

ENABLING GOOD LIVES

A report to the Minister for Disability Issues

The Independent Working Group on 'Day Options'

August 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

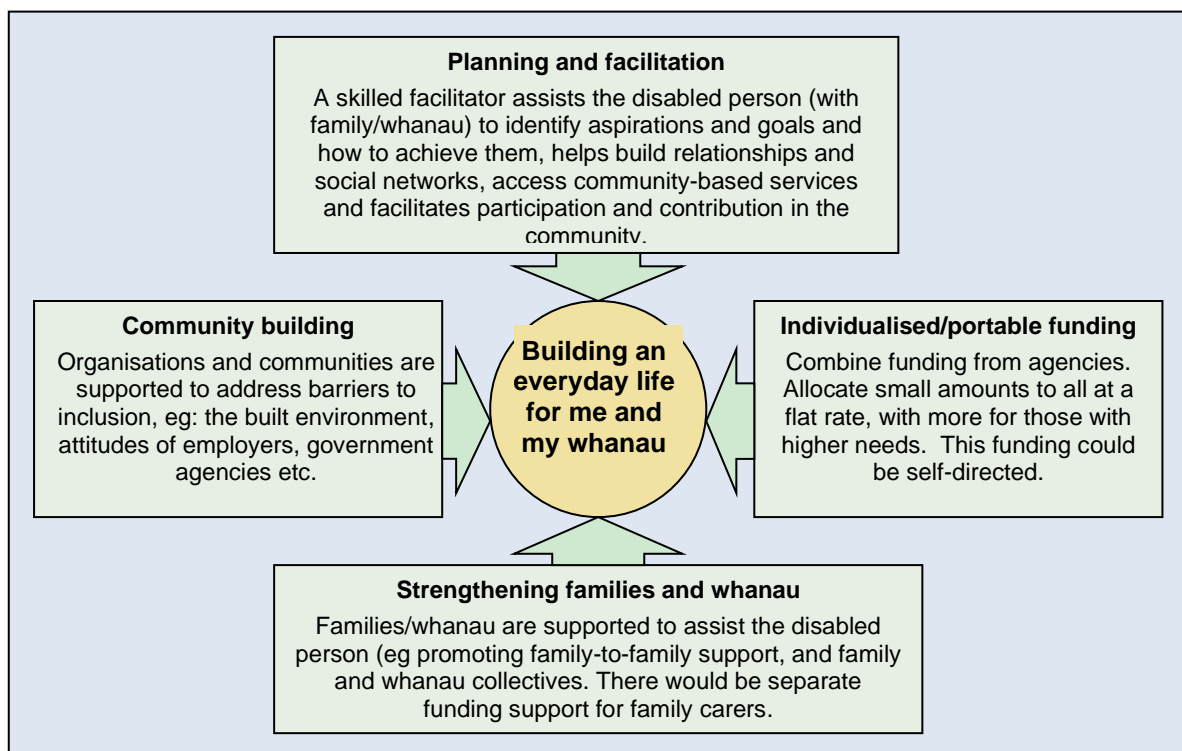
build integrity into the system, cultivate natural supports, and distinguish the legitimate (but sometime competing) needs of the individual and family.

- **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

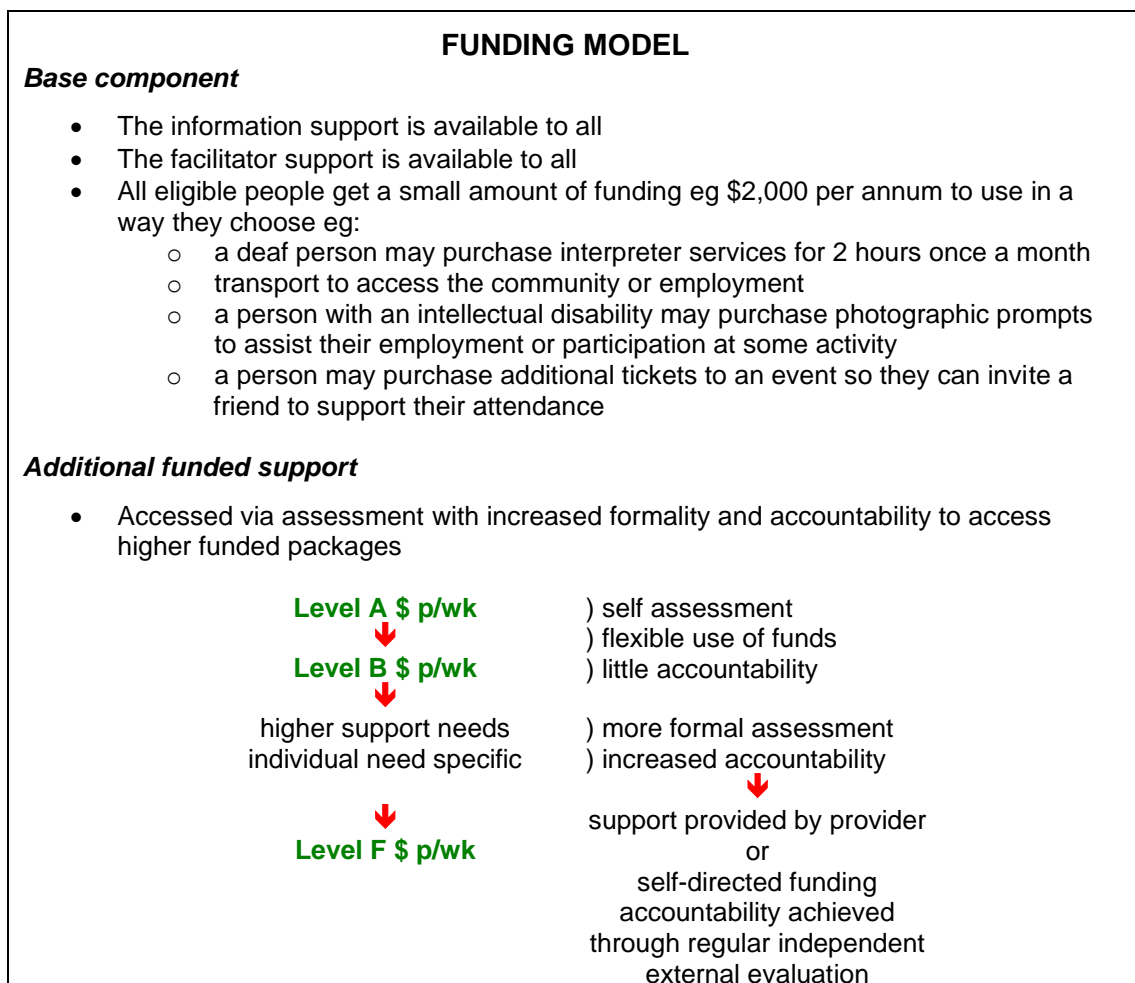
The Working Group proposes that resources equal to that already allocated for individuals by the Ministry of Health and the Ministry of Social Development be combined to fund eligible people. This could include the funding from day services and community participation services, as well as Ministry of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



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.

Additional Recommendations

At a meeting on 1 August 2011 between Minister Turia and two representatives of the Working Group (Lorna Sullivan and Mark Benjamin) it was agreed that:

- this strategy will require strong and coherent leadership from disabled people, their families/whanau and their critical allies to succeed
- disabled people, their families/whanau and critical allies should have a key role in ensuring the intent of the approach is safeguarded and the vision and principles are upheld.

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 (these figures are rounded):

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 providers for individuals who meet eligibility criteria • capped funding
Total funding	\$42 million p a	\$10 million p a	\$40.3 million p a ³

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