

Budget Sensitive

Office of the Minister for Disability Issues and Associate Minister of Health
Cabinet Social Policy Committee

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.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

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. 

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. [REDACTED] 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
[REDACTED]	[REDACTED]

[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]

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.

[Redacted text]

[Redacted text]

[Redacted text]

[Redacted text]

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. [REDACTED] 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:

- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- 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.



PUBLICITY

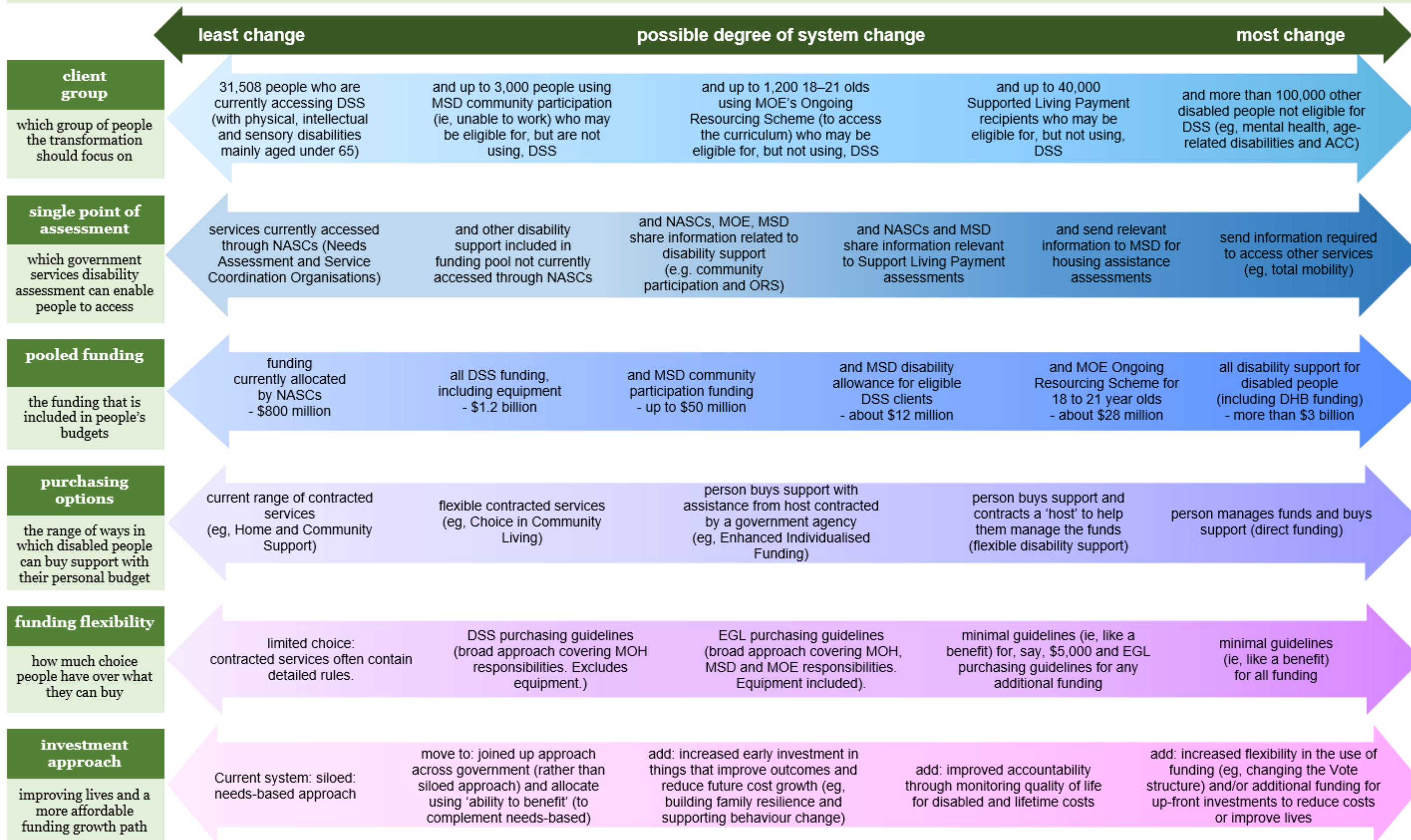
- 20 **Invite** the Minister for Disability Issues and Associate Minister of Health to make an announcement about the disability support system transformation.
- 21 **Note** that the Minister for Disability Issues and Associate Minister of Health will lead future communications about the transformation.

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.

What is included in pooled funding?

All DSS funding and, over time, integrating MSD community participation and disability allowance funding for people who are eligible for DSS.

Why: Disabled people will be able to flexibly manage the biggest feasible funding pool. Including other current funding pools at this time would raise significant challenges (eg, community participation is tied to providers and ORS funding is closely linked to general school funding). Changes to the disability allowance would require legislative change.

How much funding flexibility?

Minimal guidelines for small amounts of funding (say, \$5,000), with the EGL purchasing guidelines for amounts above this.

Why: The EGL guidelines offer considerable flexibility over what can be purchased, and have been tested successfully in practice. These guidelines underpin accountability arrangements and ensure that the funding is used for disability related outcomes. The disability community will welcome minimal guidelines and accountability requirements for lower amounts of funding.

Which client groups?

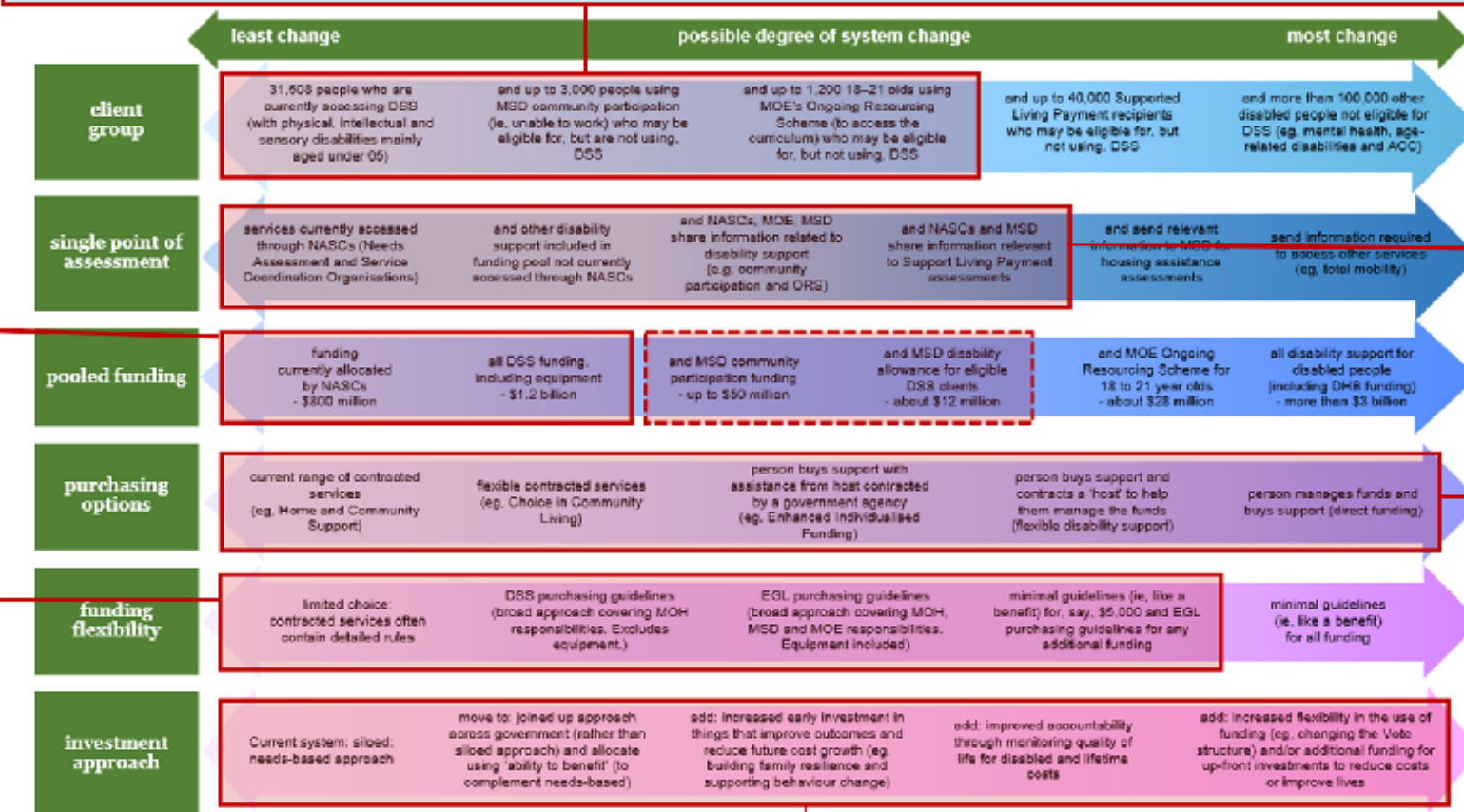
The focus is on people who are eligible for DSS. A decision is required on whether this includes only people who are currently accessing support through DSS, or whether it includes people who are eligible for DSS but who do not currently access it (eg, they receive disability support funded by MSD or MOE).

Why: The high needs of DSS' clients means that disability support can have a major impact on their life, and they have pushed strongly for the transformation. Extending the group of people would involve substantial changes to the machinery of government which would be very complex and take a considerable period of time.

What should be assessed?

Cross-agency pooled funding will be assessed. In addition, relevant information shared with between MOE and MSD so system feels seamless for the person.

Why: This will make it easier for this group of people to access a wide range of services – eg, community participation and disability allowance - without needing to tell their 'story' to a wide range of different people. One entry point will help this group of people who access a range of government services think they are dealing with a single 'system', rather than dealing with a range of 'silos'. Disabled people continue to be eligible for the general social support that all New Zealanders are eligible for.



Which investment approach?

All investment options will be included as they have the potential to improve people's lives or reduce future cost growth.

Why: The disability support system operates needs to undergo some fundamental changes if its is to achieve the improved outcomes and reduced rate of cost growth that are sought by the investment approach. Each of the proposed changes will support achieving this objective.

Which purchasing options?

All purchasing options should be available.

Why: Disabled people are able to take on the degree of choice and control they wish for over how support is purchased. While some wish for full control (ie, direct funding), many want the flexibility to decide how funds are used but don't want to manage the funding directly – they often don't want to manage employment responsibilities (eg, flexible contracted services).

Each option has already been implemented, but full implementation of direct funding will require amendments to the Income Tax Act.

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. [Redacted content]

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[Redacted text block]

[Redacted text block]

5. [Redacted text block]

[Redacted text block]

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.