



FOR PEOPLE WITH A DISABILITY

Submission to
Productivity Commission Review into
Disability Care & Support

August 2010



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16 August 2010

Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428, Canberra City ACT 2601

To Whom It May Concern.

The Board and management of Scope, thank you for the opportunity to provide input to this significant review of Disability Care and Support across Australia.

Scope is a major provider of disability support services to nearly eight thousand people with a disability across metropolitan and regional Victoria. As a service provider Scope sees the need for major reform to the way services are currently funded and delivered to people with a disability.

Scope is well placed to provide a service provider's views on changes required to existing disability care and support systems.

This initial submission aims to address the key questions identified by the Productivity Commission's Issues Paper and endeavours to provide realistic recommendations to address many of these issues.

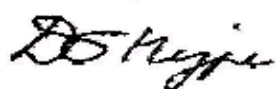
It is structured around the following three sections:

- **Scheme Design & Operation** - Covering a broad range of issues including Scheme eligibility, Scheme access and the scope of funded supports.
- **Implications and Impacts on the Sector** - implications of moving to an insurance model of funding for disability supports, and the support required for the disability support sector
- **Scheme establishment and transition arrangements**

Scope will make further submissions at appropriate times as this inquiry progresses.

We are available to discuss the contents of this submission and any other issues you may wish at a time of your convenience.

Kindest regards,



Diana Heggie
Chief Executive Officer

EXECUTIVE SUMMARY

Scope has taken this opportunity to provide input into the Productivity Commission's review into Disability Care & Support, as a major provider of disability support services in Australia. Our submission raises significant issues and endeavours to provide realistic recommendations to address these issues.

Scope believes that the current system for the provision of disability care and support requires a significant transformational change. The move from the existing rationed system to a fully funded entitlement based system is the next step in the evolution of funding of disability supports in Australia.

In summary Scope believes that:

- Australians with a severe or profound disability need increased resources and support to engage with their community, get a job where possible, and live a happy and meaningful life.
- The existing disability services system needs increased financial commitment to meet the current, future and unmet needs of Australians with a disability.
- Establishing an entitlement based, fully funded social insurance Scheme to provide long term care and support for Australians with a severe or profound disability will provide greater certainty for the future for people with disabilities (PWD) and their families.
- People who have multiple disabilities and complex needs, by reason of the difficulty they have engaging with the community, must have priority of access to supports funded by the Scheme.

This submission addresses the following:

- **Scheme Design & Operation** - Covering a broad range of issues including Scheme eligibility, Scheme access and the scope of funded supports.
- **Implications & Impacts on the Sector** - Implications of moving to an insurance model of funding for disability supports, and the support required for the disability support sector.
- **Scheme Establishment & Transition Arrangements**

Recommendations for the development of the Scheme are provided for each issue.

The recommendations are shown below.

SECTION 2 – SCHEME DESIGN & OPERATIONS

- **Relating to 2.1 Scheme Funding:**

- a. That the Scheme be a fully funded Scheme that is sustainably funded under an insurance model that is entirely premium based.*
- b. That the calculation of the premium has regard to the levels of services likely to be required, the costs of future liabilities for providing these services and the costs of other Scheme initiatives such as supporting sector reform and research.*

- c. *That funding and actuarial modelling recognize and make funding provision for the fact that, unlike other personal injury compensation schemes which have a rehabilitation and recovery focus, the levels of funded support will generally not diminish (and in many cases may increase) over time, particularly for people with cerebral palsy and like conditions.*

- **Relating to 2.2 Scheme Eligibility:**

- a. *That Scheme eligibility be based on four criteria:*
 - *The person having a disability as a result of an underlying disease or disorder and consequent impairment (not an acute illness or injury or natural aging);*
 - *The impairment/disability having caused severe or profound core activity limitations;*
 - *The person needing day-to-day support as a result of these activity limitations;*
 - *The support needs being unable to be met by ordinary family relationships and roles and community responses.*
- b. *That the assessment of eligibility for scheme participation is a once only Scheme led process conducted by Scheme appointed allied health professional or disability specialist, with input from the person, their family, healthcare team.*
- c. *That a single national assessment tool be used to determine Scheme eligibility and a similar tool be applied to the assessment of support needs*
- d. *That the Scheme eligibility assessment have regard to the person's:*
 - *Medical diagnosis;*
 - *Disability profile.*

- **Relating to 2.3 Standardised Assessments & Levels of Support Funding (Bands)**

- a. *That the Scheme develop and apply a predictive statistical methodology to determine the supports funding band (excluding equipment and modifications).*
- b. *That the scheme eligibility assessment also determines the funding band (for which the person is eligible).*
- c. *That the standardized assessment tool/s used to establish funding bands and determine the band applicable to a given person with a disability:*
 - *Have acceptable psychometric properties (validity and reliability)*
 - *Ease of administration*
 - *Enable national implementation, including with people from culturally and linguistically diverse backgrounds and indigenous Australians*
 - *Include a self-assessment component*
 - *Are consistent with WHO International Classification of Functioning, Disability and Health (ICF).*
 - *Support the identification of support needs and responses to those support needs.*
- d. *That Scheme administration (claim management) focuses on supports outside of funding the upper or lower limits of a funding band and that outliers be referred to regional disability panels for review.*
- e. *That the Scheme conducts re-assessments of the funding band at key life transition stages.*

- f. That the Scheme adopts a system for service funding that includes client complexity profiling to avoid provider skimming practices.*

- **Relating to 2.4 Range of Services Funded:**

- a. That funded supports take a whole of life approach with a focus on managing key transition points (starting & leaving school, moving to community living, starting work, retirement).*
- b. That the Scheme makes provision for the funding (or the enabling of) supported decision making and/or case management that is likely to be needed at key points.*
- c. That supports are funded to enable the person with a disability to engage with the community, get a job (where possible), attend to their personal care needs and lead a meaningful life.*

- **Relating to 2.5 – Impacts on other sources of Income:**

- a. That the Scheme allow for a person with a disability to fund the additional cost of a service that is related to personal choice and not required as a result of their disability.*
- b. That the Scheme establishes and communicates clear boundaries regarding how funding for disability supports may be spent.*
- c. That the Scheme not fund supports in relation to needs that are related to peer life styles and community living, that do not overcome barriers created by disability.*
- d. That the Scheme not assume responsibility for an aspect of income support, including carer payments*

- **Relating to 2.6 – Individual Funding Agreements:**

- a. That the Scheme provides for the creation of individual funding agreements to be entered into with people who have stable needs and circumstances.*
- b. That these individualised funding agreements require that people with a disability who have entered into an agreement be accountable for spending, with the allocation and spending of funds randomly audited annually (like the tax audits).*
- c. That the Scheme establishes systems to mitigate the risks of mismanagement under individualised funding agreements (including non-payment of providers).*
- d. That individualised funding agreements balance the rights and responsibilities of people with a disability.*
- e. That the Scheme establishes systems to maintain the quality and safety standards of services purchased under individualised funding agreements.*
- f. That the Scheme manages the expectations of people with a disability and carers regarding the cost of individualised service provision, particularly through the timely provision of information.*

- g. That the eligibility criteria for individualised funding agreements require that the person's social situation, health needs and circumstances are stable.*
- h. That decisions regarding the prioritization of spend on funded supports are led by person with a disability.*

- **Relating to 2.7 – Supported Decision Making:**

That the Scheme fosters the use of supported decision making by people with disabilities through:

- a. Supporting initiatives that will enable people with disabilities to build informal support networks to help them to make informed choices.*
- b. Supporting the development of agencies and processes to build formal support networks to help people with disabilities to make informed choices, where an informal network is either not possible or not appropriate.*
- c. Providing timely and effective information to people receiving Scheme funded support services.*

- **Relating to 2.8 – Other Scheme Functions:**

That the objectives the Scheme include:

- a. To remove physical, attitudinal and systemic barriers to community inclusion and participation for people with disabilities, particularly:*
 - Improving accessibility (particularly transport and the built environment);*
 - Promoting community development that supports the participation of all people with disabilities in all aspects of community life, including education, social activities and local community decision making;*
 - Promoting economic participation opportunities for all people with disabilities, including employment, this includes strategies to support positive discrimination in the employment of people with disabilities;*
 - Removing communication, attitudinal and systemic barriers to community inclusion and participation for all people with disabilities;*
 - Building community awareness and behavioural change.*
- b. To fund and support activities and initiatives that enable innovation to benefit people with disabilities, including:*
 - Research and development relevant to disability support, inclusive practices, social and participative outcomes for people with disabilities;*
 - Grants for specific projects, awards recognising innovation, partnerships with universities and other sectors.*
- c. To build disability sector and service provider capacity and sustainability (including infrastructure sharing & use of technology) especially for small service providers, decision makers and regulators.*
- d. Undertaking activities to enable the achievement of the aspirations of state based disability strategies such as the Victorian State Disability Plan and the achievement of*

compliance with relevant instruments such as Victorian Human Rights Charter UN Convention of rights for people with a disability.

- e. *To improve the intersection between the disability support & related systems, particularly:*
 - *Developing & implementing processes, protocols & agreements to facilitate people with a disability accessing health & mental health services;*
 - *Supporting the establishment of specialist service and support hubs with co-located disability, health & mental health services.*

SECTION 3 – IMPLICATIONS & IMPACTS ON THE SECTOR

- **Relating to 3.1 Impacts on Business Operations:**

- a. *That the Scheme support and enable the development of a strategy to manage the impact of market consolidation, including strategies to support people with a disability to transition from their current provider to a new service provider over a timeframe of 3-12 months. These strategies are needed to enable relationships and networks to be built with their new service providers.*
- b. *That the Scheme supports the development of hub and spoke models for back office service delivery and infrastructure costs (particularly ICT and asset management) to maintain market diversity and choice by supporting small agencies.*

- **Relating to 3.2 Demonstrating Effectiveness and Outcomes:**

- a. *That the Scheme fund and support providers to meet minimum standards of training, systems, performance and quality.*
- b. *That, in consultation with the relevant jurisdiction, the Scheme harmonize compliance, quality and audit requirements between related sectors such as disability and aged care while ensuring this harmonization process does not lead to a drift back to medical models being applied to disability services.*
- c. *That the Scheme develop measures of provider performance that are focused on the attainment of personal outcomes for people with disabilities, identified through person centred planning. (NB: provider performance is distinct from Scheme performance which is best measured through participation outcomes and the rate of growth in liabilities.)*

- **Relating to 3.3 Workforce Issues:**

- a. *That the Scheme partners with the disability sector to support the development and implementation of a hub and spoke service model to deliver specialist services rural and remote areas. NB: These services will necessarily have a higher cost than metropolitan services.*
- b. *That the Scheme partners with the disability sector to support the development and implementation of a disability workforce strategy including:*

- *Workforce analysis to develop an understanding of the skills and competencies required to manage the changing disability service delivery platforms, including the development of modelling tools to enable the resourcing requirements needed to support future business strategies to be planned and costed;*
- *Workforce design including, job design, career paths and wages linked to increasing skills and qualifications - supporting a person centred approach to quality client service delivery;*
- *Enhanced workforce flexibility to improve utilization of existing, and new, permanent and casual workforce with tailored employment solutions designed to meet new business strategies and changing service delivery platforms;*
- *The development of integrated training and development models to support the development of common skills and competencies (with associated training and development) aligned to the external market;*
- *The establishment of recruitment, career and employment branding with targeted vocational recruitment and clear career paths.*

SECTION 4 – SCHEME ESTABLISHMENT & TRANSITION ARRANGEMENTS

- a. That the Scheme undertakes a staged approach to the establishment of the Scheme, including developing and implementing a transition process that places priority on:*
 - *People who by the nature of their disability have most difficult engaging with the community;*
 - *People with a disability whose carers are ageing;*
 - *Access to respite services;*
 - *People with a disability who require supported accommodation;*
 - *Early intervention, for people with a disability based on age, recent onset or diagnosis or deteriorating function;*
 - *Support to enable all people with disabilities to find and sustain employment;*
 - *Support for the disability support provider sector to manage the transition to individualised funding arrangements and business models of operation.*
- b. That people currently receiving disability supports continue to receive those supports and are not disadvantaged with the introduction of a new system and Scheme transition arrangements.*
- c. That recovery arrangements are established between the Scheme and other relevant bodies to ensure that where the Scheme eligibility funding source cannot be determined within desirable timelines people with disabilities begin receiving supports and cross fund recovery happens once determination is made (may apply to people with potential eligibility for a no fault compensation Scheme)*
- d. That the Scheme establish and manage systems for data management collection and analysis on client profiles, service utilization and delivery, client and service outcomes and effectiveness.*

Thank you again for the opportunity to present this information. We are available to discuss this information and any other issues you may have at a time of your convenience.

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1 INTRODUCTION

This submission is made by Scope, a large not for profit organisation that provides disability services throughout Victoria to nearly eight thousand children and adults with physical and multiple disabilities. Over 4000 of our clients have severe and profound disabilities. Our services include early childhood intervention, open employment, accommodation, day services, in-home attendant care and community participation support.

Scope has an operating expenditure of approximately \$66 Million and employs over 1600 staff across over 90 sites across Victoria. Scope is a membership based organisation that currently has over 6000 individual and organisational members. Scope also acts at a systemic level providing advocacy, community education and research. The Scope Board includes members with a disability.

The paper will take as its central principal the Government's statement on p.3 of the Productivity Commission issues paper (highlights added for key words):

'This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life.' (Sherry, 2009)

This paper also supports the five "Guiding Principles" presented by the National Disability Carer Alliance in their submission titled "The Importance of a Social Insurance Approach to Disability Funding".

Scope believes that the move from the existing rationed system to a fully funded entitlement based system is the next step in the evolution of funding of disability supports in Australia. The past three decades have seen a change in the social responses landscape with essential services, such as hospital services or maternal health services, available to people who need them. Scope believes that this approach to funding must now also be applied to long term care and support for people with a disability. That is, supports must be available to people who need them and funded equitably through a social insurance Scheme.

In summary Scope believes that:

- Australians with a severe or profound disability need increased funding and support to engage with their community, get a job where possible, and live a happy and meaningful life.
- Establishing an entitlement based, fully funded social insurance Scheme to provide long term care and support for Australians with a severe or profound disability will provide greater certainty for the future for people with disabilities (PWD) and their families.
- People who have multiple disabilities and complex needs, by reason of the difficulty they have engaging with the community, must have priority of access to supports funded by the Scheme.

This initial submission aims to address the key questions identified by the Productivity Commission relating to building of a new scheme for Disability Care and Support. It is structured around the following:

- **Scheme Design & Operation** - Covering a broad range of issues including Scheme eligibility, Scheme access and the scope of funded supports.
- **Implications and Impacts on the Sector** - implications of moving to an insurance model of funding for disability supports, and the support required for the disability support sector
- **Scheme establishment and transition arrangements**

Recommendations regarding each of these key issues are included within each section.

Scope will make further submissions at appropriate times as this inquiry progresses.

2 SCHEME DESIGN & OPERATION

2.1 SCHEME FUNDING

The move from a charity model to a business model for delivering disability support requires that the costs of providing these supports be fully funded. The Productivity Commission report into the contribution of the not-for profit sector estimates that there is a funding gap between the costs of delivering the current level of services and the revenue received to deliver these services. It is estimated that this funding gap is 10%.ⁱ

However, under the current funding arrangements, there are also significant levels of unmet needs for disability supports with long waiting lists for supported accommodation, respite, equipment, therapy and other services. The current funding arrangements and the broader service system are heavily reliant on volunteers, unpaid care from family members; much of which is provided by aging parents of people with disabilities.

Scope supports the application of an insurance funding model, which by its design, will enable the scheme to be financially rigorous, sustainable and transparent, and will deliver fully funded entitlements for individualised supports for people with disabilities - and supporting other initiatives such as sector reform and research.

An insurance model of funding requires that the liabilities for the future costs of providing services and supports are predicted from today's costs and premiums and investments cover such future costs. An insurance model ensures that provisions for the future are made today and not left as a problem for future generations. Scope therefore proposes that the Scheme's funding be entirely premium based, with the cost of funded services required by Scheme participants being the starting point for setting this premium. That said, Scope acknowledges that the dimensions of a premium to immediately cover all those people currently receiving supports, those on waiting lists and future entrants is likely to be unacceptable to government or the electorate. Scope is advocating for a transition arrangement (refer to Section 4 Scheme Establishment and Transition Arrangements).

Recommendations:

- a. That the Scheme be a fully funded Scheme that is sustainably funded under an insurance model that is entirely premium based.
- b. That the calculation of the premium has regard to the levels of services likely to be required, the costs of future liabilities for providing these services and the costs of other Scheme initiatives such as supporting sector reform and research.
- c. That funding and actuarial modelling recognize and make funding provision for the fact that, unlike other personal injury compensation schemes which have a rehabilitation and recovery focus, the levels of funded support will generally not diminish (and in many cases may increase) over time, particularly for people with cerebral palsy and like conditions.

2.2 SCHEME ELIGIBILITY

Scope supports the proposition that the Scheme should focus on funding supports for people who by the nature of their disability have most difficult engaging with the community. This particularly includes people with multiple and complex needs and whose disability related needs cannot be addressed via ordinary family relationships and roles or community responses.

Disability can impact on a person's capacity to participate in activities at any age. People over 65 years of age who acquire disability through trauma or some other time critical incident also require support to participate in activities. The health care system's focus is on health, the focus of the aged care sector is on safety and maintenance of functional status and the focus of the disability sector is on participation in life. If a person acquires a disability and requires support to participate in life, this is best serviced by the disability sector regardless of their age. However, this does not necessarily mean that the Scheme funds the support to people age over 65 who acquire a disability, cross funding arrangements with aged care would be required.

The Australian Bureau of Statistics' definitions of core activity limitations provide one possible method for defining Scheme eligibility.

*' People with a **severe core-activity limitation** sometimes need help with self-care, mobility or communication; or have difficulty understanding or being understood by family or friends; or communicate more easily using sign language or other non-spoken forms of communication.*

*People with a **profound core-activity limitation** always need help with self-care, mobility or communication, or are unable to do these tasks.^{di}*

This definition describes the level of core activity limitation that a person may experience but does not differentiate between the various causes of these limitations. A person may have a core activity limitation as a result of illness, disadvantage (such as homelessness), disability or natural aging.

Scope supports the principle that the Scheme should focus on funding supports for people who have a disability, rather than people who have a short term core activity limitation that is a result of an acute illness or injury.

Where an injury or disease process causes a core activity limitation over a prolonged period of time (more than 12 months), Scheme eligibility criteria should have regard to the nature of the support that the person needs and the time period for which they are likely to be required.

However, because of the broad spectrum of conditions that can cause severe and profound core activity limitations and the variable durations of both these conditions and the limitations that they cause, a definition of Scheme eligibility that requires that there be an underlying disorder or disease, a consequent impairment and that defines disability and the level of activity limitationⁱⁱⁱ will ensure that the Scheme funds supports for people with a disability who have the most significant support needs and consequent difficulty engaging with the community.

In discussing eligibility and services it is important to distinguish between eligibility for the Scheme and eligibility for particular services and quantum of service. Throughout this document the term 'eligibility' is used to refer to Scheme eligibility, for which it is argued there should be a one-off assessment. It is recognised that people's need for support and the nature of the support required will change over time. Therefore it is expected that once people have been accepted as eligible for the Scheme that individual planning and support

needs assessments will be repeated, as needed, and in response to changing needs and circumstances. For example, a child might be re-assessed annually in the first five years of life, while a person with paraplegia might not be re-assessed for a decade as their needs and circumstances remain stable, whereas a person with a brain injury might be assessed annually in the early years following an injury (consistent with expectations of recovery) and then less frequently as time elapses.

Once a person with a disability has been assessed as eligible for Scheme participation two processes must be undertaken before the person can begin receiving funded supports:

- Determining the amount of funding for that is required/available; and
- Identifying the person's support needs and responses to those support needs.

While noting that determination of eligibility is a "one off" process and supports assessment a repeated process of varying frequency, the two processes are closely related and can be conducted at the same time, when a person first enters the Scheme. These processes are necessarily Scheme led and are best conducted by allied health professional or disability specialist together with the person with a disability and/or their family.

Recommendations:

- a. That Scheme eligibility be based on four criteria:
 - The person having a disability as a result an underlying disease or disorder and consequent impairment (not an acute illness or injury or natural aging);
 - The impairment/disability having caused severe or profound core activity limitations;
 - The person needing day-to-day support as a result of these activity limitations;
 - The support needs being unable to be met by ordinary family relationships and roles and community responses.
- b. That the assessment of eligibility for scheme participation is a once only Scheme led process conducted by Scheme appointed allied health professional or disability specialist, with input from the person, their family, healthcare team.
- c. That a single national assessment tool be used to determine Scheme eligibility and a similar tool be applied to the assessment of support needs
- d. That the Scheme eligibility assessment have regard to the person's:
 - Medical diagnosis;
 - Disability profile.

2.3 STANDARDISED ASSESSMENTS AND LEVELS OF SUPPORT FUNDING (BANDS)

Actively managing claims that are tracking within expected costs and outcomes is administratively inefficient. The use of standardised assessments to determine a typical range of funding linked to a particular support profile (funding band) is one strategy that can enable Scheme administration resources to be directed to managing claims that are outside of expectations. This methodology for funding supports enables the Scheme to remain responsive to the needs of individuals and to avoid the application of arbitrary caps

or limits on services. Arbitrary caps on services can prevent the Scheme from being able to fund appropriate levels of support for some clients with multiple and very complex needs.

Another benefit of this approach to funding is that it clearly separates the administrative decision of how much funding is available to the person with a disability from the personal choice of how, when and where funding is used to access supports. This approach can empower clients to exercise a high level of control over how they receive funded supports and to ensuring that the supports enable them to achieve their goals of participation in education, work and community life.

An agreed standardised assessment tool is required to determine the appropriate range of funding applicable to a person with disabilities.

SUGGESTED FRAMEWORK FOR DETERMINING THE LEVEL OF FUNDING.

A transparent and person centred framework for developing funding bands for people with a disability is recommended. For example, levels of disability related support needs could be described categorised into four bands:

- **Intensive support** – profound disability affecting functional levels such as personal hygiene, mobility, communication such that the person requires 24 hour support (at night this group can be further segmented based on full care versus occasional support)
- **Home and community based support** – severe or profound disability affecting all functional areas but the person requires support only during the day or occasionally at night.
- **Community based support** – severe or profound disability affecting some functional areas but the implications are more on daily living activities not necessarily related to personal care e.g. support to participate at school, work, community activities
- **Transition support** – severe or profound disability affecting key life transitions e.g. going to school, leaving school, moving out of home, getting a job, changes in health status

Funding for episodic services such as adaptive equipment, home and vehicle modifications would need to be considered outside of these funding bands as they are infrequently required and technological developments can make costs difficult to predict.

The use of person centred planning processes to identify support needs and responses to those needs can ensure that funding of supports remains responsive to people with a disability, their individual needs and circumstances. While funding bands would need to have regard to population norms and life transition points (such as leaving school, moving out of the family home or starting work) a person centred approach also acknowledges that service needs are likely to increase at transition points, and then move towards maintenance of supports until the next transition point. This enables early intervention to be funded to support the management of transition points. These early intervention services can reduce costs related to crisis management and enable a better planned system of service delivery.

Requests to access funding for support beyond the assessed limit of funding (outliers) could be managed by referral to regional disability panels. In Victoria a similar model is used by both the Transport Accident Commission and WorkSafe to manage requests for outlier funding of clinical services. The use of contracted panels of expert clinical consultants, clinical audits and peer review processes enable service utilisation to remain within expectations for the person's injury, for true outliers to be identified and for outlier levels of services to be funded for these clients, and for the use of evidenced-based services to be strengthened.

Recommendations:

- a. That the Scheme develop and apply a predictive statistical methodology to determine the supports funding band (excluding equipment and modifications)
- b. That the scheme eligibility assessment also determines the funding band (for which the person is eligible).
- c. That the standardized assessment tool/s used to establish funding bands and determine the band applicable to a given person with a disability:
 - Have acceptable psychometric properties (validity and reliability);
 - Ease of administration;
 - Enable national implementation, including with people from culturally and linguistically diverse backgrounds and indigenous Australians;
 - Include a self-assessment component;
 - Are consistent with WHO International Classification of Functioning, Disability and Health (ICF);
 - Support the identification of support needs and responses to those support needs;
- d. That Scheme administration (claim management) focuses on supports outside of funding the upper or lower limits of a funding band and that outliers be referred to regional disability panels for review.
- e. That the Scheme conducts re-assessments of the funding band at key life transition stages.
- f. That the Scheme adopts a system for service funding that includes client complexity profiling to avoid provider skimming practices.

2.4 RANGE OF SERVICES FUNDED

Supports funded for people with disabilities should remove barriers to the person participating in all aspects of community life. The Scheme should remain focussed on taking a whole of life approach to funding services for people with a disability.

Likely services to be funded by the Scheme include:

- Attendant care workers for personal care;
- Supports that are complementary to or alternatives to attendant care;
- Recreation and leisure programs for people with profound disability;
- Medical and allied health services;
- Aids and equipment;
- Home and vehicle modifications;
- Education support – from preschool to tertiary education;
- Services to support access to and maintain paid employment;
- Supported decision making;

- Transition planning and life planning;
- Episodic case management.

Some of the services listed above are funded through other Government appropriation lines, such as Education. We do not see this as a duplication rather that the new scheme would purchase services from these sectors on an entitlement model and that those original funds be used to offset the costs of the new scheme.

Funded services such as Case Management services may facilitate family members accessing related services such as counselling but as a principle the scheme should not fund services for people other than the person with a disability. Scope would be most concerned if families were deemed entitled to a service but the budget holder of that service did not have sufficient resources to meet the entitlements

Recommendations:

- a. That funded supports take a whole of life approach with a focus on managing key transition points (starting & leaving school, moving to community living, starting work, and retirement).
- b. That the Scheme make provision for the funding (or the enabling of) supported decision making and/or case management that is likely to be needed at key points.
- c. That supports are funded to enable the person with a disability to engage with the community, get a job (where possible), attend to their personal care needs and lead a meaningful life.

2.5 IMPACTS ON OTHER SOURCES OF INCOME

Scope acknowledges that some people have more discretionary income than others and that this situation will continue once the Scheme is operational as it will be a long term care and support, not an income equalization Scheme.

The Scheme will need to establish and communicate clear boundaries regarding the relationship between the funding for disability supports and other sources of income/support available to a person with disability and their families. In particular:

- **personal income** – i.e. Funding for disability supports is not income support so as a matter of principle the funding cannot be spent on holidays, equipment for hobbies or other personal living expenses.
- **generic supports for the person's family** - The Scheme should only fund services for people with a disability, not for their family members. However an adequately funded Scheme will allow family members to reduce their involvement in providing unpaid care and return to primarily being a family member. The provision of Scheme funded supports will reduce the pressure on family members who should continue to access generic services such as GP, generic counselling services, peer support groups.
- **Co –payments** - Where a person with a disability requests a service that costs more than that required to meet their identified support need some schemes

provide for the person to contribute this additional cost and thus receive the requested more expensive service. Requests of this nature are most commonly made in relation to aids and equipment. Scope supports the right of people with a disability to make personal choices in relation to such items provided that the additional cost of these personal choices are funded by the person and not the Scheme and that co-contribution is not applied to essential items.

In formulating this Submission some commentators have expressed a view that these requirements ought not to be applied, as currently when a child is born with a disability or family member acquires a disability, one partner must give up work to care for the person with the disability. This is confusing the current situation (having to give up work to provide care and support) with the proposed situation whereby the Scheme provides the funds to purchase care and support. Accordingly, the pressure to leave the workforce ought to be removed. In turn, this means that the above requirements are consistent with an insurance model.

In keeping with the focus on the role of the Scheme being one of disability support and not income, the Scheme should not assume responsibility for an aspect of income, including carer payments.

Recommendations:

- a. That the Scheme allow for a person with a disability to fund the additional cost of a service that is related to personal choice and not required as a result of their disability.
- b. That the Scheme establishes and communicates clear boundaries regarding how funding for disability supports may be spent.
- c. That the Scheme not fund supports in relation to needs that are related to peer life styles and community living, that do not overcome barriers created by disability.
- d. That the Scheme not assume responsibility for an aspect of income support, including carer payments.

2.6 INDIVIDUAL FUNDING AGREEMENTS

For people with stable personal circumstances, health needs and function, individual funding agreements can enable the person to have a high degree of control over how supports are provided and by whom. The ability of the person to directly employ disability support workers can enable more flexible support arrangements than those traditionally available. The level of stability needed for such self management will require a period of time (e.g. two years after birth or acquiring disability). In a newly established Scheme both people with a disability and the Scheme itself need this two year time frame. For those eligible, individual (self management) funding agreements could commence in the third year of Scheme operation.

Where recipients choose to establish individual funding agreements, it is important that the monitoring and auditing processes be established to mitigate any risks of mismanagement of the funding whilst acknowledging the rights and responsibilities of persons with a disability.

Recommendations:

- a. That the Scheme provides for the creation of individual funding agreements to be entered into with people who have stable needs and circumstances.
- b. That these individualised funding agreements require that people with a disability who have entered into an agreement be accountable for spending, with the allocation and spending of funds randomly audited annually (like the tax audits).
- c. That the Scheme establishes systems to mitigate the risks of mismanagement under individualised funding agreements (including non-payment of providers).
- d. That individualised funding agreements balance the rights and responsibilities of people with a disability.
- e. That the Scheme establishes systems to maintain the quality and safety standards of services purchased under individualised funding agreements.
- f. That the Scheme manages the expectations of people with a disability and carers regarding the cost of individualised service provision, particularly through the timely provision of information.
- g. That the eligibility criteria for individualised funding agreements require that the person's social situation, health needs and circumstances are stable.
- h. That decisions regarding the prioritization of spend on funded supports are led by person with a disability.

2.7 SUPPORTED DECISION MAKING

In May 2010 Scope made a submission to the Victorian Law Reform Commission regarding the review of Victoria's Guardianship and Administration Laws. The submission centred on the use of supported decision making and implications for guardianship and administration.

In relation to the Scheme, supported decision making should be an integral part of the process of identifying support needs and responses to those support needs. Including a self-assessment component in this process increases decision making power of people with a disability.

The level of decision making support required will be different for each person with a disability. Providing funding for supports on an individualised basis will enable and support greater choice for people with a disability but in some cases the person will require support to make informed choices. All people with a disability need portability of funding to enable them to exercise choice about and to change support providers and individual disability support workers.

Recommendations:

That the Scheme fosters the use of supported decision making by people with disabilities through:

- a. Supporting initiatives that will enable people with disabilities to build informal support networks to help them to make informed choices.
- b. Supporting the development of agencies and processes to build formal support networks to help people with disabilities to make informed choices, where an informal network is either not possible or not appropriate.
- c. Providing timely and effective information to people receiving Scheme funded support services.

2.8 OTHER SCHEME FUNCTIONS

Despite the prevalence of disability in our society (1 in 5 Australians report having some form of disability and 6.3% report having a severe or profound disability which restricts their participation in daily activities)^{iv} there is method by which a national authority both:

- Ensures sufficient funding to meet the care and support needs of people with a severe and profound disability; AND
- Leads systemic change to improve outcomes for all people with disabilities.

There is a strong precedent in social insurance schemes such as the Transport Accident Commission and New Zealand's Accident Compensation Corporation for such front-end investment. For example, the TAC invests extensively in trauma research and neuro-trauma research and development. These investments advantage the Victorian community as a whole, not just those people injured in transport accidents. The Accident Compensation Corporation, in partnership with the New Zealand rugby clubs funded initiatives to reduce the incidence of quadriplegia that has seen international changes to rugby rules and dramatic reductions in the incidence of quadriplegia.

The establishment of a scheme that has responsibility for both ensuring sufficient funding to meet the care and support needs of people with a severe and leading systemic change to improve outcomes for all people with disabilities makes social and financial sense. In particular, a focus on delivering employment opportunities to all people with disabilities will reduce reliance on funded supports and improve health and social outcomes in a way that is typical of outcomes for all people who are employed, rather than unemployed.

Acting to remove barriers to participation, promoting research and innovation and investing in cost effective responses to low incidence, high cost needs will advantage the nation and the scheme.

Australia already has a number of social insurance schemes that deliver medical, rehabilitation, vocational and disability services on a no fault basis. These schemes carry out a range of functions, acting both to bring about systemic change within a sector / industry /society and to fund services for eligible Scheme participants. As social insurance schemes they spread the insurance cost of medical services, unemployment, transport accident and workplace injuries across the population.

Scope proposes that a long term care and support Scheme could act at a systemic level to improve the work and community participation of all Australians with a disability as well as

funding long term care and support services for Australians with a severe or profound disability.

Recommendations:

That the objectives the Scheme include:

- a. To remove physical, attitudinal and systemic barriers to community inclusion and participation for people with disabilities, particularly:
 - Improving accessibility (particularly transport and the built environment);
 - Promoting community development that supports the participation of all people with disabilities in all aspects of community life, including education, social activities and local community decision making;
 - Promoting economic participation opportunities for all people with disabilities, including employment, this includes strategies to support positive discrimination in the employment of people with disabilities;
 - Removing communication, attitudinal and systemic barriers to community inclusion and participation for all people with disabilities;
 - Building community awareness and behavioural change.
- b. To fund and support activities and initiatives that enable innovation to benefit people with disabilities, including:
 - Research and development relevant to disability support, inclusive practices, social and participative outcomes for people with disabilities;
 - Grants for specific projects, awards recognising innovation, partnerships with universities and other sectors.
- c. To build disability sector and service provider capacity and sustainability (including infrastructure sharing & use of technology) especially for small service providers, decision makers and regulators.
- d. Undertaking activities to enable the achievement of the aspirations of state based disability strategies such as the Victorian State Disability Plan and the achievement of compliance with relevant instruments such as Victorian Human Rights Charter UN Convention of rights for people with a disability.
- e. To improve the intersection between the disability support & related systems, particularly:
 - Developing & implementing processes, protocols & agreements to facilitate people with a disability accessing health & mental health services;
 - Supporting the establishment of specialist service and support hubs with co-located disability, health & mental health services.

3 IMPLICATIONS AND IMPACTS ON THE SECTOR

In the past two decades disability support agencies have progressively moved from a charity to a business model of operation. The degree of progress along this journey varies significantly between organisations. The change in operating models has taken place in an environment of funding shortfalls and a 'block funding' model of delivering funds to service providers. This has impeded progress towards sustainable business operations. The move to an insurance model will enable the costs of supports to be fully funded but will also require that the disability sector rapidly adapt to operating within an increasingly competitive business environment.

The disability sector is undergoing fundamental change in its operating model from that of a charity towards that of a sustainable business. Its charity status will continue to offer benefits to people with a disability as it is unlikely that the costs of all research, development and innovation initiatives will be met by the Scheme.

The Scheme will need to:

- Establish national standards to manage quality assurance and associated compliance.
- Allow innovation in workforce development to reduce increasing costs associated with increasing demand of disability support workers.
- Build disability sector and service provider capacity and sustainability (including infrastructure & the use of technology) particularly for small service providers, decision makers and regulators.

3.1 IMPACTS ON BUSINESS OPERATIONS

The disability sector's history of operating as a business with block funding has created sector capacity constraints. Growth of services has been dependent on government grants, and under-delivery has not received a financial penalty, but instead allowed service providers a financial buffer against recognized Government underfunding.

The introduction of Individualised Funding removes this financial buffer and service providers will only receive revenue for services delivered. The providers who understand their variable and fixed costs and are in a better position to make sustainable service offerings to clients will be able to build sustainable financial models to ensure their ongoing viability.

Small less financially experienced or resourced organisations may quickly struggle to cover overhead costs if they lose clients. This is expected to lead to consolidation in the industry and the increased likelihood that commercial 'for profit' providers will enter into the market. By giving people with a disability the choice in service providers, it is likely that the support service providers who are able to deliver to people the outcomes that they seek will be the ones in greatest demand.

Currently the perception of quality of service is highly reliant on the familiarity and trust built between the person with a disability and disability support worker at the local level. The most important aspect of managing the social impact of provider consolidation will be to retain the choice of service providers for people with a disability and their families. Consolidation in itself will lead to efficiencies within the sector. However, there is a risk that in losing some organisations, people with a disability will also lose the relationships that they have built over their lifetime with their support workers. There is also a risk of losing innovation in service delivery that is often delivered by small organisations.

Service organisations often provide a community within itself for people with a disability and their families. Consolidation within the industry may mean the loss of small communities for many people who have come to rely on them, including the relationships and networks with other people with a disability and their families.

Access to cost effective back office support systems would enable smaller service providers to continue to provide high quality local and intimate services whilst maintaining the quality and compliance standards required by the Scheme.

Recommendations:

- a. That the Scheme support and enable the development of a strategy to manage the impact of market consolidation, including strategies to support people with a disability to transition from their current provider to a new service provider over a timeframe of 3-12 months. These strategies are needed to enable relationships and networks to be built with their new service providers.
- b. That the Scheme supports the development of hub and spoke models for back office service delivery and infrastructure costs (particularly ICT and asset management) to maintain market diversity and choice by supporting small agencies.

3.2 DEMONSTRATING EFFECTIVENESS AND OUTCOMES

Reporting on outcome measures by support service providers is a hallmark of an open market. The outcome measures selected by an insurance Scheme must be designed and reported with reference to the support needs of the clients receiving services. Without such baseline measures there is a risk that skimming will be promoted. That is, there is a risk that providers will compete for clients who are perceived as more likely to achieve the required outcomes and fewer services will be available to the clients who face greater difficulties. In particular, Scope has concerns for the people with complex severe and profound disabilities.

Cost effectiveness of the services will also be a focus of an open market. By giving people with a disability the choice of support service providers, it is likely that they will choose the provider who is able to meet their needs in the most cost effective way to maximise the level of support they receive within their particular funding package.

Recommendations:

- a. That the Scheme fund and support providers to meet minimum standards of training, systems, performance and quality.
- b. That, in consultation with the relevant jurisdiction, the Scheme harmonize compliance, quality and audit requirements between related sectors such as disability and aged care while ensuring this harmonization process does not lead to a drift back to medical models being applied to disability services.
- c. That the Scheme develop measures of provider performance that are focused on the attainment of personal outcomes for people with disabilities, identified through person centred planning. (NB: provider performance is distinct from Scheme performance which is best measured through participation outcomes and the rate of growth in liabilities.)

3.3 WORKFORCE ISSUES

The disability sector is influenced by prevailing labour market trends, including:

- The ageing population and ageing workforce;
- High levels of employment driving increased demand for labour at the lower end of the job market, with more opportunities for low income employees (especially women);
- Increasing numbers of women in the workforce adversely affecting informal care arrangements and in turn increasing the demand for paid care;
- Increasing pressure on the disability industry to collaborate more closely with health and community services sector, gain a better understanding of those communities and work toward building capacity within those communities;
- A high proportion of work performed under distant, intermittent supervision. This is particularly evident in the delivery of specialist services in rural and remote areas. The opportunity exists for the establishment of hub and spoke support models that support staff to provide quality services in remote areas. Such approaches can be applied to direct support workers (attendant care staff) to develop skills in manual handling, working with clients with cognitive disabilities and developing active support strategies to name a few examples. For low incidence, specialist responses a similar model can be highly effective in delivering information, advice and technical support to local professional staff.

For example Scope's Communication Resource Centre provides highly specialised, state wide support to people with complex communication needs and the staff who work with them.

Changes in the funding models for disability supports, the provider market and the labour market will provide opportunities to:

- Align the increasing demand for flexible working arrangements with the more flexible service delivery required, under an individualised service model.
- Develop new career paths and job opportunities.
- Redesign job to have links to qualifications and career development.
- Introduce higher standards of awareness and training, particularly for front line disability support workers around disability awareness and OH&S matters.

Recommendations:

- a. That the Scheme partners with the disability sector to support the development and implementation of a hub and spoke service model to deliver specialist services rural and remote areas. NB: These services will necessarily have a higher cost than metropolitan services.
- b. That the Scheme partners with the disability sector to support the development and implementation of a disability workforce strategy including:
 - Workforce analysis to develop an understanding of the skills and competencies required to manage the changing disability service delivery platforms, including the development of modelling tools to enable the resourcing requirements needed to support future business strategies to be planned and costed;
 - Workforce design including, job design, career paths and wages linked to increasing skills and qualifications - supporting a person centred approach to quality client service delivery;
 - Enhanced workforce flexibility to improve utilization of existing, and new, permanent and casual workforce with tailored employment solutions designed to meet new business strategies and changing service delivery platforms;
 - The development of integrated training and development models to support the development of common skills and competencies (with associated training and development) aligned to the external market;
 - The establishment of recruitment, career and employment branding with targeted vocational recruitment and clear career paths.

4 SCHEME ESTABLISHMENT AND TRANSITION ARRANGEMENTS

The establishment of a national scheme to fund disability support will require a staged approach to implementation to:

1. Establish an sufficient and acceptable premium sufficient to allow for investment for sustainable coverage of liabilities and Scheme development in line with transition arrangements; and
2. Enable transition arrangements with the many current funding systems and schemes to be developed and implemented

Establishment of the Scheme will involving work with relevant departments and programs at all levels of government to ensure co-ordination between funding sources and to minimise risks to people with a disability.

As noted, Scope is of the view that a staged Scheme roll out will be required and that priority needs to be placed on people with severe and profound disabilities. Responding to carers who are ageing must also be a priority and to this end there needs to be priority given to those people who require out-of-family home living arrangements in shared supported accommodation and like models.

Access to respite services to sustain family caring relationships will be essential. In this case, access to respite services may well need to extend beyond just those families where a family member has a severe and profound disability to others, to ensure sustainability of family caring and reduce the pressure for Scheme extension in its early years of operation.

Early intervention with young children and people with a recently acquired disability is demonstrably cost effective in reducing long term care and support needs. Early intervention with people with deteriorating conditions can reduce the risk of injury (for example, by delivering timely and appropriate home modifications) and break down of the family relationships.

Obtaining and maintaining employment with people with disabilities delivers desirable social and economic outcomes. Employment can transform lives and need for support.

The disability sector and Scheme participants will need a transition period to move from traditional methods of funding and fund management to individualised self managed models. Not only are individualised self managed models consistent with best practice disability and business management models, they will be essential to ensuring that a Scheme is administratively sustainable. Without most clients managing their own packages, and few clients being case managed by the Scheme, it is possible that the administrative costs would become prohibitive.

Finally, in the interests of both responsive of services and the Scheme not becoming liable for funding what rightly belongs elsewhere 'back-of-house' funds transfer arrangements will be needed.

Recommendations:

- a. That the Scheme undertakes a staged approach to the establishment of the Scheme, including developing and implementing a transition process that places priority on:

- People who by the nature of their disability have most difficult engaging with the community;
 - People with a disability whose carers are ageing;
 - Access to respite services;
 - People with a disability who require supported accommodation;
 - Early intervention, for people with a disability based on age, recent onset or diagnosis or deteriorating function;
 - Support to enable all people with disabilities to find and sustain employment;
 - Support for the disability support provider sector to manage the transition to individualised funding arrangements and business models of operation.
- b. That people currently receiving disability supports continue to receive those supports and are not disadvantaged with the introduction of a new system and Scheme transition arrangements.
- c. That recovery arrangements are established between the Scheme and other relevant bodies to ensure that where the Scheme eligibility funding source cannot be determined within desirable timelines people with disabilities begin receiving supports and cross fund recovery happens once determination is made (may apply to people with potential eligibility for a no fault compensation Scheme).
- d. That the Scheme establish and manage systems for data management collection and analysis on client profiles, service utilization and delivery, client and service outcomes and effectiveness.

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