



Wesley Mission Victoria

**Submission to the Productivity Commission 2010
Inquiry into Disability Care and Support**

Hope Compassion Justice



Part of the Uniting Church in Australia and a member of the UnitingCare network

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1. Introduction

Wesley Mission Victoria (Wesley) is pleased to have the opportunity to respond to the Productivity Commission Inquiry into Disability Care and Support. We commend the Australian Government's commitment to developing a national disability support system, aimed at enhancing the quality of life for people with a disability and their families, and at expanding their opportunities to participate in the full range of social and economic benefits that citizenship offers. We support the Government's view that the current system is not working to best meet the needs of people with a disability and their families. We applaud the Government for undertaking an inquiry which offers a genuine opportunity to rethink and redesign the ways in which people with a disability are supported to take up their place as citizens of Australia.

Wesley has a long history of working with some of the most marginalised and disadvantaged groups in the community. In addition to providing a range of services, our role is to advocate for better community and government responses to situations of need. The information provided in this submission reflects this advocacy role.

Our submission is specifically concerned with how care and support is and could be provided to address the needs of people who are living with a disability and their families and those who care for them.

Issues addressed in this submission are:

- Our values and principles in relation to people living with disability;
- Some key considerations in relation to the design of a national disability support scheme;
- Specific services and supports that such a scheme should provide; and
- Considerations for an effective and sustainable system.

2. Wesley Mission Victoria: our organisation and our disability services

Wesley's vision is for an Australia where all belong. The purpose of our organisation is to work together creatively to reduce disadvantage, so people live life to the full within inclusive communities. The fundamental values underpinning our work are hope, compassion and justice.

Wesley is a multi-service community service organisation providing services across Victoria in aged care, disability, youth services, homelessness, and counselling. Wesley employs over 800 staff and engages more than 2,000 volunteers who deliver 50 different services across 95 locations in Victoria. We work with people living with disability and their families in the following ways:

- **Supported accommodation for people with a disability, including:**
 - *Wesley disability supported accommodation;*
 - *Wesley neurological services supported accommodation;*
 - *My future my choice* (a six bed accommodation facility for young people with neuro-degenerative diseases and who were formerly living in nursing homes).
- **Respite services**
 - Facility based respite, including a medical respite pilot;
 - *Kids under Kanvas* which provides recreational respite for children;
 - Respite for carers of people with ABI.
- **Community access and participation programs**
 - Day programs, comprising regular individual or group based social and developmental activities;
 - Supported holidays, comprising tailored and supported holidays to Victoria and interstate destinations.
- **Planning and support**
 - Funded facilitation for people who have an Individual Support Package (ISP);
 - Planning with students who are about to leave school and who have an ISP or Future for Young Adults Package;
 - Planning with people who have an acquired brain injury, referred to us by TAC.
- **Vocational Services for school leavers**
 - Wesley's Pathways 2 Employment program (P2E) provides person centred planning, training, support and mentoring as part of this job skills development program for young school leavers with a disability.
- **Employment and employment support programs**
 - Support for people with disability to help them access and sustain employment;
 - A no fee employment service for employers that promotes an inclusive workforce who embraces diversity;
 - Social enterprises (Wesley Fire & Clay, creation and production of jewellery, ceramics and promotional items; Trolley Collection Service; The Last Cuppa catering services).

3. Values and principles relating to people living with disability

Wesley's activities are framed by our Social Inclusion and Belonging Policy. This emphasises the importance of people's participation in things that matter to them, including community and working life and relationships. This approach is based on the idea that each individual has the right to determine the life they want to lead.

Our values in relation to people living with disability include:

- Communities which are inclusive of all their members, and within which people are supported to enjoy relationships with others which enable them to participate as fully as they are able in things that are meaningful and important to them;
- Recognising that every individual has a voice in relation to their physical, spiritual and social needs and how those needs can best be met;
- Every individual has a unique contribution to make and a future that they desire, and as such should be able to access the supports they need in order to contribute to the best of their abilities, and
- A society which sees disability support as a universal good, in much the same way as education and health are viewed.

A socially inclusive service delivery system works to build the capabilities of individuals, families and communities so that they are able to shape their own futures, and achieve a quality of life that would be accepted by the majority of people in society. An inclusive system is consumer-oriented and focussed on ensuring that the forms of support that people want and need are available. In such a system, individuals have control and choice in relation to the provision of services. This is situated within a rights framework, where the system acts in a collaborative way to provide the best outcomes for individuals and their families.

Our principles in relation to the provision of services and supports for people living with disability include:

- The right to access appropriate supports to assist them participate and contribute as they wish and as fully as they are able;
- Supports which are designed to enhance people's participation;
- Supports which are available and commensurate with need;
- Supports which are flexible and responsive to people's changing needs and situations;
- A say in the supports they need and how they should be provided;
- Clarity and transparency around how decisions get made, especially decisions which relate to resource allocation and prioritisation, applied at both an individual and collective level;
- Organisations providing services and supports are one such avenue for people to have a voice: where possible, people receiving services should be involved in the design and delivery of those services and other organisational processes that impact them; and
- Improved quality of life is the measure of effective support, where desired quality of life is determined by the individual.

4. A national disability support scheme: key considerations

Wesley Mission Victoria supports the establishment of a national disability support scheme which would fund and provide access to essential disability supports, including personal care and support, therapy, aids and equipment, home modifications and access to the community, education and training.

We support the public funding of such a scheme through general revenue in the taxation system, or through an extension of the Medicare insurance levy or other form of public insurance. Wesley supports the elements of the scheme, outlined below, as put forward by the National Disability Insurance Scheme (NDIS) coalition of disability and community sector organisations¹:

Eligibility

Principal beneficiaries would be people with profound and severe disabilities who need assistance with daily living tasks (self care, communication and mobility) while people with more moderate disabilities could also be eligible for some assistance based on their lesser needs.

People with permanent disabilities acquired before age 65 would be eligible for life, without reference to cause and treated equally based on needs.

People born with a disability or who acquire a permanent disability through an accident, injury or as a result of a medical condition, including mental illness, would be eligible.

No fault; the provision of support and care for people with disabilities would be separated from legal action for negligence/culpable behaviour.

Benefits for people with disabilities

Care, support, therapy, access (although not income support or housing), based on functional impairment.

Person-centred services and support based on the needs and choices of each person with a disability and their family.

Case management to facilitate independence, maximise potential and plan transitions over the life course, when required.

Early intervention a top priority.

Aids, equipment and home modification needs met on a timely basis.

Training, development and access to work to build self-esteem and reduce long term costs.

New competitive market place for service provision likely to develop, helping to drive efficiency and innovation.

Benefits for families/carers

Families expected to fulfil normal age-appropriate caring roles.

Tailored support for carers, through respite, information, counselling, training and education based on family structure and disability.

¹ <http://www.ndis.org.au/theplan/keyfeatures.html>, accessed 7th August 2010

Families able to choose to work or provide informal care, as for families without disabled members.

Part-time work and labour force engagement facilitated.

Governance and scheme management

Pooling of individual risks.

Mix of Commonwealth and state schemes (including catastrophic injury schemes) with Commonwealth coordination to ensure a consistent national framework.

Coordinated approach to funding, including Commonwealth, states and territories

National standards of assessment, care, support and case management

Governance framework to manage scheme assets, liabilities and data collections to optimise scheme performance and monitor usage.

Active claims management.

Independent review/appeals process.

Whilst we support the principle that supports are provided to those in greatest need, as articulated in the NDIS position above, there are a number of issues in relation to eligibility that we believe warrant discussion.

4.1 Who should be covered by a national disability support scheme?

4.1.1 Support for participation in community and working life as determinants of eligibility

In relation to the existing definitions, we believe that limiting the provision of support to those who have a severe or profound disability would mean that many people with lesser levels of impairment would miss out on the support they need to live a full life. A means of assessing eligibility based only on a measure of a person's impairment would not be able to sufficiently comprehend the impact on the individual, which is better reached through a holistic assessment of their broader social and economic circumstances, and other supports available to them. Furthermore, limiting the provision of support to those classified as having a 'severe' or 'profound' disability would not accommodate people with mild or moderate disability who, with appropriate support, will gain the skills they need to look after themselves². An example of this would be a person with a mild intellectual disability who needs someone to help them develop the skills they need to live independently. With the right support provided at the right stage in their life, although their disability would continue, their supports could diminish.

In our view, the provision of support should be related to what is needed for an individual with a disability to participate as independently as possible in community and work. As mentioned above, the extent to which this is possible for anyone is a function of the relationship between individual factors (including ability and impairment) and the social, cultural, political and economic setting in which they live. In addition to the other supports that they can draw on, the cultural and political settings determine attitudes towards people with a disability, and the

² Productivity Commission Issues Paper, Disability Care and Support, May 2010, p.7

way in which other public resources (eg transport systems and the built environment) work to include or exclude people with physical and/or intellectual impairments. Assessing the extent to which an individual can or can't participate in activities that all community members might reasonably expect to take part in includes consideration of all these factors. Thus, we prefer the definition of disability offered by the World Health Organisation, where disability is located in the interaction between the individual's body and the society in which they live³.

4.1.2 Eligibility which is responsive to changing life circumstances

Framed by this understanding of disability, eligibility and assessment of need should be responsive to an individual's changing life circumstances. A system with sufficient emphasis on early intervention and intermittent support will be able to provide for those who can self-manage to a point, but may need extra support when their personal or environmental circumstances change (eg someone who is living independently, but drawing on the support of a family member who then dies or moves away). Such extra support may be temporary, or permanent, but will assist the individual resume the standard of living that they were accustomed to. By including those with lower functional levels of disability amongst those eligible for support, and by providing flexible and timely responses to changing needs, we believe it will be possible to prevent the kind of escalation of need that currently see some people end up in the mental health or criminal justice systems.

In relation to the duration of need for support, we note that the ABS definition includes disability which is likely to last 'for at least six months and restricts everyday activities'⁴. It is important to clearly distinguish the duration of the disability from the duration of need for support. We believe that a disability support scheme should exist to provide support to those who are permanently disabled in some way, recognising that their need for support may be temporary or intermittent. Those people who, as a result of accident, injury or illness, require support for a temporary period, associated with their recovery, should have their support needs met through the health system, as part of their treatment and recovery program.

4.1.3 Eligibility and age

In relation to the age limit, we agree with the proposal that the scheme supports people who acquire their disability under the age of 65, and then continue their supports when they are older. In order to ensure continuity of support into older age, we believe that the system needs to be flexible enough to provide for increasing support needs associated with ageing. This is particularly important in relation to the individual's living situation: the system should be able to provide additional supports to enable the individual live at home – whether that is with family, in supported accommodation, or supported to live independently – rather than require the individual to move into aged care accommodation, if this is not their preference.

³ Productivity Commission Issues Paper, Disability Care and Support, May 2010, p.7

⁴ *ibid*, p.7

4.1.4 Eligibility and mental illness

In relation to people with mental health issues, we believe that they should be included if their condition limits their ability to participate in community and work life. Whilst their mental health needs should remain treated within the mental health sector, their support needs in relation to participation in activities for a reasonable quality of life should be met within the disability system. We also note that many people with long-term disability (including physical, intellectual and neuro-degenerative) experience periods of poor mental health, which are often associated with dips in functioning and consequent increases in need for support. In both cases, an individual may require intervention from more than one sector.

4.1.5 Eligibility and income and assets

The Issues Paper asks whether eligibility and benefits received should depend on an individual's income and assets, or linked to their ability to pay for services and supports⁵.

We support a public insurance model along the lines of Medicare which would provide a base level of services for all those deemed eligible for support within the disability system. The base level of service provision would relate to the amount of support an individual needs to participate in community and working life at a basic level, in accordance with their capabilities and aspirations. Although we do not support means testing in relation to eligibility, we agree that assessment of the resources in the individual's context should be taken into account when determining the actual supports that are needed, and which should be provided through public funding.

In relation to this, we make the following observations:

- The majority of people that the disability system currently covers have a limited earning capacity, which, for most, extends throughout their life. Most are reliant on the Disability Support Pension (DPS) as their only means of income support. It is essential that eligibility and access to support recognises this limited capacity to earn and accumulate assets both in the immediate term and over the life course;
- In Victoria, publicly funded supports are available to assist people with their disability-related needs, so that they can participate in community and working life. Policy dictates that financial hardship is not a disability-related barrier to participation (eg ISP policy). However, inadequacy of the DSP means that for many people with a disability, financial hardship is, in fact, a barrier to participation. This means that, at times, access to a resource-based support is experienced by the individual and/or family as related to their disability, whereas it is seen by the funder as resource which anyone in the community might access, and therefore not an appropriate target for public funding. For instance, who should pay for the carer's coffee when an individual goes out on a shopping trip? Should internet access be provided for someone with limited mobility, who sees it as a primary means of accessing an online community? Who should pay for

⁵ Productivity Commission Issues Paper, Disability Care and Support, May 2010, p.21

a newspaper subscription for someone with an ABI, for whom their ability to complete the daily puzzle page is an important part of the way in which they maintain their sense of identity and self-esteem?; and

- The families of individuals with a disability provide a great deal of unpaid and unfunded support, often at great cost to the physical, mental and emotional health of its members. In our experience, the vast majority of families will provide as much as they can afford, in addition to the funded support that their disabled family member receives. This support needs to be recognised as a public good, and should not be counted as a private asset when assessing an individual's eligibility for support or determination of level of provision of support.

4.2 Decision-making control and choice: key funding architecture

We support a system in which individuals and families are able to determine the types of supports they need, aligned to their aspirations and suited to the kind of life they want to lead. We draw on our current experience in Victoria of the implementation of individualised funding, through Individual Support Packages (ISP) as the underpinning mechanism for giving individuals who are eligible for support control and choice in relation to the supports and services they receive.

Whilst we support the move to individualised funding, and would like to see this implemented more broadly and the model extended to give individuals even greater control, there are considerations on the 'supply side' of the service delivery system which we think need to be taken into account. Most importantly, the sector's capacity to build strong, meaningful, creative, flexible service options for individuals and their families is only possible when there is a core commitment to recurrent funding for certain vital functions that underpin high quality service delivery. Such funding is necessary to recruit and retain staff who are able to build their knowledge, practice, networks and relationships that then realistically support true community capacity and social inclusion.

We provide some examples that illuminate this point in the sections below.

4.2.1 Constraints on effective individualised funding

Individualised resources don't go as far as group resources

In choosing to design a system which offers a truly 'individualised' response, we will inevitably limit the amount of support that an individual can buy with their package. The outcome of choosing a one-on-one service or support is that it is more costly to provide (for any individual) than a group or shared service/support. Whilst individualised responses may enhance choice, at the same time, options are constrained by the resources which are available.

We have recently reviewed our facility-based day program, with a view to re-developing the model in line with individualised funding and individualised support. This review

highlights the gap between the supports an individual is able to access under block funding, and the supports they will be able to access under individualised funding. In reality, people will be faced with the choice of accessing supports which are provided on a group basis, of similar size to the groups we currently run, or face a reduction in the days in which they access the program.

System complexity gets in the way of flexibility and responsiveness

Negotiating and navigating the complexities of the disability system present a difficulty for individual, families and service providers alike. The complexity makes it hard for people to access and combine supports in the most timely and effective manner in a way which is responsive to their needs. It is not uncommon for families to come to meetings with large, lever-arch folders filled with documentation that they have received relating to the services that their loved one accesses. For many, it is a challenge to keep abreast of this mountain of paperwork – and it is hard to imagine how people with impaired communication or cognitive function or developmental delay would be able to operate without support. The complexity of the system limits choice by providing insufficient or incomprehensible information: few services offer people an opportunity to try before they buy, which would be the best way to enable informed choice and to establish ‘customer loyalty’ within the system.

We are currently undertaking a participatory evaluation of our ISP Funded Facilitation program, which involves package recipients, families, Wesley service delivery staff and managers and staff from DHS working together to evaluate the program’s effectiveness and outcomes. This project has identified that any attempts to provide greater levels of control by enabling people to make decisions about the supports they need and receive are inhibited by the complexity of the system as it currently stands. Individuals and families suggest that the current system is very complicated and difficult to negotiate, leaving them feeling as if they have very little control. This becomes particularly apparent when something goes wrong with current supports, or their needs change, where the business of renegotiating appropriate supports can be confusing, time-consuming and ineffective. Quality of information, how that is made available and accessibility and the lack of advocacy and support for individuals in relation to negotiating the system, beyond what their family and informal supporters can provide, are all inhibiting issues that individuals and families have raised during the course of the evaluation.

Whose money is it? Making the ultimate decisions about what funds can be spent on

Currently in Victoria, an individual who has an approved ISP package needs to submit a proposal to DHS to indicate how they intend to use the funds to support their disability needs. The development of a proposal is generally done in collaboration with a facilitator, working in a Funded Facilitation program that organisations such as Wesley provide. The proposal is then assessed against the ISP principles, and those proposals which meet the principles and are within the funding allocation are automatically ‘verified’. Those proposals which request supports which sit outside the principles or exceed the funding allocation are subjected to further scrutiny in order to determine whether they can be verified.

Our ISP Funded Facilitation evaluation has revealed that 'choice' is available whilst it is in line with Department-proscribed ISP principles, but once an individual or family identifies something that they consider to be a legitimate disability support need which sits outside these parameters, they feel they have no control – or at the whim of the bureaucracy who 'verifies' their proposal⁶.

In light of this, and consistent with the principles of choice of supports and control of decision-making, we prefer a position where there is not need for 'verification' when the proposal the facilitator and individual develop is within the funding allocation. This would enable the individual to use the funding in whatever way they felt fit, with the assistance of an expert in planning best use of the funds, in relation to support needs and goals and aspirations. Individuals and families would then be ultimately responsible for the quality of the decisions they made – as are those of us who have no need to have 'verified' how we intend to use the resources we have available to us.

Those proposals that requested supports which exceed the funding allocation would, however, require further scrutiny in order to determine whether additional funding was available, and could be provided.

ISPs don't work for all types of support

In addition to the comments above, we note that ISPs work well in relation to the provision of personal support. We are concerned that funding allocations do not extend to the provision of a greater range of services which we consider essential for participation in community and working life, particularly for those with higher levels of physical and/or personal support needs. These include:

- The development of independent living skills;
- Support for education;
- Support for employment, and
- Support for housing.

Our experience of working with people who are in receipt of ISPs suggests that it is those people with relatively low physical/personal support needs who are able to effectively use their funding to participate in meaningful, day-long activities, whereas those with higher levels of support need remain in situations where activities are provided through congregate arrangements.

People need support to make the move to individualised funding

The move to individualised funding is a major change for a system which has been highly protective of the vulnerabilities of people with disability (particularly those with lifelong disability). There is a great deal of fear in all parts of the system about the impact of individualised funding for individuals, their families and for service providers.

⁶ Please note: we would be happy to discuss in detail the review of our ATSS, findings from the ISP evaluation or 'Supporting the Journey through older age' project (mentioned later in this submission) with the Commission at a later date.

Through our current evaluation of the ISP Funded Facilitation program, we know that people feel uncertainty and anxiety about the continuity of funding – they worry that what they have in their current allocation may be taken away or diminished in the next allocation. This fear inhibits their preparedness to speak up when things go wrong, or don't work for them, in case they lose what they currently have. This fear combines with the complexity of the system, mentioned above, and the need for people to keep even more paperwork, and understand a yet greater number of government processes.

Our project 'Supporting the journey through older age for people with a lifelong disability' involved the development and trialling of three service innovation pilots for people ageing with a disability. One of these pilots enabled older people to stay at home for two days during the week, rather than attend their day program. They were supported to do this by staff from the day program, within the older people's home. At first, the staff wanted to run a low key program for the older people, along the lines of programs run in a day activity centre, but 'lower key'. Staff were particularly confronted by one resident who wanted to have a nap during the day, which they saw as an inappropriate thing for someone to do during the day. With some critical facilitation and support, staff were able to change their practice so that it became more responsive to the needs of the individuals – even if this did mean they nodded off. The valuation of the pilot identified the critical facilitation and management support as essential components of successful change and service development.

Our experience establishing a shared supported accommodation for young people with neuro-degenerative conditions who had previously been living in nursing homes suggests that people's goals expand as their experiences expand, and the service system needs to be flexible enough to respond to this. For these people, their personal horizons have expanded, with appropriate support, faster than the system can keep up with them, and staff are finding that they are not always able to provide timely support for new goals.

Only with empowered and resourced staff can we have empowered clients, and considerable developmental work is needed to get to this point.

Based on our current experience of working with individuals and families who are making the shift from block to individually funded services, we suggest that there should be a period of transition in which clients and families are provided with the information and support they need to gain the knowledge and skills to operate within the new funding and service regime. This is the case particularly for those individuals and families who have been involved in the disability system for many years, and for whom the change to individualised models of provision can be difficult and daunting. In our experience, the complexity of the system, and increasing requirements for individuals and families to take on responsibility for managing support arrangements, can be too much, and lead to people not accessing the supports that are theirs by right.

4.2.2 The need for block funding

In order to ensure the continuance of quality service provision across a range of needs, we suggest that the full-scale implementation of individualised funding is inappropriate. We believe that there is a place for some block-funded services, including the following:

- Shared supported accommodation, where individuals require funded support at night and funded activities during the day. A base level of funding for core activities should be provided to the house to ensure continuity of support and experienced staffing when people with differing levels of need move into or out of the house, or when the house has a vacancy for a period of time;
- Short-term respite should also be core funded in order to build service provider skills and commitment from families and individuals using the service. The provision of core funding would enable families and individuals to try out a service to see how well it meets their needs – an essential mechanism for providing people with genuine informed choice. Without core funding, the proposition of running a service which meets fluctuating and hard-to-predict levels of need, will deter many providers, limit choice for families and impact on quality of provision;
- Planning, facilitation and information services whose primary purpose is to enable people and their families access the disability support system in general, and utilise specific funding eg ISPs. Without the provision of funded services, it will not be possible for providers to build the networks and skills they need to provide a high quality service to people holding individualised funding packages; and
- Services where individual client numbers may move up and down, and where block funding of core elements is required to ensure continuity of service for existing clients.

An example of the need for core/block funding is Wesley's Homeshare program, which matches a home-owner with a disability with a home-sharer who provides them with some in-home support in exchange for accommodation. A recent review of this program has indicated that the program delivers good outcomes for the individuals involved, and allows people with disability to live independently, with the support the home-sharer provides, and, in some cases, additional support (eg personal care) funded through their ISP. The review estimates that a single worker can support 10 matches (counted as lasting for six months or more), comprising five existing and five new, at any one time. Whilst the program demonstrates good outputs in terms of sustainability of matches, and ongoing support through multiple matches, some degree of turnover and replacement is inevitable. Without the provision of recurrent funding for the core elements of the program, including recruiting participants and building staff networks and skills, the program is not viable over time due to the fluctuating and unreliable funding base (where it relies on ISPs alone). Such unreliability also makes it a risk for participants who want to try out the program, without knowing if it will meet their needs.

5. Services and supports

This section of the submission focuses on the services and supports that we believe should be included in a national disability support scheme.

5.1 Supports for individuals and families

Supports should be available to assist individuals participate in relationships and resources in their community, undertake activities which are meaningful to them and where appropriate in paid work. As identified in the NDIS campaign (NDIS 2010), and mentioned previously, we support the inclusion of the following types of services in a national disability scheme:

- Information and access;
- Early intervention services;
- Personal support and care;
- Development of independent living skills;
- Aids, equipment, technology and home modifications;
- Support to families, including a range of forms of respite, and counselling;
- Funded planning and facilitation; and
- Advocacy services for individuals and families.

Co-ordination with education and health should also be considered, in particular:

- Assistance for children and adults to access curricula;
- Allied health therapies; and
- Mental health services.

The impact of providing support that is generally unpaid over a life-time for a family member with a disability cannot be under-estimated. This takes a toll on family relationships and friendships, may limit people's work and career opportunities, and creates a financial stress all of its own, where families often subsidise supports for the person they love because the publicly funded system doesn't provide an adequate level of support to enable a reasonable quality of life. Not only is this unjust, it is also inequitable.

Most importantly, we believe that services should be provided in a person-centred way, with attention to the individual's holistic needs, including their spiritual needs.

In 2008 we undertook a research project entitled 'Towards meeting the spiritual needs of people disabilities resident in [Wesley shared supported accommodation service]'. This project followed on from a family feedback project which identified that spiritual needs were not sufficiently attended to within current service provision, and were, for some individuals and families, seen to be highly important. The research project identified the following as the spiritual needs that families felt should be attended to in the care environment:

- *Appropriate care for people in their times of pain or suffering;*
- *Support for facing issues of dying and death of family members, and support for dealing with grief and loss;*

- *Justice for people in the community;*
- *Support to take part in faith practice; and*
- *Connection with nature.*

The project also identified a model of spiritual care, consistent with Wesleyan spirituality.

5.2 Supports for the development of inclusive communities

In addition to services provided to the individual and/or their family, we believe that a national disability system should focus some attention on the development of communities which value diversity and which undertake practical work to make the community accessible to all its members. There are many resources in the general community which people with a disability use, or could use: shops, libraries, leisure centres, community centres and neighbourhood houses to name a few. When these are staffed by people who have the skills and confidence to provide services to people with disability (of different types), then individuals can access more resources and their individualised funding can go further. However, community people need to be supported and assisted to develop these skills and the confidence which comes with them.

We would like to draw the Commission's attention to Victoria's whole-of-government approach to building accessible communities eg through the funding of metro- and rural access workers, codifying the need to make new buildings, including housing, accessible, funding advocacy services for people with a disability and provision of IT solutions to aid access and communication. However, to make best use of community resources, we support the funding of support workers to assist people develop the skills they need to access community resources.

5.3 Managing transitions

Key transition points in relation to service provision include: diagnosis of disability/early intervention services; early intervention/school; school/pathways programs (eg Pathways to Employment, Futures for Young Adults); and pathways programs/disability enterprise, employment support or supported day activities. Transitions often require individuals to move from organisation to organisation, and a new system needs to ensure that transitions between service stages and providers are handled better. Key elements of a well co-ordinated system would include:

- Service providers working to a shared, single, whole-of-life plan for the individual;
- Requirements relating to the facilitation of transitions embedded in funding or service agreements, which would ensure that organisations have processes in place for managing transitions early;
- Processes ensure that key information goes with the individual (so that they do not have to 'tell their story' all over again);
- Both existing and new service providers taking responsibility to monitor the transition, again embedded in the funding or service agreement; and

- Establishment of targets to ensure that transitions are completed successfully, so that people don't drop out of the support system at critical points (eg between school/pathways, or pathways/employment).

Changes in the carer situation are not handled well at present, and things often get left until the last minute, when things reach crisis point, for instance, where someone is abandoned in respite, before the additional needs are funded.

Finally, processes for getting needs reviewed should be simple, transparent, speedy and responsive, so that individuals and families gain greater confidence that levels of support can be changed quickly in response.

5.4 Support for families and carers

Development of more and better supports for families and carers is an essential component of a fair and effective disability support system. At present, the Disability Support Register in Victoria does not take account of carer support needs – which we believe should be seen as an intrinsic part of an individual's support needs. We believe that whilst many families are resilient, resourceful and creative, such capabilities should not be taken for granted, but should be intentionally fostered. With better support for families, they will be better able to support their loved ones – with a consequent reduction in the need for funded support.

To reflect this, we propose a range of funded services which include:

- Carer support services;
- Family and individual counselling;
- Sibling services; and
- Peer support groups.

Many of these services could be provided by dedicated carer centres, which could also play a key role in ensuring consumer participation in policy development and resource allocation and planning. It would also be possible to deliver such services as part of the generic family service sector, so that the distinction between families caring for a person with a disability and those experiencing stress for other reasons are lessened. Stresses, and the need for supports are then seen as part of the life cycle of any family, and not specially and differently noted and responded to.

We prefer a model of support for families which is seen as preventative: the current system often does not respond until a family is in crisis eg when a disabled family member is left at a respite facility because the primary carer (an ageing parent with cancer) is too sick to look after them any longer, and no alternative suitable supports have been offered. If services are put in place when need is first identified, we believe that the need for more intensive (and costly) supports for longer may be averted. A good example of this relates to supports for a family with a child with autism. Educative services and supports for families, put in place as soon as a diagnosis is made, can enable the family to develop and maintain effective strategies to assist

their son or daughter participate in the broader community in the immediate term as well as into the future. Whilst such services are currently available, their potential benefits are limited by under-resourcing.

5.5 Interface with other systems

5.5.1 Housing

We note that there are limited options for people with a disability in relation to housing. For those with a life-long disability, housing generally means remaining at home with parents, or living in shared, supported accommodation. At this stage, the opportunities offered by the expansion of social housing to people with a disability appear to be limited, and have not opened up their choices to any great extent.

Whilst we support the position that the provision of housing should not be included within the funding for disability support, we believe that Australia's response should be more comprehensive. Our experience as a service provider in this area suggests that not only is the provision of shared supported accommodation inadequate, but that levels of support provided through the ISP program are inadequate for individual independent living. This needs to be considered in the context of more general and widespread moves to a system which is based on individualised models of provision and funding. At present, individual independent living is only available for people with average support needs who, in particular, can care for themselves overnight. Our experience suggests that there are people who are currently living in shared supported accommodation with higher levels of need who would prefer and be able to live alone with appropriate support, but for whom this is unavailable on the basis of inadequate funding. For this group, the ISP program would not be able to meet their support needs through a 1:1 or even a 1:2 staff-client ratio.

We also note the reality at present where individuals in their sixties are being cared for at home by a parent in their nineties – who may also be caring for a partner of a similar age – and regardless of their own health and care needs.

We hold the position that the success of individualised support for people with a range of levels of functional disability is dependant on the increased provision of accessible, affordable housing through the publicly funded sector. Expanded housing options also require action within the private rental sector to encourage landlords to lease properties to people with a disability. We know from our experience in the housing/homelessness sector, as well as in the disability sector, that people with a disability face many barriers to private rental, including lack of physical accessibility in the design of many rental properties, landlords' reluctance to make modifications to properties and prejudice relating to renting to someone on a pension (who may not be able to pay their rent over a period of time) and with a disability (who may not be able to take care of the property).

We believe that supporting increased levels of independence to people would not only enhance their quality of life but enable them to become highly productive members of society by

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building their skills and confidence and integrating them into community and work. We believe that enabling more people with disability to live independently in the community is also a key factor in changing community attitudes towards diversity.

5.5.2 Employment support

As a provider of Disability Employment Support and social enterprises, we are aware of the benefits in terms of quality of life and well-being that participation in paid employment offers people with disability. We are also aware of the limitations of the current system, and the opportunities for expanded, enhanced supports to enable more people to undertake paid work.

We are aware of, and intend to contribute to the current Australian Government review, 'Inclusion for people with disability through sustainable supported employment', but would like to make the following comments in the context of the current inquiry:

- People with disability need real incomes. The pay provisions in many awards for people with disability are poor. Poor income over the life course means that people are also disadvantaged in terms of their superannuation, thus experiencing ongoing financial hardship over their life course;
- The transition between the Disability Support Pension and part-time work does not encourage people to take up part-time employment because of the deleterious effect it has on their pension;
- There are poor linkages between disability services and employment support: for instance, Wesley runs both a Disability Employment Service (DES), including a number of employment planning programs and a number of social enterprises. There is little overlap between the two programs, and individuals rarely move between one and the other in order to gain appropriate supports. Whilst we are undertaking measures to address this within our own organisation, there is little imperative at the level of service agreement or policy to encourage such co-ordination. For instance, placement in a social enterprise may be the most appropriate outcome for an individual at a particular point in time, but this is not counted as an employment outcome that attracts funding for a DES;
- The level of resourcing required to train staff member with disability is also a major barrier, particularly for small businesses who lack a surplus of staff who would be able to meet this training need. The risk of financial hardship that such training may lead to prevents many employers from hiring a person with disability;
- Re-training of clients with a disability can also be quite costly for those not eligible for federal funding. This group tends to find 'survival' jobs rather than long term prospects which see them leaving employment more readily as opposed to those with a qualification;
- Additionally, people with disability often require flexibility in relation to working hours/days they work, which is a challenge for many employers, again, in particular, small businesses;
- There are a substantial number of people, who, as the result of acquisition of a functional disability, are unable to work in the industry that they had previously been employed in. A higher volume of entry level positions, such as pick-packing, which

- would benefit those people who aren't suited to education and would learn better through an on-job experience; and
- There is a need for better employer education in relation to hiring people with disability, which an extension of government funding in relation to disability awareness training would go some way to addressing.

It is essential that the design and implementation of a national disability support scheme is cognisant of the context of employment for people with disability – in terms of the supports available and their level of effectiveness, the limited real opportunities to gain quality paid employment that people face, and the impact that low income has on the individual's ability to participate in things that contribute to having a reasonable quality of life.

6. System effectiveness and sustainability

This section of our submission focuses on some critical issues which cut across both broad system design and the implementation of specific services, and which impact on the effectiveness and sustainability of a national disability support scheme.

6.1 Roles for families, service providers and government

One of the key features of effective system design is to identify appropriate roles for different stakeholders. We propose the following roles:

- Government departments, with appropriate input from individuals who receive or need services, families and service providers, should be primarily responsible for the development and implementation of policy, high level resource allocation and the development of broad-scale programs to meet existing and emerging needs. We believe that more effective planning is possible than currently operates, and that this is a critical role for government. In Victoria, there is scope to use the information collected through the DSR on unmet need to plan at a regional and sub-regional level (individual data identifies LGA), although this currently does not happen. A planning process which involved a broad range of stakeholders within geographical communities would assist in ensuring that relevant and sufficient services were available. A good example of local planning processes is in the mental health system in Victoria, where the State has been divided into 21 areas with responsibility for identifying need and providing services. This system requires stakeholders to work together to 'own' the individuals who need mental health assistance, and to look at ways of ensuring they have the resources they need to provide services appropriately. A principle of an individual's right to access services within their local area underpins this model.

Government departments should not be involved in the direct provision of services, which should be left to the community sector. The current situation, in which Government is both a purchaser and provider of services, as well as responsible for developing policy, is ridden with conflicts of interest and tensions when working with providers and users of services.

- Community sector organisations (CSOs) are well placed to deliver services. They have strong links with the individuals and families they work with, as well as with other service providers within the disability sector and local communities. By working closely with the people who access their services and their families, they are best placed to work out the best ways to meet people's support needs, and to identify and develop new programs to meet the new and emerging needs of those that they work with. Combined with transparent and collaborative planning mechanisms, CSOs, with the involvement of individuals and families, would then be able to make good decisions about the sorts of services they would offer. We believe that this would encourage the development of a consumer-oriented market for services and supports, which would work to the benefit of those who would be looking to purchase services. With government primarily responsible for administering service planning and resource

allocation, CSOs would also be accountable back to government to ensure that a full range of services was on offer, not just those which were the easiest to provide, or which met the commonest need. By involving individuals and families in service development and delivery processes, CSOs would also be accountable back to the people they work with.

- Families provide a great deal of unfunded support to their members who live with disability. Despite the rhetoric of control and choice, they are often left carrying the responsibility on their own, with very little real control over what they get or how it is delivered. They need a real, effective voice within the decision-making structures – not just in relation to the services they need and receive – but in relation to critical decisions about resource planning and allocation. We propose that funded positions established within the relevant bureaucracies would assist in ‘hearing’ family and carer voices in the development of policy and provision of programs.

6.2 Support for community sector organisations

In order to assist service providers move to the provision of sustainable, quality services within an individualised funding model, it is important to undertake robust feasibility studies at a local level. At present, we do not believe that the majority of service providers in the disability sector have the skills or capacity to undertake such studies.

A component of investigating the feasibility of delivering supports in an increasingly individualised funding environment should include the identification of the size a service needs to be in order that it is sustainable and capable of growth under individualised funding.

A further element relates to how to establish the cost of providing a service relates to knowing who will, or is likely to, access services. Unlike a system where ‘clients’ are allocated to providers, an individualised environment makes it much harder for service providers to estimate the local need for any given form of support. There is a risk of duplication of provision in some areas, or lack of provision in others (particularly working with people with complex needs and/or behaviours of concern), and the possibility that the most available services will be those which are easiest to deliver, or most broadly applicable – meaning that those with very specific needs may miss out.

6.3 Funding for innovation

We support a system which encourages innovation, both in the identification of and response to need. However, we note that whilst ideas come from current practice and from working alongside the people who use our services, the development of innovative models of practice require additional and specific resourcing.

The ISP system in Victoria encourages responsiveness to individual circumstances and flexibility in the way that supports are provided. In our experience of a provider of funded facilitation to *Wesley Mission Victoria: Submission to the Productivity Inquiry into Disability Care and Support, August 2010* 21

people with ISPs, we know that working closely with individuals to identify their needs and ways to meet them leads to new ideas for the ways in which services and supports can be provided. However, case loads and targets allow no time for development of innovative responses, leading to cynicism that ISPs are about 'doing it cheaper' rather than better.

6.4 Workforce development

Many staff have minimal training and are poorly remunerated. As mentioned earlier, these two factors impact on the implementation of wide-scale, fundamental change, and should not be under-estimated.

Individualised funding also poses risks in relation to training and development. We do not believe that the funding for staff training and development is most effectively provided by charging service users as a component of the cost of providing a service to them. There is a risk that a strategy which requires organisations to raise the costs of staff development through an 'administrative levy' on service costs, will result in those organisations picking the individuals who are easiest to work with, thus lessening the need for highly skilled staff, or staff who will need ongoing skill development.

We are also concerned that this is an unfair arrangement, and one which is not in the interests of social justice for vulnerable people. We prefer a model where organisations are partly funded on a recurrent basis for the core function of workforce development. This will ensure that organisations can provide appropriately skilled staff, who have the capacity to provide skills development to those staff to meet changing community need.

6.5 Measuring the impact of services and support

Finally, we support the development of a system where organisations are funded to build their capacity to measure the impact that an intervention is having, so they can continue, change or cease their current practice and services. At present, this is in place for with Early Intervention Services across Victorian services and in schools, but not in other parts of the system. Broader implementation would assist with service co-ordination for individuals who access supports from more than one area or organisation.

We believe that impact/outcome measures which are developed with the input of people who participate in our services are the only way of making sure that we are making a difference that matters to them. This is a key tenet of Wesley's approach to social inclusion, where individuals have the right to say what they want to do with their lives, and what they most want assistance with (in terms of services we provide). However, it is important to recognise that the development of such measures takes more time than the development of measures in isolation from those whose lives and aspirations they refer to. Moreover, this takes skills which many community sector organisations do not have, and are not resourced to access. Thus funded support to enable organisations to develop and implement impact or change measures should be a feature of a newly designed national disability support scheme.

Impact/outcome measures should be accompanied by the development and implementation of KPIs around what 'quality' service provision looks like in terms of service outputs across service continua involving multiple providers and agencies within the disability system and in systems which interface with it.

One example of a quality review process which we believe is effective in developing better service provision at system and practice levels is the peer review process in health and mental health sectors. Here, service quality is looked at in terms of 'pathways of care', where all stakeholders involved in providing services along a continuum to a single individual are involved in a developmentally focused review of effectiveness of current practice. The process gathers data from the point of intake to the implementation of supports, and involves all stakeholding organisations, including bureaucracy and providers in a process of reviewing what happened and how it worked. The process is perceived as non-threatening, and, in mental health is lead by the Office of Chief Psychiatrist (whereas in the disability system in Victoria, it could be lead by the Office of the Senior Practitioner). In the mental health sector, the process is seen to be highly effective in identifying points for improvement within the system, because it was focussed on identifying outcomes for clients.