The issues that will need to be addressed are expected to include:
 - 37.1. Increasing demand, as a result of more people seeking government funding, or people being allocated higher amounts of support. This demand will come from people finding that the flexible support is more attractive to them than existing services.
 - 37.2. A reduction in demand for traditional support, which may lead to providers combining, looking to develop new ways of working, or some going out of business if they do not successfully transition to new ways of working.
 - 37.3. Some providers may decide that it is not financially viable to continue providing some traditional services, even though there is demand for them, or require higher prices to provide them. Both of these will have flow on effects for disabled people.
 - 37.4. The disability community generally considering that they are 'entitled' to a specific level of support funding, which would limit the ability to manage fiscal costs. Some people already consider that their disability support allocation is an entitlement.
 - 37.5. Adverse impacts on the management of the existing system because management attention is devoted to the new system.

GOVERNANCE

38. The EGL approach involves shifting a greater degree of choice and control over disability support to disabled people (and their whānau), and a corresponding reduction in the authority of funders and providers. While this transfer of authority should be recognised in governance arrangements, it cannot over-ride either Ministers' authority or officials' responsibilities, such as those relating to the use of public funds and the requirement to follow the lawful directives of Ministers.
39. Governance arrangements for the transformation involve the following:
 - 39.1. The National EGL leadership group will safeguard the EGL vision and principles through, for example, providing advice to Ministers and the senior officials group on whether the transformation reflects the EGL vision and principles.
 - 39.2. The co-design of the transformed system will be led by a working group of leaders from the disability community nationally and in the mid-Central region (including disabled people, families and whānau, providers, and iwi) and officials from the Ministries of Health and Social Development. There will be consultation and engagement with other government agencies and with the wider disability community on the proposed design.
 - 39.3. Transformations in each region will be supported by a local leadership group from the disability community.

MONITORING AND EVALUATION

40. The Minister for Disability Issues and Associate Minister of Health will keep the Ministers of Health, Social Development, Education, and Finance informed about progress with the transformation. Cabinet will also be updated through the regular reports seeking approval for any expansions in scope. That reporting will be based on the results of monitoring and evaluation that will provide information on how the following are tracking against a baseline that will be gathered for mid-Central by 30 June 2017:
 - 40.1. the impacts on disabled people's quality of life outcomes;
 - 40.2. current and expected future fiscal costs; and
 - 40.3. the transformation process and how the transformed system is operating in practice.

TRANSITIONAL ARRANGEMENTS

41. Transitional arrangements are required for the period between the end of the EGL demonstrations in Waikato and Christchurch and the full system transformation in those regions. As far as feasible, the transitional arrangements will reflect the arrangements that are currently in place to avoid churn, which would distract from the overall transformation process. This means:
 - 41.1. In Waikato, the current demonstration which has a primary focus on children and young people, Māori disabled, and alternatives to residential care, would continue beyond its currently scheduled ending on 30 June 2017.
 - 41.2. In Christchurch, the arrangements that were put in place for existing participants and school leavers on 1 July 2016 would continue.

Financial Implications

BUDGET INITIATIVES

42. As the transformation proceeds, the required funding will be sought through annual Budget processes. The potential for budget initiatives is outlined below.

EGL Contingency funding

43. Approval is sought to draw down \$1.8 million of the \$3 million Budget 2016 contingency that is intended to support further work on EGL. The draw-down of this funding is subject to approval by the appropriate Cabinet committee (SOC) [CAB-16-MIN-0189.27 and SOC-16-MIN-0193 refer].

44. It is proposed that the funding be used by the Ministry to cover additional costs between February and June 2017, in preparation for the launch in mid-Central. Costs are expected to arise in relation to co-design activity with the disability community, programme management, communications, a feasibility study for information sharing, and gathering baseline data for future monitoring and evaluation. Good baseline data will allow us to draw more robust conclusions in the future about the impacts that the transformation is having on people's lives and on costs. Estimates of these costs are set out in Table Four.

TABLE FOUR: ESTIMATED COSTS TO BE MET FROM EGL CONTINGENCY FUNDING

Type of Costs	\$
Programme management office (including staff)	1,000,000
Gathering baseline data for future monitoring and evaluation	250,000
Feasibility study for information sharing	200,000
Co-design process with the disability community	250,000
Communications	100,000
Total	1,800,000

Budget 2017

45. Approximately \$22 million is being sought through a Budget 2017 initiative to cover the costs of transforming the mid-Central region and \$5 million for the transitional arrangements in Christchurch and Waikato, for the period 2017/18 to 2020/21. The additional funding is necessary to minimise risk to disabled people and the Crown by making it possible to manage the transformational change, while maintaining and then transitioning existing services. Cabinet's decisions on the Budget 2017 initiative could impact on the timing, scope and speed of the mid-Central transformation.

46. The costs associated with transforming the mid-Central region that are included in the budget initiative are:

- 46.1. making independent facilitators available, and doubling the capacity of NASCs in the transformed regions (\$8.6 million);
- 46.2. addressing the demand-side risk that people will use more of the funds they are allocated as they will be able to use them more flexibly (\$3.4 million);
- 46.3. based on the outcome of the feasibility study, the development of information sharing arrangements (which may lead to a subsequent capital investment case) (\$0.2 million);
- 46.4. increasing community participation funding to address unmet demand (\$2.0 million);

- 46.5. family and whānau capacity building (\$0.4 million);
- 46.6. provider capability development (\$0.6 million); and
- 46.7. increasing departmental capacity to support the transformation (\$6.9 million).

Subsequent Budgets

- 47. Additional funding may be sought through subsequent Budget processes for the costs associated with transforming other regions. Those costs will primarily be for the independent facilitators, expanding the capacity of NASCs, and addressing the risk that people will seek additional funds if they can use them more flexibly. Those additional costs could be in the order of \$100 million per annum on top of the existing baseline by the time the transformation is rolled out across the country.⁴ Further work will be done to provide more detail on likely future costs following the detailed design work. The timing and extent of these additional costs will depend on decisions by Cabinet on the future roll out.
- 48. There is also a risk that more flexible and individualised support options that are more attractive may result in higher demand for support. This includes unmet demand where people have not taken up current services (such as MSD Community Participation services) but take up a flexible allocation. The Waikato EGL demonstration suggests that the additional costs could be in the order of 4% (about \$40 million a year), although there is a considerable uncertainty about this estimate.
- 49. There are a range of ways that this risk could be responded to. They include changing allocation practice, or seeking to improve efficiencies within the system. Additional expenditure may also be justified should it correspond to improvements in people's lives.

Consultation

- 50. This paper was prepared jointly by the Ministry of Health and MSD. The Ministry of Education, the Ministries for Women and for Pacific Peoples, Inland Revenue, ACC, Te Puni Kōkiri and The Treasury were consulted. Their views have been included in the paper. The Department of Prime Minister and Cabinet was informed about the content of the paper.
- 51. To date, the disability community has been actively involved in the development and implementation of EGL. A group from the disability community developed the initial EGL proposal. A National Leadership Group of people from the disability community provides strategic advice on EGL, and the demonstrations in Christchurch and Waikato were co-designed with local leadership groups.
- 52. A working group of officials and representatives from the disability sector reviewed the evidence on what works. As outlined in this paper, the disability community would continue to be actively involved in the design and monitoring of the transformed system. Appendix Five includes a statement from the Waikato EGL Leadership Group on what is required for successful transformation of the system.

Disability Perspective

- 53. The disability community strongly supports a transformation of the disability support system that is based on the EGL vision and principles. Such a transformation is consistent with the New Zealand Disability Strategy 2016 and sits at the heart of the Disability Action Plan. There is likely to be strong support from within the disability community if the transformation proceeds, and substantial negative reaction if it does not proceed.

⁴ The 2016/17 baseline for National Disability Support Services is \$1.2 billion.

54. The disability community may have concerns that the proposals outlined in this paper will not deliver the transformation it is seeking. For example:

- 54.1. It has taken a long time to begin the overall system transformation (eg. the Social Services Select Committee's 2008 report envisaged that the transformation would be substantially complete by now). This is the result of officials' efforts to date focusing on pilots and demonstrations rather than on transforming the whole system.
- 54.2. The transformation is expected to take up to 10 years, which aligns with the international evidence about the time required for effective change and to enable time to do this in a way that does not disrupt support for individuals. However, this means that many people face a considerable delay before they can benefit from the changes.
- 54.3. NASCs may have a significant role in the transformed system, despite many disabled people considering they are responsible for many of the shortcomings of the current system.
- 54.4. Government agencies have taken decisions in recent years – such as on the type and level of services that would be funded – that are seen as inconsistent with the EGL principles. For example, process improvements to mainstream services have sometimes reduced flexibility, one of the outcomes sought under EGL. These decisions reflect the need for ongoing management of the existing system, including more clearly explaining to the sector how the strategy development work currently underway in DSS links to system transformation.

55. These concerns have also resulted in many people expressing the view that a Crown entity that is governed by a majority of disabled people and family and whānau members should be established to govern the disability support system and carry out the transformation. It should be noted that establishing such a Crown entity would likely involve considerable resources and take several years and divert resources from the transformation process proposed in this paper.

Publicity

56. It is proposed that the Minister for Disability Issues and Associate Minister of Health will lead future communications about the transformation. The first announcement will be about the process for co-designing the transformed system after this paper is approved by Cabinet. Further announcements could be made regarding Budget decisions, the outcome of the co-design process and progress with implementation.

Regulatory Impact Analysis

57. There are no proposals in this paper that require a regulatory impact analysis.

Human Rights Implications

58. The proposals outlined in this paper are consistent with the Human Rights Act 1983. They are expected to improve the rights of disabled people.

Legislative Implications

59. There are no legislative implications arising directly from the proposals outlined in this paper. Further work on the transformation may, however, lead to proposals relating to, for example, the Disability Allowance and direct funding of disability support that may need to be supported by legislative amendment.

Gender Implications

60. More males than females will be affected by the transformation because a higher proportion of people currently supported by DSS are male. Although the overall proportion of males and females with a disability is similar, there are significantly more males with intellectual disabilities, which is almost half of the DSS client group.

Recommendations

The Minister for Disability Issues and Associate Minister of Health recommends that Cabinet Social Policy Committee:

- 1 **Agree** to a nationwide transformation of the disability support system that has the objectives of:
 - 1.1 improving the lives of disabled people and their families and whānau; and
 - 1.2 more cost-effective government disability support expenditure.
- 2 **Agree** that the transformation be:
 - 2.1 based on the Enabling Good Lives (EGL) vision and principles that are set out in Appendix Two to this paper; and
 - 2.2 underpinned by a social investment approach.
- 3 **Agree** to the goal of transforming the disability support system within 10 years.
- 4 **Agree** that the transformation initially focus on the group of people who receive support that is funded through the Vote Health: National Disability Support Services non-departmental Appropriation.
- 5 **Agree** that the first region to be transformed will be mid-Central.
- 6 **Note** that the transformation will require significant change for the existing Needs and Assessment Service Coordination.
- 7 **Note** that it is intended to subsequently roll out the transformation to other regions, beginning with Waikato, Christchurch and Bay of Plenty, with the goal of commencing the transformation in all regions by 2024 (and completed by 2027).

IMPLEMENTATION

- 8 **Note** that the mid-Central transformation will be co-designed by representatives of the disability community and officials between March and June 2017.
- 9 **Invite** the Minister for Disability Issues and Associate Minister of Health to report back to Cabinet Social Policy Committee:
 - 9.1 in mid-2017 on the proposed design, scope and timing of the transformation in the mid-Central region; and
 - 9.2 in subsequent years on progress with and outcomes of the transformation, any changes to existing transformations, and the design, scope and timing of the transformation of other regions.

GOVERNANCE

- 10 **Agree** to the following governance arrangements for the transformation:

- 10.1 The Minister for Disability Issues and Associate Minister of Health will have Ministerial level responsibility for the transformation.
- 10.2 The National Enabling Good Lives Leadership Group will provide national level leadership that promotes and safeguard the EGL vision and principles.
- 10.3 The transformation of each region will be supported by a local leadership group from the disability community.

TRANSITIONAL ARRANGEMENTS

11 **Agree** to the following transitional arrangements for the existing EGL demonstrations until the transformation commences in the respective region:

- 11.1 In Waikato, continue the current demonstration that is scheduled to end on 30 June 2017.
- 11.2 In Christchurch, continue the arrangements that were implemented on 1 July 2016.

MONITORING AND EVALUATION

12 **Note** that there will be ongoing monitoring and evaluation of:

- 12.1 the impacts on disabled people and their families and whānau quality of life;
- 12.2 current and expected future fiscal costs; and
- 12.3 the transformation process and how the transformed system is operating in practice.

13 **Note** that it is expected that there will be ongoing refinement of the transformation in light of the monitoring and evaluation findings.

FINANCIAL IMPLICATIONS

14 **Note** that Cabinet approved \$3 million of tagged contingency funding in 2016/17 for supporting further work on EGL, with its drawdown being subject to consideration by the appropriate Cabinet committee [CAB-16-MIN-0189.27 and SOC-16-MIN-0193 refer].

15 **Agree** that the Ministry of Health can draw down \$1.8 million of the \$3 million contingency to enable it to commence the disability support transformation work programme, which includes the design process, engaging with the disability community, programme management, gathering baseline data for monitoring and evaluation, a feasibility study for information sharing, and transitional costs.

16 **Agree** that the expenses incurred under paragraph 15 above be a charge against the tagged contingency, Supporting Further Work on Enabling Good Lives, established as part of Budget 2016.

17 **Approve** the following changes to appropriations to give effect to the policy decision in paragraph 15 above, with the corresponding impact on the operating balance:

Vote Health Minister of Health	\$m – increase/(decrease)				
	2016/17	2017/18	2018/19	2019/20	2020/21 & Outyears
Departmental Output Expense: Managing the Purchase of Services	1.800	-	-	-	-

(funded by revenue Crown)					
Total Operating	1,800	-	-	-	-

- 18 **Agree** that the proposed changes to appropriations for 2016/17 under paragraph 16 above be included in the 2016/2017 Supplementary Estimates and that, in the interim, the increases be met from Imprest Supply.
- 19 **Note** that an initiative is being prepared for consideration in the Budget 2017 process for the costs associated with the transformation of the disability support system in mid-Central.

PUBLICITY

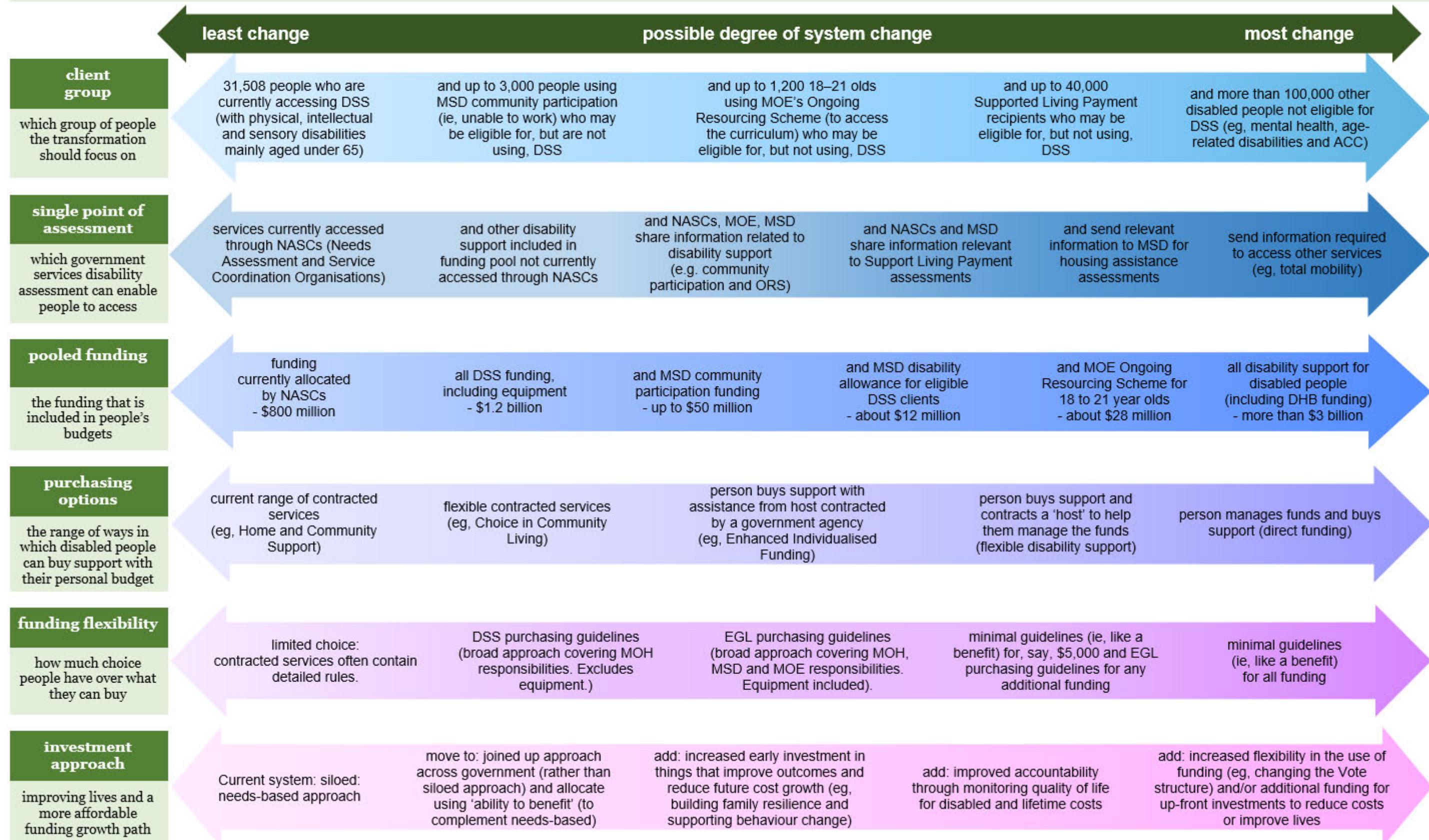
- 20 **Invite** the Minister for Disability Issues and Associate Minister of Health to make an announcement about the disability support system transformation.
- 21 **Note** that the Minister for Disability Issues and Associate Minister of Health will lead future communications about the transformation.

Authorised for lodgement.

Hon Nicky Wagner
Minister for Disability Issues
Associate Minister of Health

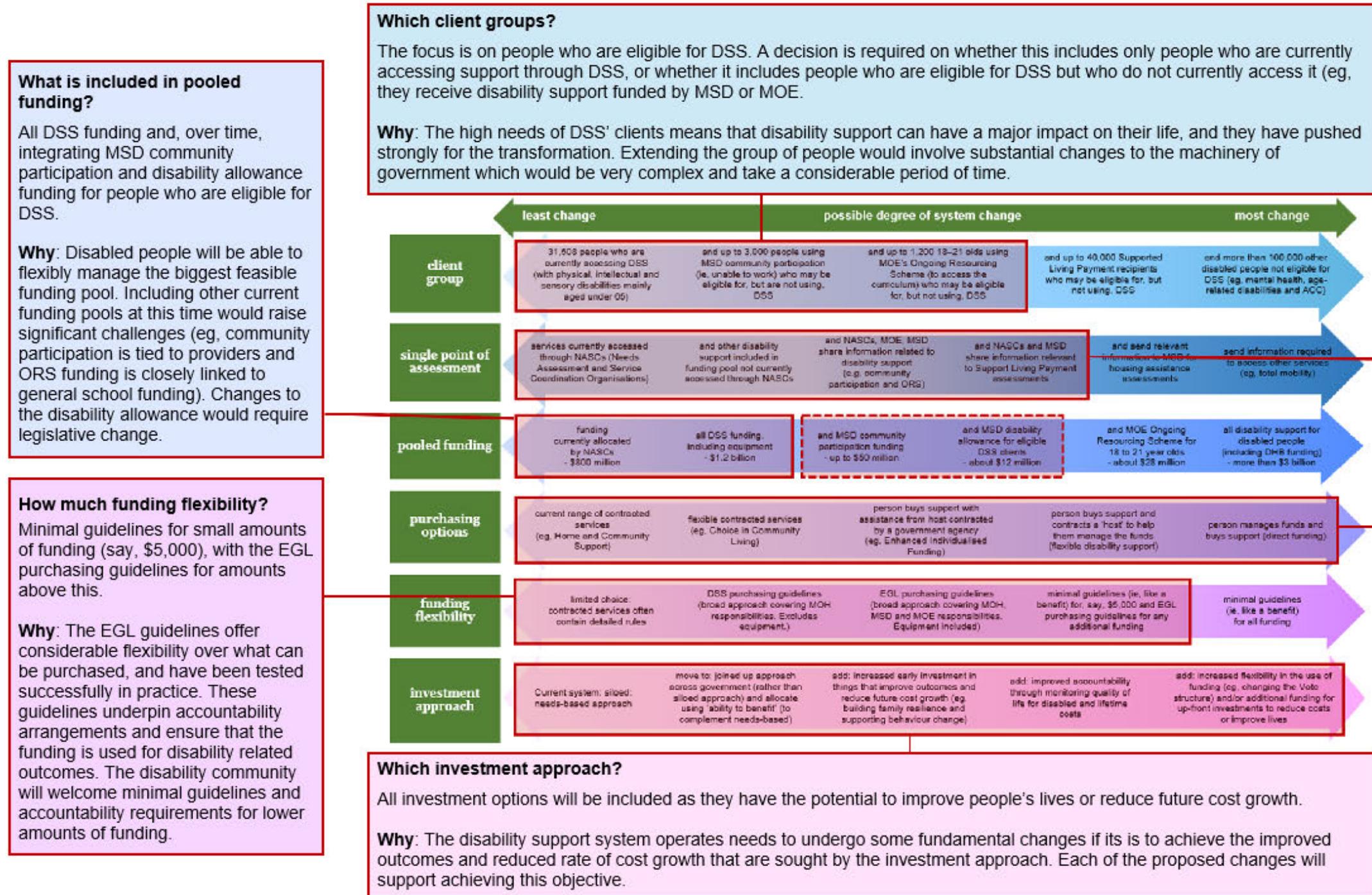
Transformation scope

A transformation of the disability support system that is underpinned by an investment approach requires substantial changes across the entire disability support system. It is not feasible to make all changes at once. Decisions are needed about the degree of system change the Government wishes to make initially. The key choices are outlined below. The transformed system would be managed by one Government agency.



Preferred choices

This slide sets out the approach recommended by cross-agency officials on the main dimensions of a transformed system that improved outcomes for people and reduced future cost growth.
The system would be managed by a single agency – the Ministry of Health.



High Level Implementation Timeline

2017	Co-design of a transformed system.	Ultimately, full national transformation could take 10 years. This reflects the time it will take for disabled people, families, providers, the community and the overall system to learn about, and make, the necessary changes. In addition, some changes may require legislative change if they are to be operationalized nationally.
July 2017 to 2020	Implement a fully transformed system within a region.	
2019 onwards	Roll out the transformation in other regions.	

There would be ongoing learning and modification of what is rolled out, to reflect what we learn about what works and what doesn't work.

Appendix Two: EGL Vision and Principles

VISION

1. In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.
2. Disabled people and their families and whānau, as appropriate, will be able to say:
 - 2.1. I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
 - 2.2. I have real choices about the kind of support I receive, and where and how I receive it.
 - 2.3. I can make a plan based on my strengths and interests.
 - 2.4. I am in control of planning my support, and I have help to make informed choices if I need and want it.
 - 2.5. I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
 - 2.6. The level of support available to me is portable, following me wherever I move in the country.
 - 2.7. My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
 - 2.8. My family, whānau, and friends are recognised and valued for their support.
 - 2.9. I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
 - 2.10. I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed.
3. The Government will get better value for the funding it provides because:
 - 3.1. the new approach will generally provide better quality of life outcomes for disabled people and their families and whānau (based on international evidence);
 - 3.2. less money will be spent on providers premises and more on support;
 - 3.3. government agencies will work more closely together, for example using shared way to determine support needs, integrated funding and contracts.

ACKNOWLEDGING THE RELATIONSHIP BETWEEN MĀORI AND THE CROWN UNDER THE TREATY OF WAITANGI

4. The Treaty relationship as set out in the New Zealand Disability Strategy, and the Māori Disability Action Plan, will continue to be core to this future vision. It will be based on three key principles of participation at all levels; partnership in delivery of support, and the protection and improvement of Māori wellbeing.

PRINCIPLES

Self-determination

Disabled people are in control of their lives.

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

Person-centred

Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

Ordinary life outcomes

Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

Mana enhancing

The abilities and contributions of disabled people and their families and whānau are recognised and respected.

Easy to use

Disabled people have supports that are simple to use and flexible.

Relationship building

Supports build and strengthen relationships between disabled people, their whānau and community.

Appendix Three: Required core elements from a Review of the Evidence

1. A working group of people from the disability community, supported by officials, reviewed the available evidence. The Working Group's review led to the conclusion that some core elements must be present if the disability support system is to improve disabled people's lives:
 - 1.1. The EGL vision and principles be at the centre of any decisions about the design, implementation, evaluation, and monitoring of a transformed system. Achieving this involves a 'culture change' in which people shift from thinking about the system using the DSS framework (with its emphasis on meeting people's needs) to the EGL vision and principles (with its emphasis on people living good lives and building on strengths).
 - 1.2. The transformation should be led by a dedicated entity that reports directly to a senior Government Minister.
 - 1.3. Local, regional and national leadership of the transformed system by disabled people, their families and whānau, and disability-related organisations should be supported through capacity and capability building.
 - 1.4. Independent facilitators (who are not linked to service provision and funding allocation) should be available to support disabled people to identify what they want for their life.
 - 1.5. Disabled people identify their own outcomes, and these are the measures of success, and the basis of accountability for funding.
 - 1.6. Disabled people have a personal budget focused on support them to live a life, not just support for their impairment.
 - 1.7. Personal budgets be financed from funds that are currently within multiple government agencies.
 - 1.8. There should be a range of options for managing a personal budget, and changing those management arrangements should be straightforward.
 - 1.9. Disabled people (with assistance from others where necessary) will be accountable for spending their personal budget based on the proposal they develop, with the accountability arrangements commensurate with the level of funding.
 - 1.10. The transformed system should be able to respond to the degree / level the individual wants to use the system, and recognise that this will change over time.

Appendix Four: Designing the transformed system

INITIAL DESIGN

1. The initial design of the transformed system will involve building on a combination of existing systems, processes, guidelines and other material from the demonstrations, what officials have been learning about how to implement investment approaches. This means that the design process can concentrate on bringing these together into a single, consistent, system. Implementation will then involve the organisational, operational, and cultural changes needed to realise the design.
2. Table One below summarises the design elements that have already been implemented within the demonstrations and their corresponding building blocks.

TABLE ONE: BUILDING BLOCKS FOR SYSTEM DESIGN

Design element	What we will build on
Being able to access independent facilitators who walk alongside people to help them plan and build a life, if the person wishes to do so.	Processes and documentation already developed in the Bay of Plenty, Christchurch and Waikato demonstrations and as stand-alone functions by NASCs in two other regions.
Having a new single point of entry for funded support, which involves transforming NASCs and Disability Information and Advisory Services (DIAS) functions so they become focused on supporting people to live good lives. This changes to NASC culture, resourcing and ways of working, and a focus on early investment.	The different approaches to NASCs taken in the Bay of Plenty, Christchurch and Waikato demonstrations. Also, the recently completed NASC and DIAS review.
Disabled people being allocated a personal budget by the new single point of entry for funded support based on a strengths-based assessment. The personal budget will include all DSS funding and Vote Social Development: Community Participation Services funding.	Processes already developed in Waikato and Christchurch EGL and the Bay of Plenty New Model demonstrations.
People being able to spend their personal budget flexibly, although the degree of accountability may differ. For example, up to, say \$2,000 to \$5,000 a year may be subject to minimum purchasing guidelines (for example, anything related to a person's disability but not gambling, tobacco, alcohol, or anything illegal) and accountability requirements. For higher amounts of funding, there would be stronger purchasing guidelines and accountability arrangements.	New Model and EGL have purchasing guidelines that can be adapted for use.

Design element	What we will build on
A range of options for disabled people to buy support with their personal budget. The options include: traditional services; flexible contracted services (where a provider delivers the services a person wants or arranges to buy them from other people or organisations on behalf of the disabled person); or individualised funding (where purchasing is managed by a contracted host organisation that does not deliver services itself).	A variety of options exist now in different parts of the country – Choices in Community Living, Individualised Funding scheme, direct funding in EGL Waikato – with documented frameworks.
Capacity building for disabled people, families and whānau, and providers.	EGL demonstrations have had this as a major feature.

3. The design is expected to incorporate the following elements of an investment approach:

- 3.1. Development of a better understanding of the cross-government costs of supporting disabled people and understanding options for managing those costs. This better understanding will use the Integrated Data Infrastructure, information gathered from introducing a single point of assessment.
- 3.2. Increased investment in particular supports that are shown to improve long-term outcomes for disabled people and reduce long term costs. For example, investing in proven early supports, such as child development services, can improve outcomes for children and lower the risk of family breakdown that precedes costly, long-term residential care.
- 3.3. Using improved accountability arrangements that monitor quality of life of disabled people and their families and whānau to drive system change. For example, when the intensive wraparound service for children was introduced, 16 children and young people who were at risk of entering residential care (quoted cost, \$4 million a year) were supported to remain with their families, reported improvements in their lives – and costs were only \$1.4 million a year.
- 3.4. Introducing a social investment fund allows people to seek funding for innovative ideas that improve outcomes and lower long-term costs. For example, a young school leaver employs a behaviour support specialist to help her and her employer put in place strategies to manage work situations that cause her stress and to maintain work relationships – so she can keep the job that is essential for her overall wellbeing.

SUBSEQUENT DESIGN

4. In the medium term (two to three years), there may be changes to the design as a result of extensions to the scope of the transformed system. Possible extensions include:

- 4.1. Expanding the group of people who are part of the transformed system to people who meet DSS' eligibility criteria but who do not seek support from it. These people could, for example, be accessing MSD's Community Participation Services and Disability Allowance. There could also be a reaching out to disabled people who do not seek support from DSS, such as some Māori and people living in rural areas.
- 4.2. Seeking legislative change to support 'direct funding' arrangements. Under direct funding, disability support funding is paid directly into a person's nominated bank account, and they have full responsibility and accountability for the funds. Inland

Revenue, however, considers that there is uncertainty over whether payments made in this way are taxable income under the Income Tax Act 2007. Clarification of this issue is needed to reduce uncertainty and compliance costs for both Inland Revenue and disabled people.

- 4.3. Integrating complementary initiatives under the Disability Action Plan into the design of the transformed system, such as:
 - 4.3.1. 'A Good Start in Life', which aims to make all government support and services used by children with disabilities aged 0 to 8 and their parents simpler and more focused on what works for them;
 - 4.3.2. a Transitions Review, which aims to improve young people's transitions from education into work and further study.
- 4.4. Considering whether the single point of access can be extended to a wider range of services and support across government that disabled people access.

5. In the longer term (more than three years), consideration could be given to even broader scope expansions. For example, consideration could be given to including social housing and transport assistance for disabled people. Disabled people often report that difficulties with housing and transport have significant impacts on them. Consideration could also be given to including further groups of disabled people such as those with long-term conditions who currently receive support funded through DHBs.
6. These sorts of scope expansions would, however, require considerable policy work before Ministers could be asked to make decisions on them and are not part of the current proposal.

DESIGN CONCERNS

7. The Disability Community is expected to have particular concerns about two aspects of the design process.
 - 7.1. There is a view among some people in the disability community that there should be no purchasing guidelines, with people able to use their personal budget as they see fit. This appears to be based on a view that disability support seeks to cover the additional costs that a disabled person faces, so should be treated in a similar way to income support, which has almost no rules around how it can be spent.

It is, however, quite reasonable to put in place accountability arrangements for the sometimes rather substantial amounts (some well over \$100,000 a year) that disabled people are allocated. The approach taken in this paper is to adopt accountability arrangements that reflect the amount of a personal budget.
 - 7.2. NASCs are currently regarded by many people in the disability community as the source of much of what they consider is wrong with the disability support system. They will, therefore, want them playing little role in the transformed system. They will not want the independent facilitation to be associated with NASCs.

Many of the problems ascribed to NASCs stem from the overall design of the system (for example, officials determine the services that people are allocated, but NASCs are often seen as being at fault for allocating them). It is envisaged that the transformation will build on the existing infrastructure, but fundamentally re-think what it does and how it does it, as well as changing the brand. This re-thinking will extend to understanding the role and location of independent facilitation.

8. Changes arising from the fundamental re-thinking of NASCs are expected to include:
 - 8.1. A culture and paradigm shift so that they focus on supporting people to live a good life in the short, medium and long term, rather than responding to immediate needs.
 - 8.2. Changing processes so they support the culture change, such as:
 - 8.2.1. A single point of access for all disability support (rather than separate processes for different types of support)
 - 8.2.2. moving to supported self-assessment (rather than the current professional needs assessment)
 - 8.2.3. introducing processes to support early investment that improves longer-term outcomes processes and, where possible, preventing them needing long-term supports (rather than only responding to immediate need)
 - 8.2.4. clarifying the role of NASCs so that they complement and build on independent facilitators roles (rather than overlapping with them).
9. These changes would be complemented by other changes within the system, particularly the move to personal budgets that can be used flexibly. That change will mean that the funding that is allocated by NASCs can be used in ways that directly respond to a person's situation and what is best for them. That contrasts with the current situation in which NASCs responses are usually limited to the particular services that the Ministry has contracted for.

Appendix Five: Statement from the EGL Waikato leadership group

1. EGL Waikato is based on collaborative leadership. The Leadership Group is made up of disabled people, families, Māori, providers and government officials. This co-development approach has facilitated powerful and visionary leadership by disabled people, families, Māori and providers. The Group provides advice in a high trust environment in the Waikato, both as part of the demonstration and in championing and promoting the principles into the wider community. Transparency, trust and communication between Government officials and the Leadership Group has developed. Direction given by disabled people and families and whānau, at every level, has seen a shift in authority to where they have increased choice, control and ability to influence.
2. To ensure mutual and reciprocal communication so that all voices are heard, the Waikato Leadership group has identified the following key learnings: the value of the early investment in the development of local leadership; the importance of early and ongoing capacity development of disabled people and families and whānau; and the value in the disabled person, family and Māori forums, and the provider community of practice which inform, educate and build capacity.
3. We note that these many voices underpin the strong and effective Leadership Group, giving it clarity, confidence and an ability to hold authority with integrity. We strongly support the early development of local and regional leadership groups with a balance of representation similar to the Waikato model. We see these groups as: central to the change process; ensuring disabled people and families and whānau are able to effectively influence and monitor development; and enhancing networks and collaboration.

Disability Support System Transformation

Safeguarding Working Group Detailed Design @ 7/2/2018

Safeguarding Framework for the Prototype in MidCentral July 2018

SAFEGUARDING FRAMEWORK MidCentral Prototype

A safeguarding approach that is person directed that assists disabled people and whānau to make informed choices and have control over their supports to live the lives they choose, which includes taking risks and having equality of opportunity

... its primary function is concerned with promoting the human rights and wellbeing of the person, while helping to ensure they are not at risk of harm, abuse, neglect and exploitation

... by providing a continuum of responses and activity aimed at protecting, enhancing and promoting people's human rights, health, safety, culture and wellbeing AND enabling people to live the life they choose, free from harm, abuse, neglect, violence and exploitation.

The Safeguarding Framework is underpinned by:

The Enabling Good Life Principles The Treaty of Waitangi

The human rights and quality of life outcomes that safeguards aim to uphold are contained within the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**, and the **United Nations Convention on the Rights of the Child (UNCRC)**.

This includes the right to dignity and respect, to participation and full inclusion in the community, to equal recognition before law, access to justice and the right to live free from harm, abuse, neglect, violence and exploitation.

The Safeguarding Framework will support the:

**New Zealand Disability Strategy (NZDS) 2016 -2026
Disability Action Plan (DAP) 2014-2018**

**Whāia Te Ao Mārama 2017 - 2022: The Maori Disability Action Plan
Faiva Ora 2016–2021: National Pasifika Disability Plan**

Purpose

“To ensure safeguarding is integrated into every aspect of the new disability support system.

Safeguarding is integral to all aspects of the new system design and crosses all the system transformation elements and ways of working”.

The safeguarding framework for the new system

A Safeguarding Framework is required to ensure that the rights of disabled people are upheld, that helps empower and support disabled people and their whānau to have greater choice and control over their supports and their everyday lives and remain safe. It will ensure appropriate safeguards are in place to minimise the risk of people experiencing compromised human rights, and/or harm, abuse and neglect. The Framework establishes expectations for everyone in the disability support system, including providers, the workforce and wider community, to ensure the delivery of high quality supports. It will make it easier for disabled people and their whānau to understand what they can expect of providers and the workforce, and roles and responsibilities of the wider community for safeguarding disabled people.

A nationally consistent approach to safeguarding is essential to support the EGL vision. The Framework is designed to ensure that disabled people and whānau have the same protection, regardless of where they live in New Zealand.

A common understanding, connected and consistent approach

The Framework establishes a common understanding, connected and consistent approach to safeguarding across the new system. This approach places the disabled person at the centre, and provides a continuum of responses and activity that protect, enhance and promote disabled people’s human rights, health, safety and wellbeing and includes measures to build the capability of disabled people and whānau to make decisions about their lives, to take control and direct their support, as well as measures to prevent abuse and neglect, to recognise and respond when abuse and neglect is happening to reduce the risk of further harm.

SAFEGUARDING FRAMEWORK PRINCIPLES

In addition to the EGL principles, these safeguarding principles underpin the Framework:

1. **Human rights:** Disabled people's human rights are protected, promoted and applied – including rights as consumers
2. **Respect for individual identity and culture:** Protect and promote disabled people and their whānau's culture, sexual orientation, gender identity and spiritual identity, including their practices, values and beliefs
3. **Presumption of capacity:** Adults with disability are presumed to have the capacity to make and take part in decisions affecting all aspects of their life. Children and young people have the right to participate, in whatever capacity, in decisions that impact on their lives
4. **Proportionality and risk responsiveness:** Safeguards are proportionate to risks and to a person and their particular circumstances and should, as far as possible, minimise risk, with due consideration for an individual's dignity of risk (all people have freedom to make choices that involve a level of risk, to flourish and grow from trying)
5. **Empowerment:** Disabled people are able to make informed choices that may involve risk, in the same way as other citizens
6. **Prevention:** All disabled people have equal rights to protection from harm. Taking action before harm occurs. Safeguarding is everyone's responsibility
7. **Protection:** The safety and wellbeing of disabled people is paramount – support and representation for disabled people in greater need. There is zero tolerance of abuse and neglect
8. **Partnership:** Local solutions through individuals and providers working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse
9. **Accountability:** Accountability and transparency in safeguarding practice.

How will the safeguarding principles impact upon practice?

Practice will be:

- person-directed
- a strengths-based, whole-of-life holistic approach
- whānau-centred
- a whole community, collective approach to preventing, recognising and responding to abuse and neglect.

Background

The review of the regulatory framework for quality and safety in the health and disability system, focusing on disability support, commissioned by the Ministry of Health (the Ministry) in December 2014.

The recent review of safety regulation in disability support (the Review) identified significant gaps in safeguards (formal and informal supports and mechanisms), that promote, protect and enhance disabled people's human rights, decision-making, choice and control, safety and wellbeing, citizenship, and quality of life,

such as the right to make decisions about your own life and the lack of a shared understanding of supported decision making that enables people to exercise real choice and control in their lives.

The Review Working Group recommended changes to:

- strengthen safeguarding for disabled people, that enable disabled people to exercise choice and control over their supports and their everyday lives, and remain safe; and
- the regulatory framework under the Health and Disability Services (Safety) Act 2001.

The Review Working Group proposed establishing a single and nationally consistent monitoring system for all residential services, and that the system should be based on developmental evaluations, and that the regulatory framework should not focus solely on the concept of 'safety', but on 'safeguarding' - which aims to promote people's human rights and wellbeing and protect people from harm, abuse and neglect.

Scope

The System Transformation Safeguarding Working Group supports the recommendations of the Review Working Group; and has concentrated efforts on further developing the safeguarding spectrum of safeguards, developed by the Review Working Group (see Appendix A), by designing a safeguarding framework that is integrated across the new system and provides a continuum of responses and activity that:

- aim to protect, enhance and promote disabled people's human rights, health, safety and wellbeing, citizenship, and quality of life; and
- enable disabled people (includes children, young people, adults and vulnerable adults (see page 7 – vulnerable adults) to live the life they choose, free from harm, abuse, neglect, violence and exploitation.

The changes to the regulatory framework under the Health and Disability Services (Safety) Act 2001 and safeguarding legislation are beyond the scope and timeframes for the Safeguarding Working Group's detailed design for the Safeguarding Framework prototype for MidCentral. The Framework needs to be further developed to include regulation, contractual safeguards, quality and monitoring. Further development of the Framework needs to include (this is not an

exhaustive list), a disabled people and whānau controlled programme of developmental evaluation to monitor the new system (Lead - Evaluation Project), additional safeguards that protect and promote the rights of disabled people with behaviours that concern or challenge others and restrictive practices (Lead – High and Complex Framework Project) and additional safeguards that protect and promote the rights of disabled children. Oranga Tamariki has developed a framework to ensure that the experience of children and family informs the design of the future vulnerable children's system – this framework will inform the service design for the new system (Lead – Detailed Design of Interface with Government Systems – Care and Protection). The Working Group's focus was largely on disabled people aged 17 years and over, as there are many gaps that cause critical situations of risk for disabled adults, such as the current lack of legislation and systems and no statutory organisation in New Zealand that is responsible for safeguarding adults, in the same way that Oranga Tamariki protects children.

Safeguarding cuts across all of the system transformation projects for the new system. It is anticipated that the scope of the required work programme will become clear once the detailed design of the transformed disability support system has been developed. We expect the Framework to change substantially over time as disabled people and whānau increasingly tell us what elements of the new system really make a difference and we build people's experiences and lessons learned back into the system for continuous improvement. Disabled people and whānau will be actively involved in the on-going and re-design of the Framework.

A whole-of-government (early intervention) and community approach

A whole-of-government approach is required for safeguarding. The new system recognises the increased risk of violence, abuse and neglect that some disabled people experience and will address issues identified with current systems. Safeguarding is everyone's responsibility and cannot exist in isolation, however while the New Zealand Government can provide strong leadership, the task of stopping the abuse of disabled people also involves communities, organisations and individuals taking action and playing a part in preventing, detecting and reporting abuse and neglect. The inaccessibility of community safeguarding mechanisms means that concerns of disabled people and their whānau are often not responded to effectively. Safeguarding mechanisms that are available to all New Zealanders, such as the Police, may not respond adequately to concerns raised by disabled people or may be inaccessible and difficult for disabled people to use, for example police powers and the tools available under the Domestic Violence Act 1995 do not protect all victims of violence and abuse as they can only be issued in the context of a domestic relationship, which excludes all perpetrators, for example: paid care workers and staff. Services may be under-resourced or ill-equipped to effectively respond to disabled people, such as people may lack the skills, knowledge and confidence to enable disabled people to effectively use their services. The lack of appropriate response from general community safeguards often results in concerns having to be addressed through disability specific services, rather than through the ordinary mechanisms.

Safeguarding vulnerable adults from harm, abuse and neglect

No statutory organisation in New Zealand is responsible for safeguarding adults, in the same way that the Ministry for Vulnerable Children, Oranga Tamariki protects children. Safeguarding adults is the responsibility of all agencies and organisations and cannot exist in isolation. While the New Zealand Government

can provide strong leadership, the task of stopping the abuse of disabled people also involves communities, organisations and individuals taking action and playing a part in preventing, detecting and reporting abuse and neglect.

A whole-of-government approach that places disabled people at the centre and enables individuals and organisations to work together as part of an integrated safety response to safeguarding adults will lead to the development of consistent, high quality safeguarding adults work across the country.

A systematic approach to the collection of data and statistics on the prevalence and nature of reported cases of abuse of disabled people will inform policy, services and future research to support a whole-of-government approach to safeguarding disabled people. Data collected should include the type of abuse that is experienced, the age, ethnicity, gender of the person, whether they are a victim, or perpetrator of any form of abuse or neglect, which includes family violence and sexual violence and should align with existing cross-government initiatives and work programmes, which includes: (including but not limited to)

- Elder Abuse Response Service (EARS)
- New Zealand Carers' Strategy Action Plan 2014 – 2018
- New Zealand Police Family Harm Integrated Safety Response (ISR), and Whangaia Nga Pa Harakeke
- Ministerial Family Violence and Sexual Violence Programme
- ACC Sensitive Claims scheme and Sexual Violence Prevention / Disability Project
- Better Public Services: Vulnerable children
- New Zealand Disability Strategy 2016-2026
- Disability Action Plan 2014-2018
- Whāia Te Ao Mārama 2017-2022: The Maori Disability Action Plan
- Faiva Ora 2016–2021: National Pasifika Disability Plan
- Older Adults and Vulnerable Adults Abuse and Neglect, Waitemata DHB Policy (2016)
- Disability Rights Commissioner awareness raising campaign
- Human Rights Commission – Bullying in schools programme and the Access Alliance delegation - Access Matters Campaign.

Abuse, neglect, violence and exploitation of disabled people

Research has found that compared to the general population disabled people experience an increased level of abuse, neglect, and exploitation; adults and children with psychosocial or learning (intellectual) disabilities are among the most vulnerable, with nearly four times the risk of experiencing violence; and disabled children are three to four times more likely to be abused and neglected than non-disabled children. Disabled people are systemically and specifically vulnerable to abuse by people they know and by those who provide care for them (Hague et al 2008).

There are disabled people for whom the current systems to prevent and address abuse are not working. The people who frequently slip through the gaps, whose needs are not met, are often disabled people with greater care and support needs. Safeguarding is of particular importance to disabled people who, because of their care and/or support needs, for various reasons are not able to remove themselves from a risk of serious harm and keep themselves safe.

The Crimes Amendment Act, 2011 expands the legal duties of those caring for children and includes new provisions for protecting children and vulnerable adults.

A vulnerable adult is defined in the Crimes Amendment Act, 2011 as:

“a person unable, by reason of detention, age, sickness, mental impairment, or any other cause, to withdraw himself or herself from the care or charge of another person”.

Who is a vulnerable adult?

Any person, of any age, who is experiencing any form of abuse, is vulnerable. We recognise that the term “vulnerable adult” is contentious. No person is inherently vulnerable. Abuse is about perpetrators - perpetrators are individuals who have different levels of power over people’s lives and who use their power to abuse or neglect others. Any person can become at risk of violence, abuse and neglect when there is no system in place to enable that person to escape violence and/or abuse or keep themselves safe. They may or may not fit the Crimes Act definition of a vulnerable adult.

While “vulnerable adults” can be considered a homogenous group in legislation, a person is not ‘vulnerable /at risk’ just because they have a disability. In other words a person’s disability should not lead to the automatic assumption that the individual is vulnerable or at risk.

SAFEGUARDING FRAMEWORK THREE FOCUS AREAS

The Framework consists of elements within three focus areas that are targeted at disabled people, whānau, government agencies, the workforce, providers and the wider community:

1. **Being aware**
2. **Being heard**
3. **Being responsive**

BEING AWARE

The importance of a common understanding and a consistent approach to safeguarding across the new disability support system, and the community, that is responsive and consistent with the United Nations Convention on the Rights of Persons with Disabilities

BEING HEARD

Ensuring that *everyone* has a voice and can speak up if they are not living the life they choose and/or they don't feel safe. For example being at risk of experiencing compromised human rights harm, abuse, neglect, violence and exploitation

BEING RESPONSIVE

Building the capacity of the new disability support system and the strength and capacity of individuals and organisations to ensure a person-directed, whānau-centred and whole community approach to safeguarding a good life; and safeguarding disabled people from harm, abuse, neglect, violence and exploitation.

Across each of the focus areas, the developmental, preventative and responsive components are designed to interact to create a framework that ensures that the rights of disabled people are upheld and disabled people and their whānau are empowered and supported to exercise real choice and control in the new system and remain safe. There are naturally some overlaps between the elements within each of the three focus areas.

SAFEKEEPING FRAMEWORK SPECTRUM OF SAFEGUARDS

What is safeguarding?

The principles for safeguarding require far more than consideration of safety issues. Safeguards will enable people to live the life they choose and remain safe and not restrict people from taking risks and learning through living life - having equality of opportunity and equity of outcomes.

Safeguarding is a range of activities and responses aimed at protecting, enhancing and promoting people's health, wellbeing and human rights AND enabling people to live the life they choose, free from harm, abuse, exploitation, violence and neglect. Safeguarding seeks to ensure safety and wellbeing while supporting and empowering disabled people to exercise choice and control over their everyday lives to have a good quality life, to be an active and equal citizen, and to be able to reach their full potential.

Safeguarding is of particular importance to people who are significantly dependent on support, who are not always able to speak up for themselves and, for various reasons, are not able to remove themselves from a risk of serious harm (to keep themselves safe). The extent of what safeguards need to be considered is determined by the level of vulnerability of an individual and the risk of the person experiencing compromised human rights and outcomes, harm, abuse and neglect this requires having an in-depth knowledge and understanding of an individual and their particular circumstances and situation. Safeguards are considered and determined in relation to a person's: ongoing everyday life; a particular decision choice or situation.

The Framework is designed to be risk-responsive and recognises that risk is experienced differently by individuals (what is risky for one person may not be risky for another). Disabled people should be involved, as far as is possible to the extent of their capacity, in determining their own safeguards. To support this people will have the support they need to build their capacity and capability to exercise choice and control over their supports and their everyday lives and take control of their own safety. Safeguarding vulnerable adults from harm, abuse and neglect requires a whole community and multi-disciplinary approach and new way of working together to create safety for adults with greater needs for care and support who are at risk of and/or experiencing any form of abuse and because of their needs, are unable to remove themselves from unsafe situations.

What are safeguards?

Safeguards are informal and formal supports and mechanisms that protect, enhance and promote people's human rights, health, safety and wellbeing, decision making, choice and control, citizenship and quality of life. Safeguards include natural safeguards such as personal relationships and community connections, and formal safeguards such as service standards, regulations and quality assurance systems that apply to providers. Ensuring that supports are safe and of high quality is critical to the quality of life of disabled people and whānau. Safeguards are important in enabling a good life, minimising risk, risk enablement, preventing abuse and neglect and improving quality of service provision and safe environments.

SAFEGUARDING FRAMEWORK SPECTRUM OF SAFEGUARDS

PERSONAL SAFEGUARDS

Personal safeguards focus on building capability, skills, knowledge, opportunities for learning through living life, communication, self-advocacy and decision-making, self-determination, financial security, personal worth, identity and security of home. It includes all the things that focus on building up people's capability to live an everyday life and enabling people to live the life they choose, free from harm, abuse and neglect.

RELATIONSHIP-BASED SAFEGUARDS

Relationship-based safeguards focus on strengthening existing relationships and networks and building up new relationships with people who have an ongoing relationship with the disabled person and whānau and care about their wellbeing, who can (when necessary) support them to communicate with others and have their voice and self-determination respected.

COMMUNITY SAFEGUARDS

Community safeguards include people in the community and all the things that everyone can use to respond to the risks they face in the place they live, their wider community and with the people with whom they interact. It includes building capacity and capability of the community and increasing people's community connections and using the safeguarding mechanisms available to the community generally (such as Community Law Centres, Family Violence Services and Police).

DISABILITY AND COMMUNITY SERVICES SAFEGUARDS

Disability and community services safeguards include putting in place mechanisms (such as legislation, regulations, funding and purchasing arrangements, and monitoring arrangements) to protect and promote people's human rights against the risks that arise within the disability support system and wider community. It includes disability services, mainstream services and community organisations having the knowledge, skills and confidence to effectively include and be responsive to disabled people, and preventing, recognising and responding to abuse and neglect of disabled people.

SYSTEM SAFEGUARDS

Broader system safeguards include the things that focus on promoting a person's human rights, health, safety and wellbeing and ability to participate in the community generally and preventing and protecting from harm, abuse and neglect, through legislation, regulations, policy and other mechanisms that have a broader focus than disability support. It includes legislation, regulations, policy and mechanisms for disability services and the wider community, that have a safeguarding function.

COMPONENTS OF THE SAFEGUARDING FRAMEWORK

Underpinning foundations: The Enabling Good Life Principles, The Treaty of Waitangi, United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the United Nations Convention on the Rights of the Child (UNCRC).

BEING AWARE Developmental components	BEING HEARD Preventative components	BEING RESPONSIVE Responsive and corrective components
<p>Building capability of disabled people and whānau Supporting and empowering people to build knowledge, skills and confidence to exercise choice and control and remain safe by providing:</p> <ul style="list-style-type: none"> • quality and accessible information, education and training; and • ongoing opportunities and support for building capability and learning through living life 	<p>Advocacy services</p> <ul style="list-style-type: none"> • Formal individual and systemic advocacy services through the new system • Ensuring easy access to an independent advocate, when needed • An independent statutory body in New Zealand, that takes on the roles and functions similar to that of the Office of the Public Advocate (OPA) in Australia 	<p>Whole community response to preventing, detecting and reporting neglect and abuse of disabled people</p> <ul style="list-style-type: none"> • Local leadership, vision and strategic direction • A whole community approach to preventing, detecting and reporting neglect and abuse of disabled people • A common understanding and consistent approach to safeguarding vulnerable adults from harm, abuse and neglect • A code of conduct for workers • The EGL connector/tuhono and network builder are highly skilled in safeguarding, and have an excellent analysis of the dynamics of family violence, sexual violence and abuse and neglect.
<p>Supporting decision making and communicating decisions</p> <ul style="list-style-type: none"> • Promoting a common understanding, connected and consistent approach of supported decision making to ensure that disabled people, who need support to make decisions, can make their own decisions with the support that is right for them. • Ensuring people are aware of their right to make their own decisions about their lives, and the supports available for making informed choices and decisions • A positive risk taking policy 	<p>Supporting decision making and communicating decisions</p> <ul style="list-style-type: none"> • Ensuring disabled people who need support to make decisions have people they trust and the support they need to make their own decisions about their life • Providing a range of ways, tools, resources and supports to ensure people have a voice and are heard • Providing a range of ways and channels for people to make a complaint or report concerns or actual abuse and neglect • 	<p>A comprehensive framework of standards for safeguarding vulnerable adults from harm, abuse and neglect</p> <ul style="list-style-type: none"> • The establishment of a local Safeguarding Vulnerable Adults from Abuse (SAFA) team • A multi-disciplinary approach to safeguarding vulnerable adults from harm, abuse and neglect • Integrated safety response (ISR) model
<p>Building a welcoming, inclusive and responsive community</p>	<p>Building and strengthening natural relationships and networks</p>	<p>Positive risk taking policy to safeguard against system level risk aversion implementing policies</p>

<ul style="list-style-type: none"> • Growing communities and strengthening community connections so that communities are welcoming and inclusive • The role of whānau, carers and other support people is to be recognised, respected and resourced. 	<ul style="list-style-type: none"> • Supporting disabled people to strengthen family and other support networks and participate fully in their community • Ensuring that disabled people have unpaid people in their lives who have an enduring commitment and care about them, have the support they want to build healthy relationships and networks and have access to an independent advocate if needed 	<p>and/or operational procedures that reduce choice and risk taking</p> <p>Vulnerability and risk assessment to protect people from experiencing compromised human rights and outcomes, and the risk of harm, abuse or neglect</p>
<p>Building capability and capacity of government, the workforce, providers and the wider community</p> <ul style="list-style-type: none"> • Build the capability and capacity of whānau • Build skilled and confident whānau • Building a skilled and safe workforce • Promoting a common understanding, connected and consistent approach to safeguarding disabled people • Ensuring disability services, mainstream and specialist violence prevention services are responsive to disabled people who are at risk of or experiencing abuse and neglect (includes family harm and sexual harm) • Align with existing cross-government initiatives and work programmes 	<p>Making a complaint/Reporting abuse and neglect</p> <ul style="list-style-type: none"> • Providing quality information about rights, providers (what they should expect), the complaints process and how to make a complaint • An independent complaints system for making complaints and ensuring that the rights of disabled people are upheld • Safeguarding vulnerable adults from abuse and neglect team and integrated safety response for coordinating a multi-disciplinary approach to concerns or actual abuse and neglect of vulnerable adults • Disability abuse and neglect reporting options and community coordinated response 	<p>Responding to complaints, serious incidents, and reports of concerns or actual abuse and neglect</p> <ul style="list-style-type: none"> • No wrong door- disabled people, whānau, carers, advocates, and the wider community are able to make complaints and report abuse • Third party reporting when people are unable (ensuring people have the support they need to make their own decisions about their lives) or unwilling to make a complaint • Integrated safety response for reports of abuse and neglect of vulnerable adults • Corrective measures for when things go wrong • Mediation and the resolution of complaints • Investigating alleged breaches of the code of conduct

<p>Understanding abuse, neglect, violence and exploitation of disabled people</p> <ul style="list-style-type: none"> • Promoting a common understanding, connected and consistent approach to safeguarding disabled people from abuse and neglect • Zero tolerance to abuse: physical/ emotional/financial • Providing quality and accessible information, education and training for disabled people and whānau so that they can keep themselves safe, and know who and how to tell and where to go for help and support. • Individual and collective roles and responsibilities in preventing, recognising and responding to abuse and neglect of disabled people • Support social and disability campaigns that promote disability awareness, abuse is not ok, and affirms action to prevent abuse and neglect of disabled people. 	<p>Vetting and Screening workers</p> <ul style="list-style-type: none"> • Providing quality information, education and training about recruitment and becoming an employer • Risk-based worker screening is available through the system for employees/ workers (or prospective employees/workers) • Comprehensive risk assessment 	<p>Monitoring and evaluation</p> <ul style="list-style-type: none"> • A Developmental Evaluation (DE) approach will be used for the monitoring and evaluation • A DE approach supports the 'Try-Learn-Adjust' approach being adopted for the MidCentral prototype • Evaluators will be independent • Evaluators will have a lived experience of disability including whānau to ensure the view of people with learning disability are reflected in the evaluation • Evaluators will and have an excellent analysis of power and control and the dynamics of abuse of disabled people. <p>A whole-of-government approach to safeguarding disabled people, including children and vulnerable adults from abuse and neglect</p> <ul style="list-style-type: none"> • Systematic approach to the collection of data and statistics on the prevalence and nature of reported cases of abuse of disabled people • Safeguarding framework to align with existing cross-government initiatives and work programmes
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See next pages for detailed design

Being aware	Being heard	Being responsive
<p>Quality information, education and training</p> <p>Providing access to quality information and opportunities for continued learning by providing, education and training in a range of formats and channels to support and empower disabled people and whānau to exercise choice and control and remain safe, by:</p> <ul style="list-style-type: none"> • building disabled people and whānau's knowledge, confidence and skills; and • enhancing disabled people's ability to safeguard themselves (keep yourself safe) • enhancing whānau's ability to safeguard their family member. <p>Information, education and training to build knowledge, confidence and skills including but not limited to:</p> <ul style="list-style-type: none"> • understanding and asserting rights and responsibilities • self-advocacy and speaking up • leadership skills • decision-making skills • goal setting skills • managing money • communication and negotiation skills • recognising and responding to abuse • recognising good and bad supports 	<p>Access to independent and systemic advocacy</p> <p>Access to independent and systemic advocacy is an essential component of the Framework. There will be a range of advocacy supports available in the new system.</p> <p>Funding Advocacy Services</p> <p>The Working Groups identified the need for advocacy services to be funded so that they are available and easy to access by disabled people and whānau. One option is that the New Zealand Government funds advocacy services through the new system. This includes capability building funding for disabled people and whānau to build their skills and confidence to exercise choice and control.</p> <p>The Government could fund advocacy services through a national disability advocacy programme. This would be available to all disabled people. A national disability advocacy programme could provide a coordinated approach that enables disabled people to have easy access to advocacy support provided by disability advocacy services across the country.</p> <p>Independent advocacy</p>	<p>Whole community response to preventing, detecting and reporting neglect and abuse of disabled people</p> <p>An effective safeguarding system requires everyone to be clear about their roles and responsibilities. It is essential that there is coherent local leadership, vision and strategic direction, where everyone understands their roles and responsibilities in safeguarding disabled people, children and vulnerable adults from harm, abuse and neglect.</p> <p>Focus on prevention</p> <p>Recognising and responding to any problems early to minimise risk of harm, and identifying when a person is at risk of experiencing compromised human rights and abuse, exploitation or neglect, and is crucial when people do not or cannot complain, such as a child or vulnerable adult who is not verbal and/or cannot remove themselves from an unsafe situation.</p> <p>A proactive approach is taken when assisting a person to think about what they want out of their lives, i.e. person centred planning, when a person identifies their goals – how a person wants to live their live and what is required to make that possible – 'good planning leading to positive change in people's lives and supports'. Safeguards and safeguarding activities specific to a person's goals</p>

<ul style="list-style-type: none"> • how to make a complaint/how to report abuse • how to keep yourself safe: physical/ emotional/financial safety • understanding abuse, how to tell and who to tell • safeguards and safeguarding activities specific to a person's goals, discussed with the connector/tuhono and /or other people who know the person well • identifying and managing risks • building healthy relationships and making friends • sexuality • understanding the system, planning process and types of support available • recruiting and managing staff • employer/employee employment rights • responsibilities as an employer • network building options and tools. 	<p>The Working Group identified the ongoing need for an independent advocacy service to protect, promote and enhance the rights of disabled people.</p> <p>For disabled people who have no unpaid people in their lives who have an enduring commitment and care about them, safeguards will be put in place to build a network around the person; and appoint an independent advocate so that everyone has people in their life who care for them and have ongoing contact/relationship with them.</p> <p>Easy access to an independent advocate, when needed, ensures that every disabled person has someone to support them to speak up, that is independent of providers and the system, and can address their individual issues and broader system issues that affect disabled people in general.</p>	<p>are discussed with the connector/tuhono and /or other people who know the person well.</p> <p>Long term planning - Identify and flagging transition points 'life turning points'</p> <p>Connectors/tuhono have the skills and tools they need to assist them to identify transition points and for long time planning, and can assist and support people to think well enough in advance, to consider 'life turning points'.</p> <p>Long term planning will ensure that any support that a disabled person may want and need is considered and planned for, insofar as it is practical and possible using good practice and proactive planning principles, to avoid crisis situations, for example a child moving from child services to adult's services, a person who had ageing parents and or parents/carers who are struggling to cope with their caring role.</p> <p>Helping people to think ahead, to know what things are possible and make life and leadership choices.</p>
<p>Funding: Disabled people and whānau capability</p> <p>"THINK-PLAN-DO" Positive risk taking policy</p> <p>The Framework plays a central role in safeguarding the human rights of disabled people. This includes 'walking alongside people' who want or need support to assist them to think</p>	<p>“...what is needed is someone who has a mandate to act”</p> <p>Independent statutory body</p> <p>The Working Groups identified the need to establish an independent statutory body that takes on the roles and functions similar to that of the Office of the Public Advocate (OPA) in Australia. The independent body would aim to</p>	<p>The system acts as the champion within communities for safeguarding disabled people from harm, abuse and neglect. The establishment of a local Safeguarding Vulnerable Adults from Abuse (SAFA) team would take on the function of developing:</p> <ul style="list-style-type: none"> • local leadership, vision and strategic direction

<p>about what they want out of their lives and what they need to get there.</p> <p>“THINK-PLAN-DO” Building confidence and enhancing ability of disabled people to think about what they want out of their lives and what they need to get there.</p>	<p>uphold the rights and interests of people with a disability and work to eliminate abuse, neglect and exploitation.</p> <p>http://www.publicadvocate.vic.gov.au/</p>	<ul style="list-style-type: none"> • a common understanding and consistent approach to safeguarding vulnerable adults from harm, abuse and neglect • a whole community approach to preventing, detecting and reporting neglect and abuse of disabled people.
<p>For some disabled people, who may need more support to get to where they want to be, this involves identifying levels of vulnerability and risk and assisting people to think about what risks are acceptable, how to minimise and manage the risk.</p> <p>Risks can be the risk of:</p> <ul style="list-style-type: none"> • a person experiencing compromised human rights, e.g. not having the support they need to make decisions, and/or • the risk of harm, abuse or neglect. <p>IF PEOPLE ARE AT RISK:</p> <p>“What needs to change to make you safe and regain control”?</p> <p>“How can I help make that happen”?</p>	<p>In addition there was an identified need for the new system to make provisions for a Public Guardian to be independently appointed and monitored on a regular basis – supported decision making is encouraged, but when a person's will and preference is not known and where supports have not led to a decision a nominated person will be appointed.</p> <p>NETWORK BUILDING</p> <p>The Network Building Options and Tools Working Group identified and designed a range of tools (including but not limited to) to support disabled people to strengthen and build networks and make new friends and form healthy relationships.</p> <p>Network Building Tool – A tool that connects people/places/interests</p> <p>The Network Building Tool will be available on the Information Hub.</p>	<p>A whole community, collective approach</p> <p>Fragmented services make it hard for people to achieve safety. Services that are integrated can provide the holistic support that is needed to create safety for people who have greater needs for care and support and meet their individual and cultural needs. The Network Builder and the Government Connector will support services to work together collectively as part of an integrated system to safeguard disabled people, including children and vulnerable adults, from abuse and neglect.</p> <p>Multi-disciplinary approach to safeguarding vulnerable adults from harm, abuse and neglect</p> <p>Establish a multi-disciplinary approach, which involves various strands of intervention and cross-agency collaboration, in recognition that abuse and neglect are complicated issues and that no single method of response is effective.</p>
<p>Risk assessment</p> <p>Risk assessment is a person-centred, holistic assessment of the risks a person faces, which</p>	<p>Who is it for?</p> <ul style="list-style-type: none"> • Disabled people • Family/ Whānau • Carers/Supporters 	

<p>means getting to know the person, their goals and aspirations such as their culture, history and support needs, and their level of vulnerability, such as their ability to self-direct and control their own lives and keep themselves safe.</p> <p>Understanding and identifying a person's level of vulnerability and risk is a prerequisite in determining safeguards.</p> <p>Formal risk assessment can take place when the connector/tuhono is assisting a person to think about what they want out of their lives and what they need to get there.</p> <p>Questions will be developed to assist the person to consider any risks and how the risk can be managed to enable them to do the things they want and in doing so remain safe (taking risks and learning and growing from trying), such as questions to find out the person's understanding of their own safety and how they would keep themselves safe and identifying existing support and any additional safeguards that could be put in place.</p> <p>Positive risk taking policy</p> <p>A positive risk taking policy and risk enablement tools will be developed, as part of the safeguarding tool kit, to safeguard against system level risk aversion implementing policies and/or operational procedures that reduce choice and risk taking. Values based training will be developed and delivered, as part of the safeguarding training for the EGL team and</p>	<ul style="list-style-type: none"> Advocates Connector/Tuhono Network Facilitator Anyone taking an interest in improving the lives of disabled people. <p>The Tool contains information and pathways that connect people/places/interests, such as:</p> <p>Network options and tools -</p> <ul style="list-style-type: none"> Examples of different network What support networks look like for different cultures Tools and guidance for growing and developing networks Someone who can help disabled people/ whānau to connect and build their networks Good news stories and 'stories for learning from' including stories which are 'works/lives in progress. <p>Connecting people/interests -</p> <ul style="list-style-type: none"> Family/ whānau information to connect people with other families and build family networks People who have the same interests, hobbies and activities What's going on for people the same age? Peer networks Volunteering/ job and training opportunities <p>Connecting people to places and creating opportunities to create new friendships and relationships</p> <ul style="list-style-type: none"> Events/forums/workshops/festivals/clubs 	<p>No statutory organisation in New Zealand is responsible for safeguarding adults, in the same way that the Ministry for Vulnerable Children, Oranga Tamariki protects children.</p> <p>The working group identified the need for:</p> <ul style="list-style-type: none"> A comprehensive framework for safeguarding vulnerable adults from harm, abuse and neglect Safeguarding Adults legislation A multi-disciplinary approach to safeguarding vulnerable adults from harm, abuse and neglect An integrated safety response to family violence and safeguarding adults A social investment approach for safeguarding vulnerable adults Systemic data collection of abuse and neglect of disabled people (includes children, young people, adults and older adults) - a strategy to collect disability data about abuse and neglect (includes family violence and sexual violence) to inform social investment approach Building capability of the workforce to prevent, recognise and respond to abuse and neglect of disabled people (includes children, young people, adults and older adults) Building provider capacity to be responsive and inclusive A code of conduct for all workers/providers Safeguarding adults from abuse and neglect standards for everyone who has a responsibility
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<p>wider community, to ensure the tools are used effectively.</p>	<p>Vulnerability/Risk Assessment Tool</p> <p>Discussing possibilities and developing plans is an opportunity for an open discussion about actual and potential risks and provides the opportunity to identify safeguards and develop risk enablement strategies.</p> <p>A structured way of determining a person's level of vulnerability and their risk of experiencing compromised human rights and outcomes, and the risk of harm, abuse or neglect.</p> <p>The Vulnerability/Risk Assessment Tool can be used by the connector/ tuhono, to assist the disabled person, their whānau and network to identify potential risks and provides the opportunity to identify safeguards and develop risk enablement strategies.</p> <p>Person-centred safeguards that are effective will support the person to take acceptable risks, rather than prevent people from doing what they want to do, which involves taking risks and learning from trying. This approach recognises that risk is not the same for everyone. Regular review provides opportunity to reassess risk and the safeguards for managing risk.</p>	<ul style="list-style-type: none"> • Local Marae, Churches and other places where people congregate • On-line communities <p>For an example of current good practice see: http://kudoz.ca/</p> <p>See Appendix D for list of Network Building Options and Tools identified by the Working Group.</p> <p>The Network Facilitator</p> <p>A Network Facilitator was identified by the Working Group as being a crucial role to supporting and empowering a person to exercise real choice and control. The Network Facilitator could be a paid position to drive, coordinate, facilitate and sustain the network and supporting a person's natural relationships where they exist into a more formalised network of support around the person.</p> <p>Network facilitator – skills and attributes (including but not limited to):</p> <ul style="list-style-type: none"> • Teach/educate • Highly skilled • Extensive local knowledge and strong local networks • Relationship builder • Excellent communicator • Conflict management/difficult conversations • Negotiation • Facilitation • Trustworthy 	<p>for safeguarding adults from harm, abuse and neglect</p> <ul style="list-style-type: none"> • Providing emergency accommodation /safe house and pathways, such as women's refuge or respite care • Providing accessible trauma/recovery support and programmes • Accessible keeping safe programmes and stopping violence programmes that meet individual's needs, for example safety programmes funded under Domestic Violence Act 1995, government contracts for people with cognitive impairments that have the information delivered to them in a way that they understand. <p>An overarching safeguarding vulnerable adult's inter-agency strategy is an effective way to develop an effective multi-disciplinary approach in New Zealand. Such an approach would bring together the disability sector with the violence prevention sector and could foster closer inter-agency collaboration with police, health, women's refuge and specialist violence prevention services as well as closer involvement with disabled people's organisations (DPOs).</p> <p>Establishing a local safeguarding adult from abuse (SAFA) team for MidCentral prototype. SAFA would be a multi-agency partnership, made up of a wide range of statutory agencies and voluntary organisations working together and sharing</p>
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***"If you don't take risks
you don't learn from trying"***

<p>For example, risk assessment may identify that the person needs more support to make informed choices – strategies can be put in place to provide access to specific supports to build capability to make informed choices, such as self-advocacy skills, goal setting and decision making skills programmes, peer support and mentoring programmes.</p> <p>Additional personal safeguards focus on:</p> <ul style="list-style-type: none"> • Support for decision making and communicating decisions Access to preferred communication mode and support and supported decision making model • Health and wellbeing Ongoing opportunities to promote and enhance health, physical fitness, emotional and spiritual wellbeing • Identity and self-worth Continued opportunities and support for learning through living life - to flourish and grow through experience • Financial security and independence Opportunities and support for employment, access to money, managing money and financial planning • Independence and self determination Easy access to equipment and communication aids • Security of home Choice and support for where you want to live and who you live with, such as home 	<ul style="list-style-type: none"> • Genuine interest • Purposeful intent to create opportunities • Flexible • Tenacious • Transferable skills • Creative <p>Networks require funding, in addition to the Network Facilitator, as the cost to the disabled person can prevent them from inviting people into their lives, and to provide for and to create a welcoming and valuing atmosphere.</p> <p>Network Facilitation Agency and Network Facilitator</p> <p>The Network Building Options Working Group identified the need for an agency (not a service) that actively recruits and employs skilled network facilitators that can provide a range of skilled and trained network builders for people to engage/employ, that match/meet people's individual interests, needs and aspirations.</p> <p>Networks (unpaid people in people's lives) can provide effective safeguarding. However, further safeguards must be considered, to promote the human rights and wellbeing of the person and to protect from harm, especially when there are concerns that these relationships are:</p> <ul style="list-style-type: none"> • placing the person at risk; and • not acting in the person's best interests. <p>Strengthening existing natural relationships</p>	<p>information to better address the issue. Their aim is at facilitating joint working in adult protection and their responsibilities would include:</p> <ul style="list-style-type: none"> • informing, influencing and inspiring the direction of future practice and policy • promoting human rights , such as the right to make decisions • developing multi-agency policies and procedures and supporting key stakeholders to put them in place so that cross-agency responses take place • creating new pathways for disabled people for whom the current system is not working and mainstream services are not effective • developing and enhancing referral pathways and networks to facilitate appropriate and tailored responses • developing pathways so that disability and mental health services are part of the integrated approach to safeguarding adults from harm, abuse and neglect • developing safeguarding adults standards (monitoring and evaluation) support the delivery of safe and high quality support/services for everyone who has safeguarding adults from abuse and neglect responsibilities • coordinating an integrated safety response - of multiple types of services that are connected being available to an individual • identifying and developing safeguarding champions/leads across agencies • conducting serious case reviews
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<p>ownership, lease in own name, and choice of 'flat mates'</p> <ul style="list-style-type: none"> • Network building <p>Opportunities and support to strengthen family and other natural supports, build new relationships and develop networks.</p>	<p>Natural (informal) relationships can:</p>	<ul style="list-style-type: none"> • providing advice and consultancy • providing information, resources, education and accredited training – safeguarding adults from abuse • sharing knowledge about what works, what's new • identifying good practice and developing practice. • research and evaluation.
<p>Capability building strategies</p> <p>The availability and coordination of capability and capacity building activities and safeguards are easily accessible through system information channels and funding arrangements. For example, the connector /tuhono can assist people to put together individualised capability building strategies to increase knowledge and skills and create opportunities for 'learning through living life'.</p> <p>'Safeguarding for Success' Programme</p> <p>Disabled people, whānau, carers and advocates can attend a programme called 'Safeguarding for Success'. The Programme is designed to create an opportunity for people to come together and connect with their peers, where they can receive quality information and experience 'taster' sessions about programmes, courses, mentoring, peer support groups and self-advocacy, listen to stories of success from peers to help people to make informed choices about their lives, and an opportunity to discuss options with a connector/ tuhono, and put together a Safeguarding for Success package. The package can include an assortment of</p>	<p>Family/whanua, friends, carers and community connections, who know the person well, can support them to make informed choices and decisions to live their lives, they see the person regularly enough to notice if something is wrong, can speak up if there are concerns and can support the person to speak up if something goes wrong, if things change or if they don't feel safe.</p> <p>Whānau-centred practice</p> <p>Recognises the important role of family and whānau and promotes positive relationships between the disabled person, and whānau; the central role that family and whānau play in individual wellbeing, which can be threatened if safeguards for an individual are considered and determined independently of the context of the whānau.</p> <p>Recognising that a disabled person's close relationships and relationships with professionals can also be a source of abuse</p>	<p>The local safeguarding adult from abuse (SAFA) team for MidCentral prototype may build on the prototype previously established at Waitemata District, Auckland where utilising the Waitemata DHB policy (2016), the Waitemata DHB, SAFA Collective and the Police established a multi-agency multi-disciplinary process for a safeguarding adults from abuse utilising Vulnerable Adult Response Group (VARG) and Integrated Safety Response (ISR) models.</p> <p>The Network Builder could take on the role of the Safeguarding Coordinator and would be part of the SAFA team, however in the Waitemata prototype a specialist SAFA Safeguarding Coordinator role was identified as crucial for supporting the coordination of the VARG, advocating for the need for an integrated safety response to safeguard vulnerable adults from harm, abuse and neglect. The Safeguarding coordinator is highly skilled and will have an excellent analysis of the dynamics of</p>

<p>activities that will assist people to build their knowledge, confidence and skills to enable their good life vision.</p> <p>Safeguarding for Success brings together individuals, mainstream services and specialist services and the wider community and works towards building a whole community approach to working with and for disabled people.</p> <p>Safeguarding mobile ‘roadshow’</p> <p>The safeguarding roadshow provides an opportunity for anyone to attend regular local workshops that take place in their community, that aim to support, capability building, networking building opportunity, information sharing, inclusive communities and a whole community approach and common understanding to safeguarding.</p> <p>Disabled people and their whānau decide what the content of each roadshow will be, to ensure that it is responsive to local issues and needs.</p> <p>Tools and resources</p> <p>EGL tools and resources [My good life tool kit], will assist disabled people and whānau to think about what they want out of their lives “<i>to imagine the possibilities</i>” and what they need to get there.</p> <p>The Safeguarding Tool Kit.</p> <p>Safeguarding information is contained in the Safeguarding tool kit. The tool kit is a useful</p>	<p>Capability building activities, regular opportunities to check-in to see how things are going, advocacy supports and monitoring arrangements are safeguarding mechanisms that will act as preventative measures to safeguard people from abuse and neglect.</p> <p>A common understanding and consistent approach to safeguarding, a highly skilled EGL team, who can identify levels of vulnerability and risk of harm, abuse and neglect (see roles), and a whole community approach to preventing, detecting and reporting abuse and neglect of disabled people will enable disabled people to ‘have a voice’, be heard, to access services and supports that enable them to live a life free from abuse or neglect, and ensure that the community has the knowledge, skills and confidence to be responsive to disabled people who seek support from their services.</p> <p>Supporting the safeguarding role of natural relationships</p> <p>The role of whānau, carers and other support people is to be recognised, respected and resourced:</p> <ol style="list-style-type: none"> 1. <i>RECOGNISE</i> My role and contribution 2. <i>RESPECT</i> Me, my worth, lived experience, skills and expertise 3. <i>RESOURCE</i> Support me to be strong and resilient in my safeguarding role. 	<p>family violence and abuse of disabled people and vulnerable adults.</p> <p>Vulnerable Adults Response Group (VARG)</p> <p>Abuse of vulnerable adults can be complex and multi-layered, and therefore bringing together the person, or a representative for the person when they are unable to be part of the group, people that are in the persons’ life that know them well, different services and providers to assess risk and develop a multi-agency safeguarding plan can help lead to the most effective response to the individual and whānau.</p> <p>Integrated safety response (ISR) model</p> <p>VARGs involve people from the health sector joining with other key people, such as whānau, carers and an advocate, and organisations, such as police, WINZ, Hospice, GP, women’s refuge, to discuss issues facing the vulnerable adult and ensuring that they foster an environment that supports the individual and responds effectively to cases.</p> <p>Why the need?</p> <p>Currently services for disabled people who have been affected by abuse are in short supply, and there is little evidence as to the efficacy of current services or collaboration between different service providers. These gaps can cause critical situations of risks for vulnerable and older adults. The SAFA</p>
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<p>resource for everyone that provides information about “<i>everything you need to know</i>” about safeguards and safeguarding, including details of organisations and services, programmes, workshops, training, education, resources, tools, policy, quality standards and safeguarding practice, including how to make a complaint, what you should expect from providers, roles and responsibilities and your rights, and legislation.</p>	<p>Supporting the development of new friendships and healthy relationships</p> <p>Building and strengthening supportive networks can be discussed with a person when they are thinking about what they want out of their lives and what they need to get there. Building and strengthening supportive networks may be one thing that they want/need to help them to get there.</p>	<p>ISR is an effective way to improve services without the need for significant resources.</p> <p>The Waitemata District Health Board, New Zealand Police Waitemata District and the SAFA Collective inter-agency safeguarding approach: SAFA – safeguarding vulnerable and older adults from abuse is an excellent example of a SAFA integrated safety response (ISR) in practice.</p> <p>https://nzfvc.org.nz/sites/nzfvc.org.nz/files/Synergia-final-report-of-the-SAFA-Pilot-5-April-2017.pdf</p>
<p>BUILDING CAPABILITY AND CAPACITY OF GOVERNMENT, THE WORKFORCE, PROVIDERS AND THE WIDER COMMUNITY</p> <p>Quality information, education and training</p> <p>Mainstream services and community organisations may need to build their skills, knowledge and confidence to effectively safeguard disabled people (protect, enhance and promote disabled people’s human rights, health, safety and wellbeing, citizenship, and quality of life; and enable disabled people to live the life they choose, free from harm, abuse, neglect, violence and exploitation).</p> <p>Providing quality information, education and training to government, the workforce, providers and the wider community to (including but not limited to):</p>	<p>Right to participation and full inclusion</p> <p>Full inclusion means being fully accepted and connected in your community. Recognising that assisting a person to make connections in their community, to make new friends and to build healthy relationships, requires more than just providing opportunities for the person to attend a particular event or specific venue, it requires ongoing help to establish new relationships and to establish their identity within new situations, groups and places.</p> <p><i>“Close friendships don’t just happen”</i></p> <p>Building skills of disabled people to overcome obstacles to making friends, for example knowing how to be a good friend and to know what a good friend should look like; and providing opportunity for people to meet new people, such as volunteering, at work, joining a group, taking a class, finding local places where</p>	<p>The Waitemata District Health Board and Police SAFA integrated safety response key features include:</p> <p>SAFA PRINCIPLES & KEY FEATURES</p> <ul style="list-style-type: none"> • Person-led decisions and informed consent • Taking action when there are concerns a vulnerable adult is at risk of abuse or neglect • Identifying and addressing needs and risks early • Risk assessment that takes account of wider risk factors to the adult, whānau, carer, and others • Multi-agency and multi-disciplinary Vulnerable Adult Response Group • Providing a range of supports and responses that focus on supporting the person and their whānau • Timely and accurate information sharing • Appropriate action for the person causing harm

<ul style="list-style-type: none"> Build a skilled and safe workforce <i>Changing attitudes to create a culture in which disabled people are valued, people who support and care for disabled people are valued; and one which minimises risk and the likelihood of abuse occurring</i> Ensure all services disability, mainstream and community and specialist violence prevention services are able to help and support disabled people in situations of abuse <i>Supporting the development of skills and knowledge to meet the needs of disabled people and address barriers to accessing mainstream and community services</i> Build communities of practice <i>Disabled people can actively contribute to leading, shaping and influencing their community.</i> <p>Information, education and training, includes:</p> <ul style="list-style-type: none"> The EGL principles – making the principles real The social model of disability Human rights (UNCRPD) The Safeguarding Framework – individual roles and responsibilities whole community approach to safeguarding disabled people Safeguarding vulnerable adults from abuse (SAFA) integrated safety response Supported decision making model 	<p>people “hang out” and meet up, and opportunities for people to share experiences while also building relationships and making friends, such as peer support groups, buddyng and mentoring.</p> <p>MAKING A COMPLAINT / GETTING HELP</p> <p>An independent complaints system for making complaints and ensuring that the rights of disabled people are upheld would ensure that people have the confidence and feel safe to raise any issues or concerns; to ensure the quality of supports and services, putting in place corrective measures for when things go wrong; and responding to concerns or actual abuse or neglect.</p> <p>What's needed to enable disabled people and whānau to make complaints and have them responded to?</p> <p>Disabled people can experience many barriers to making a complaint and reporting abuse and neglect. Providing people with quality information about rights, providers (what they should expect), the complaints process and how to make a complaint.</p> <p>The need for an effective complaints system and a mandate to act was a strong theme in the safeguarding working group. Members emphasised the need for a complaints system that will:</p>	<ul style="list-style-type: none"> Dedicated Police and DHB SAFA Coordinator Multi-agency intensive case management (ICM) for high risk victims Record and monitor results to inform practice Improving the collective understanding of Safeguarding Adults. <p>Safeguarding vulnerable adults stakeholder group</p> <p>The creation of a dedicated stakeholder group that incorporates a multi-disciplinary approach would be a relatively inexpensive way to begin identifying the best ways forward to enhance protective mechanisms in New Zealand. These discussions would also be a good first step in exploring the possibility of an enhanced legislative approach.</p> <p>Safeguarding vulnerable adults from abuse and neglect community development plan</p> <p>In addition to establishing the SAFA team, a collective impact approach to stopping the abuse of disabled people – this involves communities, organisations and individuals taking action and playing a part in preventing, detecting and reporting abuse and neglect.</p> <p>Develop and deliver a comprehensive SAFA safeguarding programme, including an Orientation Programme, for the workforce, government, providers and the wider community, that aims to</p>
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<ul style="list-style-type: none"> • Safeguarding legislation – rights based Recognising and responding to abuse and neglect • Dealing with disclosures of abuse. <p>Asset-based approach: A model for community development</p> <p>An asset-based approach places the emphasis on people's and communities' assets, alongside their needs and could be a framework for person and community-centred approaches which supports local capacity-building. Asset-based approaches, amongst other positive outcomes, can enhance health, wellbeing and resilience of individuals and enable people to participate in their community. Importantly the approach reframes the narrative from 'needs' to 'assets'.</p> <p>Building and strengthening relationships and networks</p> <p>The Connector/Tuhono and the Network Builder and network facilitators will consider the person's own strengths and capabilities, and what support might be available from their wider support network or within the community to help connect people to each other and to wider community assets, and will play a key role in growing and mobilising community assets.</p> <p>UNDERSTANDING ABUSE</p>	<ul style="list-style-type: none"> • help people understand their rights and what they should expect of providers • ensure a code of conduct • give people the confidence to complain and report abuse and neglect • support mediation and the resolution of complaints • be accessible and easy to use by all – 'no wrong door' • enable people to complain by providing the supports, person to person, that people want and need to • respond to serious incidents, concerns or actual abuse and neglect, as well as complaints • enable others, such as whānau, carers, advocates, and the wider community, to make complaints • ensure 'whistle-blower' protections • ensure a coordinated approach – Ombudsman, Human Rights Commission, Health and Disability Commissioner who have a broader role in responding to complaints. • allow for disabled people and whānau to have a range of tools and channels to raise concerns and make complaints safely, including easy access to advocacy • recognise and respond to abuse and neglect of vulnerable adults and ensure an integrated safety response • third party reporting - when people are unable or unwilling to make a complaint 	<p>build the capacity and capability of the workforce, government, providers and the wider community about the abuse and neglect experienced by disabled people so that everyone understands their role and responsibilities in safeguarding vulnerable adults from abuse and neglect – safeguarding is everyone's responsibility. Of particular importance is the need to equip police in recognising abuse of vulnerable adults and improving their responses.</p> <p>There are currently available educational aids to build on, for example, the Waitemata DHB have developed an interactive e-learning available on the Ko Awatea learning platform that assists Health staff to recognise Vulnerable Adult Abuse and Neglect, to understand their responsibility and to know what to do.</p> <p>A framework of standards for safeguarding vulnerable adults from abuse and neglect</p> <p>To assist health, police, specialist services, mainstream and the community, including disability service providers with a safeguarding adult's responsibility to provide a safe environment and high quality service and supports within a framework of standards for safeguarding adults from harm, abuse and neglect.</p> <p>Development of safeguarding adult standards that are part of a sector led response, in which government and community take responsibility for</p>
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<p>People (disabled people, whānau, government agencies, the workforce, providers and the wider community) have awareness of the abuse and neglect of disabled people, and understand their roles and responsibilities in preventing, recognising and responding to concerns or actual abuse or neglect.</p> <p>Professional development, education and training for preventing, recognising and responding to abuse:</p> <ul style="list-style-type: none"> • Promote and apply human rights (UNCRPD) • Understand causes of abuse • Taking risks but still staying safe • Recognise that abuse is not ok and that there is zero tolerance to abuse • Safe recruitment procedures and employment practices • Recognise vulnerability and indicators of abuse • Risk assessment and risk enablement • Understanding behaviours of concern – identify causes of behaviours, use of positive behaviour support in the commitment to the reduction and elimination of restrictive practices • Safeguarding legislation and responsibilities, such as Crimes Act • Safeguarding approaches for people who experience abuse in different ways and need information, education and training in ways that meet their individual needs, are 	<ul style="list-style-type: none"> • enable the identification of systemic issues to feedback into the system, such as addressing barriers people face in making complaints, and the development and implementation of training. <p>System level safeguards, such as external review of decisions and actions that directly impact on a person, such as access to relevant tribunals or commissions.</p> <p>Mediation / restorative justice Local (free) mediation if things go wrong was discussed as a helpful and valued tool in supporting self-determination. Mediation can be used, for example to help older adults address issues that occur as a result of life cycle events, transitions, and/or losses often associated with aging and dying.</p> <p>Supported decision-making The Framework should be used to promote a shared understanding of supported decision making to protect people's right to make their own decisions about their lives and promote supported decision making for people who need support to make decisions; it provides appropriate support and safeguards to ensure that disabled people, who need support to make decisions, can make their own decisions with the support that is right for them. Including but not limited to:</p>	<p>leadership and safeguarding vulnerable adults from harm, abuse and neglect, that focus on improved outcomes for disabled people and whānau</p> <p>Safeguarding Adults Standards could be developed that protect any adult aged 18 years and over, who meet the Crimes Act 1961 definition of a vulnerable adult – a current gap in adult protection legislation, police and processes and social investment.</p> <p>Safeguarding Vulnerable Adults from Abuse Standards could cover:</p> <ol style="list-style-type: none"> 1. Outcomes for and the experiences of disabled people (quality of life) 2. Leadership and planning/strategy (safeguarding is embedded in government, providers, services and community wide plans, including family harm and sexual harm) 3. Performance, service delivery and effective practice 4. Working together – multi-disciplinary and SAFA integrated safety response. <p>For example, standards would include:</p> <ul style="list-style-type: none"> • Ensuring that safeguarding activities are in line with the EGL principles • Ensuring that people's rights are respected and upheld (UNCRPD)
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<p>accessible and easy to understand, for example people with learning disability, people who are non-verbal and use other ways to communicate – augmentative and alternative communication (AAC)</p> <ul style="list-style-type: none"> • Screening/asking about abuse – identifying if a person feels safe now, if there is any historic or current abuse to identify any immediate safety needs and therapy/recovery requirements • Recognising that a disabled person's close relationships and relationships with professionals can also be a source of abuse • Safeguarding collaborative, whole of community, collective approach to preventing, detecting and reporting neglect and abuse, for example drugs and alcohol services, mental health, family violence, sexual violence, police, health, counsellors, housing, WINZ, others • An integrated safety response to investigating and responding to alleged or identified abuse, neglect or harm of vulnerable adults that co-ordinates services to address all the issues that the disabled person and whānau may have • A whānau-centred approach • Dynamics of family violence – power and control. <p>Zero tolerance to abuse of disabled people project</p>	<ul style="list-style-type: none"> • identifying what supports a person wants and needs to make informed decisions, for example time to discuss options and time to make decisions • information available in accessible formats, for example, easy read, braille or large print • ensuring access to preferred communication mode, such as Augmentative and alternative communicators (AAC) and easy access to NZSL interpreting service and NZSL fluent Support People • education and workshops • Protections in law • People who need support to make decisions have the right to legal representation within all formal processes relating to capacity • A range of advocacy supports are available when needed • Setting up an agreement between a person with a disability and a family member or friend who would act as a decision supporter. • Improving the monitoring mechanisms of guardians of people with impaired decision-making abilities • routine checks on supported decision making to ensure the level of support provided and that decisions made represent the will and preferences of the person • routine checks on supported and substituted decision makers • mechanisms and opportunities within the EGL Team for people to speak up if things 	<ul style="list-style-type: none"> • Whānau and people's support networks are engaged when appropriate • Ensuring advocacy is available when it is needed, e.g. a person who is experiencing abuse • People who are victims or witnesses have the support they need through the justice system • Supports are available for whānau and carers <p>To help providers, services, workers to reach the standards a self-assessment tool could be developed.</p> <p>Systemic disability data collection</p> <p>Collect data that will enhance the lives of disabled people and whānau and improve quality and consistency of outcomes and align with other disability data collection and recording initiatives and abuse data collection, such as family violence and sexual violence.</p> <p>Capture and record disability abuse data, including documenting and reviewing considerations of vulnerability, risks, and individual safeguards applied to enable a person to live the life that they choose for themselves</p> <p>Code of conduct</p> <p>A code of conduct will be a mechanism that can have a preventative and a corrective effect, to promote safe and ethical service delivery. A code of conduct will help to set expectations for providers</p>
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<p>Changing attitudes and behaviours to ensure safer organisational cultures and high quality supports, providing guidance, resources, tools and training on preventing, recognising and responding to abuse and neglect of disabled people</p> <p><i>“Making the Framework real”.</i></p> <p>Develop and deliver a safeguarding training package and specialist safeguarding vulnerable adults from abuse training, across MidCentral, for mainstream and specialist abuse prevention services, including police, to support a shared understanding and consistent approach to safeguarding, and collaborate with organisations who deliver safeguarding education, such as Child Matters to ensure training includes disabled children and young people.</p> <p>Social and disability campaigns</p> <p>Support social and disability campaigns that promote disability awareness, abuse is not OK, and affirms action to prevent abuse of disabled people.</p> <p>Specialised services and projects</p> <p>Specialised services' refer to organisations and services that provide support specifically to safeguard adults who are victims of abuse and neglect (includes family harm and sexual harm) and to special training aimed at professionals,</p>	<p>change, they don't feel safe or their decisions are not being respected</p> <ul style="list-style-type: none"> • recognising, respecting and resourcing opportunities for families and organisations, for example DPOs, to share their growing wealth of knowledge and practice experience on 'how' supported decision making should and can happen • developing a mentoring scheme where people are trained to support people to build their capacity to make autonomous and informed decisions about their lives • pathways and facilitation of supported decision making agreements – an agreement between a disabled person and a family member or friend who supports the person to make decisions • pathways when there are concerns that a person may lack capacity to make a particular decision. <p>Supported Decision Making Tools</p> <p>There are a variety of ways and tools to assist supported decision making. These include:</p> <ul style="list-style-type: none"> • Intentional networks, circles of support, and effective communication partners • Information available in accessible formats, for example, easy read, braille or large print • Education and workshops • Augmentative and alternative communicators (AAC) which are low and hi tech. These include electronic speech 	<p>and workers, shape the behaviour and culture of organisations and individual workers, and empower consumers in relation to their rights.</p> <p>EGL Team will have skills knowledge and confidence to safeguard disabled people (includes children and vulnerable adults) from harm, abuse and neglect.</p> <p>Community funding programme: Asset based community development approach</p> <p>Funding an asset based approach to support community inclusion – making sure people with disability are connected and included into their communities. Individuals and communities have access to funding that supports community-led development, such as community capacity building towards more welcoming and inclusive communities.</p> <p>Funding decisions are based on the outcomes for disabled people and whānau and deliver upon the EGL principles and the principles for safeguarding that underpin the Framework.</p> <p>Crisis situations and immediate safety concerns</p> <p>System has capacity to respond to emerging issues on quality and safety and/or immediate safety concerns/crisis situations – immediate needs to be addressed/ or support offered as appropriate</p>
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<p>and the wider community, who work with victims and perpetrators of abuse and neglect.</p>	<p>generation devices and apps, plus decision mats and other visual aids.</p> <ul style="list-style-type: none"> • Time to discuss the options • Time to make the decisions. 	<p>Crisis / immediate safety needs could be the need for respite care, emergency accommodation, a carer who can provide immediate support if a person's whānau/carer is unwell or is a perpetrator of domestic violence (this allows for the person to remain in their home and not be re-victimised by having to move out of their home in order to receive the support they need).</p>
<p>Accessibility of specialised services in New Zealand is an area where we are failing. These gaps in services can provide critical situations or risk for disabled people, in particular vulnerable adults. Women's refuges in New Zealand are not accessible to some disabled people, nor are special support services offered for disabled women, men and children who are victims of abuse. This lack of accessibility and support can be a major barrier to some disabled people and vulnerable adults getting the help they need to remove themselves from unsafe situations.</p>	<p>The Working Group acknowledges the work of the Office for Disability Issues (ODI) to identify improvements for disabled people exercising their legal capacity or decision making and recommends that the Disability Support System Transformation drives this crucial work.</p>	<p>Serious incidents – harm, abuse and neglect</p> <p>The term serious incident can be misleading in relation to abuse and neglect – the person's level of vulnerability, ability of the person to keep themselves safe and risk of harm are key factors in responding to incidents. Responding to serious incidents requires inter-agency collaboration in cases of suspected or actual abuse and neglect - to provide an effective integrated safety response to incidents and crimes.</p>
<p>Health programmes and projects</p> <p>Professionals ranging from medical workers to law enforcement agencies are likely to encounter abuse and neglect and are in pivotal positions to offer intervention.</p> <p>Spreading awareness, about the abuse experienced by disabled people and a supported decision making model, among medical practitioners is an effective way:</p> <ul style="list-style-type: none"> • to ensure disabled people who are experiencing abuse or neglect are identified and get the support they need to access services be safe and feel safe, such as women's refuge, Shine, and counselling, for example counselling for sexual abuse through ACC Sensitive Claims 	<p>REPORTING SYSTEMS</p> <p>Speaking up about abuse</p> <p>Create more opportunities where people feel safe to speak up, for example community led forums about housing issues, police forums where people can meet the police that work towards building trust and confidence in police.</p> <p>Disability Abuse and Neglect reporting options</p> <p>'Everyone', including disabled people, whānau, carers and advocates can report concerns or actual abuse and neglect to skilled and trained individuals and in a variety of different ways, channels and locations independent of providers. The working groups identified a number of options:</p> <p>A disability abuse and neglect hotline</p>	<p>Responsiveness to Maori and Pasifika disabled people</p> <p>Te Ao Māori concepts, values and practices The safeguarding approach to promoting, protecting and enhancing human rights, health safety and wellbeing, applies the Te Whare Tapa Wha Maori Health model and takes a whānau-centred approach - Maori disabled people and Pasifika</p>

<ul style="list-style-type: none"> • to ensure that people have the supports they need to make decisions and the recognition of decisions as valid decisions • pathways, for supported decision making, for professionals when they have concerns that a person may lack capacity to make a particular decision and the person is at risk of harm. <p>Therapy and recovery</p> <p>Support for people who have experienced abuse and trauma. People have access to specialists and therapy.</p> <p>Therapy is easily accessible (particularly in crisis situations) to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of disabled people who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.</p> <p>MidCentral prototype:</p> <ol style="list-style-type: none"> 1. Work with the national Violence Intervention Programme (VIP) manager to ensure that disabled people and vulnerable adults are 	<p>A National Disability Abuse and Neglect hotline - establish a telephone referral service for reporting abuse and neglect of disabled people and vulnerable adults.</p> <p>The EGL Helpline</p> <p>The EGL Helpline is available 24 hours a day, seven days a week– skilled operators can provide advice and information, respond to immediate safety needs, conduct a preliminary risk assessment when necessary to identify immediate safety risk and provide advice, support and appropriate referral pathways, such as existing helplines who could be trained and resourced to respond to abuse of disabled people.</p> <p>Other helpline services</p> <p>Work with other helpline services to ensure they are responsive, including but not limited to: It's Not Ok, Shine, Women's Refuge, Youthline, Mental Health Foundation of New Zealand, Anxiety New Zealand Trust, Samaritans, Need to talk?</p> <p>Disability Third Party Reporting Centre</p> <p>Disability Third Party Reporting Centres are community venues, like Victim Support, CAS, community centres where anyone can report abuse. Third Party Reporting Centres can</p>	<p>disabled people are understood in the context of their disability, whānau, aiga community and cultural preferences and are the centre of any safeguarding activity.</p> <p>Roles – safeguarding responsibilities</p> <p>The Enabling Good Life Team is well-trained and skilled in safeguarding; in particular the EGL Connector/Tuhono and Network Builder are highly skilled in safeguarding, and have an excellent analysis of the dynamics of family violence, sexual violence and abuse.</p> <p>Network Builder - builds relationships with specialist violence prevention services and work with them to build their capacity and capability to be responsive to disabled people who access their services.</p> <p>Developmental evaluators are experts in the needs of disability providing guidance and expert opinion on how providers can improve services. Evaluators have the skills, knowledge and confidence to recognise and respond to abuse (includes family harm).</p> <p>Ontario Code of Practice can be used to inform and support role descriptions and practice for Facilitator/Connectors/ Tuhonos.</p> <p>Improvements to the justice system</p>
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<p>included into the national VIP programme - family violence routine enquiry within DHBs</p> <p>2. Work with the District Health Board to establish their role in safeguarding vulnerable adults from abuse (Waitemata SAFA approach)</p> <p>3. Work with local Primary Health Organisations' to develop the PHO Family Violence Intervention Programme (FVIP) for General Practice - family violence routine enquiry within general practice.</p>	<p>address barriers to reporting and being heard. For example, not everyone is comfortable reporting their experiences and dealing with the police. Disabled people can make a report and other people who may have concerns or witnessed abuse can make a report (third party reporter). People First's Bullying, Abuse and Neglect Easy Read Reporting Form is an excellent example of a resource that assists people with learning disability to self-report, be in control and addresses barriers to having their complaint dismissed or ignored. The form can be used by the police and specialist services and is part of a whole community response to preventing, detecting and responding to abuse and neglect of disabled people.</p> <p>An Online Disability Abuse Reporting Form</p> <p>Available on the information hub and through a variety of channels, such as the police website.</p> <p>Safe Places scheme</p> <p>Establish a Safe Places scheme - places in the local community where people can go if they don't feel safe, get information and advice, make a complaint or report abuse. The scheme helps build capacity and capability of the community, encourages bystanders to take action and is part of a whole community approach to safeguarding.</p>	<p>The working group identified the need to ensure that the ministry of justice, corrections, police and professionals working in the justice system are included in the system transformation. Policies and practices to ensure that disabled people have their right to equal access to justice.</p> <p>For example, this should include:</p> <ul style="list-style-type: none"> • Professional development for solicitors about economic abuse and enhanced police capacity to investigate and prosecute economic abuse. • Independent Third Persons (ITPs) attend police interviews for adults and young people with disability to ensure that they are not disadvantaged during the interview process • Communications assistants for people who need help to understand what is being said and what is happening, such as being a witness at court. • Equipping and enabling police in responding to the abuse of disabled people and improving their responses, in particular to vulnerable adults <p>WORKFORCE VETTING/SCREENING</p> <p>The working group identified the need for establishing a more comprehensive check for working with vulnerable people. Police checks are not sufficient for working with children and vulnerable groups.</p> <p>Screening is a safeguard used in recruitment processes to inform whether someone will pose an</p>
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	<p>Reporting disability abuse and neglect – a coordinated collective approach and integrated safety response</p> <p>Developing a model of practice, a shared understanding and consistent approach for supported decision making if crucial in ensuring that disabled people's rights are upheld.</p>	<p>unacceptable risk to people. It is an essential component of safeguarding, but used independently is insufficient for preventing abuse and neglect.</p> <p>The need for an employee screening system to assess/ensure the suitability of anyone who wants to work with children and/or vulnerable adults, to prevent unsuitable people from working with vulnerable groups. This is in addition to police vetting.</p> <p>Risk-based screening could identify 'workers' who have had criminal or civil charges laid against them that have not been pursued, or in the circumstances where a 'worker' left employment before a thorough investigation had been conducted or they have been dismissed from their job for misconduct. Potential predators can easily move from one organisation to another. Excluding a person from future employment in the sector can minimise the risk of harm, violence, exploitation and abuse. The screening system will need to include appropriate privacy provisions.</p>
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Key recommendations from the Safeguarding and Network Building Working Groups:

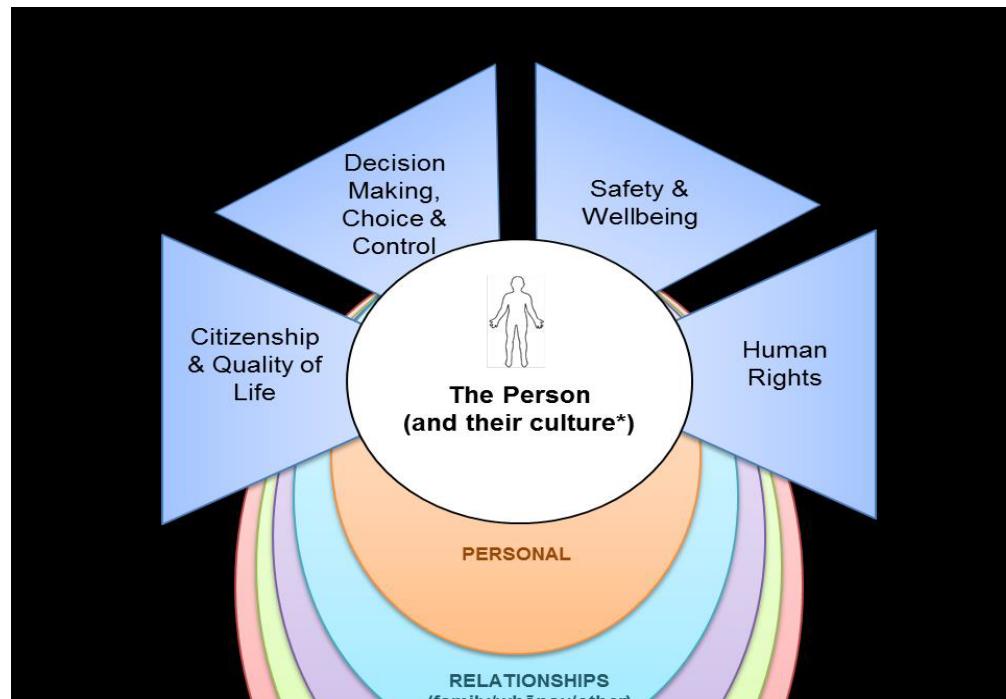
- Establish an independent statutory body that has roles and functions similar to the Office of the Public Advocate (OPA) in Australia
- Introduce new legal capacity legislation in line with the UNCRPD. Article 12 should guide and shape the new law

- Updating New Zealand's legal frameworks to include safeguarding legislation that safeguards disabled people's human rights and introduce new safeguarding adults legislation to protect vulnerable adults

APPENDIX A

Safeguarding Framework

The Review Working Group developed a Safeguarding Framework, which consists of an objective, principles and the spectrum of safeguards to assist it to understand the range of safeguarding supports and mechanisms that are available and to guide its work.



APPENDIX B

SAFEGUARDING

Legislation, Policy and Legal Framework:

- Protection of Personal Property and Rights Act 1988
- Crimes Act 1961
- Crimes Amendment Act (No 3) 2011
- Human Rights Act 1993
- New Zealand Bill of Rights Act
- Oranga Tamariki Act 1989 /Children's and Young People's Well-being Act 1989
- Vulnerable Children Act 2014
- Health and Disability Services (Safety) Act 2001
- New Zealand Health and Disability Standards (the Standards),
- Health and Disability Commissioner Act 1994
- Domestic Violence Act 1995
- Health and Safety at Work Act
- Mental Health Compulsory Assessment and Treatment Act 1992
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

- Treaty of Waitangi
- United Nations Convention on the Rights of Persons with Disabilities
- Nations Convention of the Rights of the Child -
- Code of Health and Disability Services Consumers' Rights
- Older Adults and Vulnerable Adults Abuse and Neglect, Waitemata DHB Policy (2016)

The role of legislation and regulation

The Protection of Personal and Property Rights Act 1988, the Human Rights Act 1993 and the Health and Disability Commissioner Act 1994 provide protections that are specific to or include disabled people. Disabled people supported by providers may also be subject to the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MH(CAT) Act) or the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

Both the MH(CAT) Act and the ID(CC&R) Act restrict disabled people subject to these Acts to some degree. They also give these people specific rights that are intended to protect them and prevent exploitation and abuse. The Health and Disability Services (Safety) Act 2001 enables regulation through the New Zealand Health and Disability Standards (the Standards), which residential services are required to meet. The Standards include requirements such as to uphold consumer rights (NZS8134.1.1) and provide a safe and appropriate environment (NZS8134.1.4).

Community responsibilities in preventing abuse are also recognised. Article 16 of the UNCRPD, for example, states that disabled people have the right to 'Freedom from exploitation, violence and abuse' and requires community members to take steps to prevent exploitation and abuse.

Laws such as the Crimes Amendment Act 2011 give legal responsibilities to all community members in relation to disabled people. The Crimes Amendment Act requires people to report harm to vulnerable adults. A vulnerable adult is defined as 'a person unable, by reason of detention, age, sickness, mental impairment, or any other cause to withdraw himself or herself from the care or charge of another person'. The Domestic Violence Act 1995 covers individuals in a domestic relationship but does not include paid carers or support workers so it does not provide protection for many people with disabilities.

The Vulnerable Children Act 2014 is designed to create a better life for children in New Zealand. Providers who have children in their services are required to work in a manner that fosters the wellbeing of those children. In addition, these providers now have a legal responsibility to check the safety of potential staff before they work with children. This measure is to ensure that providers select appropriate staff who are not going to put children at further risk.

Providers are subject to the United Nations Convention on the Rights of the Child (ratified by New Zealand in 1993). Of particular relevance is that the Convention prohibits mixing children with adults in institutions where they are deprived of their freedom unless it can be demonstrated that it is in the best interests of the child. In addition, Article 23 relates specifically to disabled children, stating, 'If you have a physical, mental or intellectual disability, you have the right to reach your full potential. You have the right to extra help with your education care and support if you need it.'

Ministry of Health. 2016. *The Prevention and Management of Abuse: Guide for services funded by Disability Support Services*. Wellington: Ministry of Health.

APPENDIX C

Tool Kit for Network Builders (including but not limited to):

Values based Training Principles Framework (aligned with EGL principles) to use the tools effectively

<p>Person Centred Thinking and Planning</p> <ul style="list-style-type: none"> ○ Visual Planning using PATH, MAP ○ PC Planning Tools Helen Sanderson & Associates ○ and PC Reviews using PC tools e.g. Who Am I? ○ How's it going? APP ○ All My Life's a Circle (Inclusion Press) 	<p>Decision Making Tools (to make decisions, supported decisions and substituted decisions)</p> <ul style="list-style-type: none"> ○ Circles/Intentional Networks – workshop on the techniques in developing Circles that teach us how to involve and engage people. ○ How I Make Decisions- People First NZ ○ Advocacy workshops- information, resources and skill building ○ Auckland Disability Law Supported Decision Making resources 	<p>Personal Networking Building Tools</p> <ul style="list-style-type: none"> ○ You're Welcome ○ Out & About Inclusion Toolkit (Imagine Better) ○ Circles (Paid Facilitators to build, maintain and sustain the network over time. ○ Relationship Map
<p>Community Capacity Building Tools</p> <ul style="list-style-type: none"> ○ Community Mapping Tool ○ Be Friend training: Starter Kit including using social media ○ Barnwood Trust www.barnwoodtrust.org/what-we-do/growing-communities ○ ABCD approach to building asset based community development 	<p>Building Family Capacity and Resiliency</p> <ul style="list-style-type: none"> ○ Research – so we have evidenced based practice to support families ○ Failing Well. Chapter 7. The parent's practical guide to resilience for children aged 2-10 on the autism spectrum. Purkis & Goodall. 2018. Jessica Kingsley ○ Workshops for Families on topics including; <ul style="list-style-type: none"> ● Family Governed Collectives/Co-ops ● Intentional Networks ● Microboards 	<p>Building Person Centred Teams and Re-Imagining Support- Values based Training/Professional Development</p> <ul style="list-style-type: none"> ○ Social Role Valorisation SRV ○ Michael Kendrick ○ Open Future Learning ○ Communities of Practice <p>SRV is “a set of ideas useful in addressing the marginalization of people in society by supporting them to have access to the same good things in life enjoyed by typical people” http://www.socialrolevalorization.com/en/</p>

