Forward: Introduction to Melbourne Citymission:

Melbourne Citymission is widely recognised as a leader and innovator in the provision of services to the community. Established in 1854, Melbourne Citymission is a non-denominational organisation that assists Victorians who are marginalised, at risk, disadvantaged, frail or denied access to services. Melbourne Citymission aims to build an inclusive community through personal and social transformation. We work towards this by providing a range of support services to people across all life stages from early childhood to palliative care. This work reflects the organisation's interest in life transitions and the ways in which people can best be supported to achieve sustainable transformation in their lives.

Melbourne Citymission assists over 4,000 Victorians on average each week through programs in the following areas:

- Children, Youth, Adult and Family Services
- Disability Services
- Palliative Care
- Youth Homelessness
- Employment, Education and Training

The range of services and programs offered by Melbourne Citymission are underpinned by the key principles of:

- Engagement of the individual as a basis for assessment of needs and experiences,
- Continuity of support through a strengths approach to case based practice, and
- Providing an integrated suite of assistance and resources matched to individual goals.

Melbourne Citymission aims to build inclusive communities by facilitating equitable access to opportunities and resources for people who are living with disadvantage.
To advance this agenda, the agency has engaged as a leader or partner in programmatic initiatives which promote social inclusion for particular populations of people who experience exclusion.
Additionally, Melbourne Citymission has used community development approaches to address social exclusion in under-resourced places or communities.

Support for a National Social Insurance approach to the needs of people with a disability, and their families/carers.

Melbourne Citymission welcomes the initiative of the Commonwealth Government in referring the breadth of issues being experienced across the Disability Services sector, to the Productivity Commission. We support the approach in looking at fundamental reforms, rather than continuing to attempt to further 'patch together' systems that are clearly straining to address demand with the resources currently available.

Fundamental principles:

Melbourne Citymission supports the principles developed by the National Disability and Carer Alliance, as a starting point to the development of a new approach to Disability Care and Support:

Universal

Disability does not discriminate in its effect on individuals and families. While there are some specific types of disability that occur as a result of genetics, the majority of disability occurs unexpectedly whether at birth or acquired later in life. In line with this experience, Melbourne Citymission agrees that it is important to respond as a whole community.

The Australian cultural expression of a 'Fair go' would suggest that a system of universal contribution to a scheme, along the lines of the highly valued universal access to health care through Medicare, is important and would be accepted across the Australian population.

Fair

Melbourne Citymission recognises that there are a wide range of disabilities in our community, and a common element of experience is the effect these have on an individual's ability to function equally as a citizen. All people with a disability should have access to appropriate and adequate support, no matter how their disability is acquired.

There is clearly a need to provide services and supports that target the specific needs of individuals, but a new system also needs to recognise the common elements across all disability types and ensure access is not limited by the type of disability experienced.

Comprehensive

The occurrence of disability requires significant adjustment to lives and expectations by individuals and families, and mostly requiring timely and skilled intervention, in many cases for the rest of life. In our experience in providing services, there are many dimensions to the support needs in response to disability, and these include:

- targeted assistance provided by skilled, knowledgeable and experienced workers,
- training and mentoring to people with disabilities and the families/carers;
- assistive technology (aids and equipment) to provide access capacity and management in the community, work and home
- a built environment and social media which are universally accessible
- community awareness and inclusion
- research and innovation that continues the development of new options in a world of fast http://www.eciavic.org.au/advocacy/moving scientific and social advances in our lives

Efficient and Effective

A social insurance scheme means that there needs to be accountability for the use of universally provided resources. This requires that the administration of the disability care and support scheme is designed to ensure that benefits flow as efficiently as possible to those who need them, while being responsive to need.

Melbourne Citymission supports a system that is administered as close as possible to the 'coal–face' and that policy development and service contracting is not burdened by unnecessary levels of bureaucracy.

The current system of rationed services for people with a disability means that not everyone gets to achieve their maximum potential and independence. The lack of access to timely, adequate and appropriate services and supports, particularly sufficient early intervention opportunities means there is wasted opportunity for people with disabilities and their families/carers to contribute effectively to the community. It also involves costs to the community that are unnecessary.

Early intervention systems have proven to prevent an escalation of costs later-on, and this has shown to be particularly important in the case of children with complex needs, acquired brain injury and autism spectrum disorder. Additionally, the timely provision of supports to people who have diagnosed mild or moderate disability can halt the escalation of these conditions from becoming more severe and costly later.

Despite the evidence of the importance of early intervention for children with a disability, over 1,000 Victorian children are waiting for a place in an early childhood intervention service[1]

Evidence-based practice, regular evaluation and continuous quality improvement systems have ensured that there is increased efficiencies and use of resources and Melbourne Citymission supports continuing these processes in any new approach.

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[1] Early Childhood Intervention Australia (Victoria Chapter) http://www.eciavic.org.au/advocacy

Self-determining

A person-centred and self-directed approach to the provision of services, based on the choices of the person with a disability and their family/carers is the ultimate goal of any service provision in a disability care and support system. This approach allows for the people who have the greatest understanding of their needs to be in the driving seat, and prevents intervention in lives through the unnecessary imposition of intermediaries.

Underpinning this ‘individualised’ approach is the need to ensure that there is not an undue burden on people, requiring that they manage the complexities of negotiating service opportunity, access and selection when they are experiencing stress and trauma, or as a direct result of the disability.

Melbourne Citymission also recognises that some aspects of disability compromise the capacity to be able to cope with individual management of a disability care and support system, particularly for those with cognitive disability and limited communication. Access to appropriate skills and experience, information, case management and/or case co-ordination, either life-long or for limited periods of time needs to supplement individualisation of the system.

Key overview from the Melbourne Citymission experience:

The Disability Services portfolio at Melbourne Citymission currently accounts for about six per cent of Victorian *Department of Human Services (DHS)* funding for the metropolitan north-west region. Melbourne Citymission is one of the two largest non-government providers in the region in resource terms. This region is the Department’s largest (home to 30 per cent of the State’s population, with four of Melbourne’s five urban growth corridors within its boundaries). It is also the Department’s most complex region, in terms of need, diversity, social disadvantage and number of service partners.

While disability advocates – particularly those involved in the self-advocacy movement – have made significant gains in removing or mitigating infrastructural, institutional and attitudinal barriers over the past 30 years, people with a disability continue to be amongst the most marginalised in our community. Across the board, people with disability experience poor outcomes on a wide range of indicators.[2]

The fact that Melbourne Citymission’s disability services are ‘cross-disability’, are delivered through a range of specialist **and** universal platforms, and have varying levels of integration with other Melbourne Citymission client service areas (such as Children’s Services), provides us with unique insights into disability and social inclusion/exclusion.

We have identified **five key priority areas** that require addressing in the disability field:

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[2] Anne Pate, *Disability: Maximising Participation and Inclusion, Melbourne Citymission Scoping Paper*, Melbourne Citymission, September 2006, pp. 8 - 12

1: Homelessness and disability

People who are both homeless and living with disability do not appear to be considered in mainstream discussions of disability or in mainstream discussions of homelessness. In this sense, they are perhaps one of the most deeply excluded population groups.

2: Individualised funding

Individualised funding is arguably the most significant systemic reform in the disability arena since deinstitutionalisation. It will have wide-ranging impacts. The available literature on individualised funding shows that while personal budgets are "the current catch-all solution"[3], it doesn't overcome all difficulties.

3: Access to social housing for people with a disability

In recent research commissioned by the Australian Housing and Urban Research Institute (AHURI), Beer and Faulkner note that housing options for people with a disability have *"become increasingly restricted due to the reduced availability of public and private rental housing, the high cost of relocation, limited earning capacity and general housing inflation."*[4]

4: A national disability research agenda

Australian governments have traditionally invested very little in disability research. While there is leadership being shown through the tertiary sector such as the Disability Studies and Research Centre attached to the University of New South Wales, and the Australian Institute of Health and Welfare have done some significant work, there is an opportunity through this new scheme to address a key gap in the knowledge base through national collaboration. **The Disability Investment Group report: *The Way Forward- A New Disability Policy Framework for Australia*, indentifies that there is a need to 'fund a National Disability Research Institute as a centre of excellence to lead and promote disability research', and Melbourne Citymission supports that approach.**

5: Compliance with the new United Nations Convention on the Rights of Persons with a Disability (UNCROPD)

A move away from the 'old welfare approach' towards a rights-based/social inclusion framework continues to require attention, despite legislative milestones such as the Victorian State Disability Plan 2002 – 2012, the Victorian Human Rights Charter and the new mandatory Disability Action Plans under the Disability Act (2006)

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[3] David Boyle, *Assets that can't be bought*, The Guardian, 16 July 2008, accessed at http://www.guardian.co.uk/society/2008/jul/16/longtermcare

[4] Andrew Beer and Debbie Faulkner, *The housing careers of people with disabilities and their carers*, AHURI Research and Policy Bulletin, Issue 107, May 2009

While all these areas may not be addressed solely through the opportunity provided by a new national Disability Scheme, they cannot be overlooked if the scheme is to address the needs of people with a disability and their families across Australia.

Workforce participation

As well as the listed priorities, the particular area of under-participation in the workforce by people with a disability remains a major challenge. In essence, there are barriers at all stages of the pathway into employment. Melbourne Citymission believes that the causes of, and solutions to, the disadvantaged position of people with disabilities in the labour market are complex and interrelated:

Barrier 1) Lack of access to pre-vocational and pre-employment training

Under the Commonwealth, States, and Territories Disability Agreement, there is inadequate provision for pre-vocational and pre-employment training for people with disabilities, including those with an ABI. The Commonwealth Rehabilitation Service and the Disability Employment Network require participants to be ready for work in the open employment market. They are under-resourced with respect to the intensity and length of time that is required to assist people with cognitive impairments into work. State-operated Adult Training and Support Services are funded to provide social and community support rather than preparation for employment.

Barrier 2) Lack of appropriate job pathways, eg. out of supported employment services into competitive employment, or between different career stages

People with disabilities are often treated as a homogenous group. There is a risk that they will be relegated to menial jobs in skill shortage areas regardless of their abilities and regardless of how their capacities develop as they move through their working lives. People with a disability who are successful in obtaining supported employment find it difficult to move on from this to other forms of employment. One of the barriers that prevents this transition, apart from insufficient systemic support to help people with disabilities progress through different options, is inflexibility in the funding structure for those living in supported disability accommodation.

Case Study: Shared Supported Accommodation (or Community Residential Units)

Due to limited funding through the Shared Supported Accommodation (SSA) option, residents are required to be out of the house between 9am-3.30pm unless they are able to spend the day at home without support. This funding structure requires clients to either have a full-time work or day placement, or to be able to be unsupported at home. Many residents are not able to work a full day, and would need support if they stayed at home. As a result, they gravitate towards 'safer' options such as full day placements or full time supported employment, rather than open employment. Clearly, greater flexibility in the accommodation funding model is needed to support the transition into employment of people living in Community Residential Units.

Barrier 3) Community and employer attitudes and understanding

A critical barrier to the employment of people with disabilities is the attitudes held by employers and the broader community. Additionally, employers often lack understanding of the supports that some people with disabilities, particularly those with cognitive disabilities including Acquired Brain Injury, need in order to flourish in the workplace. People with disabilities themselves also frequently lack confidence in their ability to work, and may not see it as a realistic option.

John worked with a case manager to identify return to work goals after sustaining an ABI through an assault. He then participated in work-readiness programs through his local DEN provider. John, who presents well in interview, was able to use his previous history in clerical work to show that he is familiar with the expectation of the workplace. He was able to secure employment in a local firm through his own initiative. After a short time, however, issues of lack of stamina became apparent and his ability to organise his work day became problematic for this employer.

Fortunately John's case manager had continued the relationship, and John was able to arrange a three-way meeting with his employer where the longer-term affects of his ABI were able to be discussed. The use of supplementary Occupational Therapy to implement some memory strategies, equipment that John could use to prepare his day's work and a reduced span of work hours each day has meant that John has been able to continue his employment. The 'hidden' nature of his disability required additional expertise, not readily available to an employer.

Barrier 4) Inflexible welfare system

People with disabilities may be discouraged from exploring particular employment opportunities because of the inflexibility of the welfare system. Melbourne Citymission's experience indicates that some Centrelink staff undertaking assessments for eligibility for the Disability Support Pension lack the skills and competence to assess the particular skills and support needs of people with disabilities, particularly people with a cognitive impairment such as an acquired brain injury, who may present with low insight into their abilities and strengths. Their stamina at work may also fluctuate, requiring a more flexible system that would allow them to combine access to benefits and employment as needed.

Barrier 5) Inflexible and inadequate supports for daily living - eg. transport, assistive technology and attendant care

A significant barrier for many people with a disability to finding and keeping employment is the inflexible and inadequate nature of current supports for daily living. Accessible transport, appropriate assistive technology, and timely and adequate attendant care are not luxuries for people with disabilities – they are essentials. Current access to these supports is inadequate and unreliable for too many people with disabilities.

…. due to lack of building and toilet access there are less jobs available to me. One can only work in an accessible building. But my lack of employment is also due to attitudes about disability and the perceived difficulties of employers about access among other things. If there was funding for appropriate desks, hardware and software, workspace and access at workplaces which employ People with Disabilities then employers may be more interested.[5]

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[5] qualitative data emerging from the soon to be published *Equipping Inclusion Studies: AT Costs and Outcomes in Victoria,* Deakin University 2010

Response to the Productivity Commission Issues paper May 2010

Specific questions raised:

5. Key design elements of a new scheme

Melbourne Citymission has identified through its work over many years in providing disability services that a solution to the dilemma of the level of need for people with a disability, is best done through streaming at the entry point to this proposed scheme. This assumes that this scheme is designed to cater to the needs of all people with a disability, rather than only some.

The use of early intervention processes, implemented at the entry point to a broader disability care and support scheme can provide the deciphering required between those whose needs can be effectively met through short-term and/or intermittent service response and those who will require a longer term or life-long engagement.

Early intervention strategies have shown to be effective in many areas of disability[6]. There have been a variety of long-term outcome studies that show this approach can make significant differences to the quality of lives lived for people with even very high levels of disability. Demonstrating clear short-term financial savings through this approach, though, has been more difficult, and this has been a challenge for a system driven by the political cycles of three and four years.

Early intervention has shown to be very effective in building resilience in families where there is a complex developmental presentation in children. Meeting developmental milestones with the support of skilled and experienced interventions then offers improved long-term outcomes for the child, and reinforces preventative strategies so that future 'falling behind' can be avoided.

In the case of acquired disabilities such as ABI, there are clear reasons why the use of early intervention is useful to outcomes:

- At the mild and moderate end, engagement in disability supports and therapies can prevent the escalation of conditions to more severe, particularly in the behavioural dimension of support need.

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[6] Dr Jack Shonkoff: From Neurons to Neighbourhoods: http://www.childrenofthecode.org/interviews/shonkoff.htm#From_Neurons_to_Neighborhoods: accessed 06/08/10

- At the more severe end of the spectrum, the prevention of the onset of contractures through community based therapies, while the person is still in early stages of recovery can prevent the need to expensive surgical and long-term therapeutic interventions in the community.
- With Autism there is now emerging evidence that early intervention can also prevent the need for more complex interventions later in life.

There is a strong evidentiary base for society's investment in the early years.. Intervening earlier and more effectively is a major theme of all the recent State and Federal Policy documents in both the disability and children's services fields7. The Commissions for Children and Young People in NSW and Queensland 'A Head Start for Australia' give the main findings of literature reviews on the subject as:

- 'The early years of life are an important period of brain development, setting the base for competence and coping in later life.
- Early childhood development programs have demonstrated cost-effectiveness, with benefits for the child, the family and the community.
- In the context of rapid social and economic change, there is evidence that some health and wellbeing outcomes are worsening. This suggests that existing systems and structures need to be improved.
- Apart from any cost benefit analysis of ECD [Early Childhood Development]programs, society has a moral responsibility towards children.'8

A second approach that requires implementation is for those whose needs can be primarily addressed through a self-directed process, through the development of plans, either self-managed or with the support of planning agencies. This system has been developing in Victoria and is proving to be effective for those who have the capacity and desire to frame and oversee their own supports. With additional support, many people with profound disability can self-direct, even if they do not wish to administer the service contracting, payments system and quality reporting that may be required.

A long term care and support system would be able to be managed separately to the early intervention and planning streams, and may incorporate elements of both of those. However, the complexity of assessment and service tailoring, frequently occurring co-factors such as marginalisation, health conditions, dual and multiple disability and substance use, and cultural and family specific needs

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[7] Llewellyn et al, Supporting Families: Family wellbeing and children with disabilities [2003]; Gordon in Ozanne, Bigby, Forbes, Glennen, Gordon & Fyffe, Reframing Opportunities For People with an intellectual disability[1999]; Moore, Review of the Research Evidence on Early Childhood Development [2002]; Wagstaff, Review and Development of Support for Children with a Disability and their Families, Final Report [2005]

[8] A Head Start for Australia: An Early Years Framework. NSW Commission for Children and Young People, Commission for Children and Young People [Qld} [2004]

require a more detailed response. Separating this stream would mean efficiency can be achieved for the majority of those whose needs are more straight-forward.

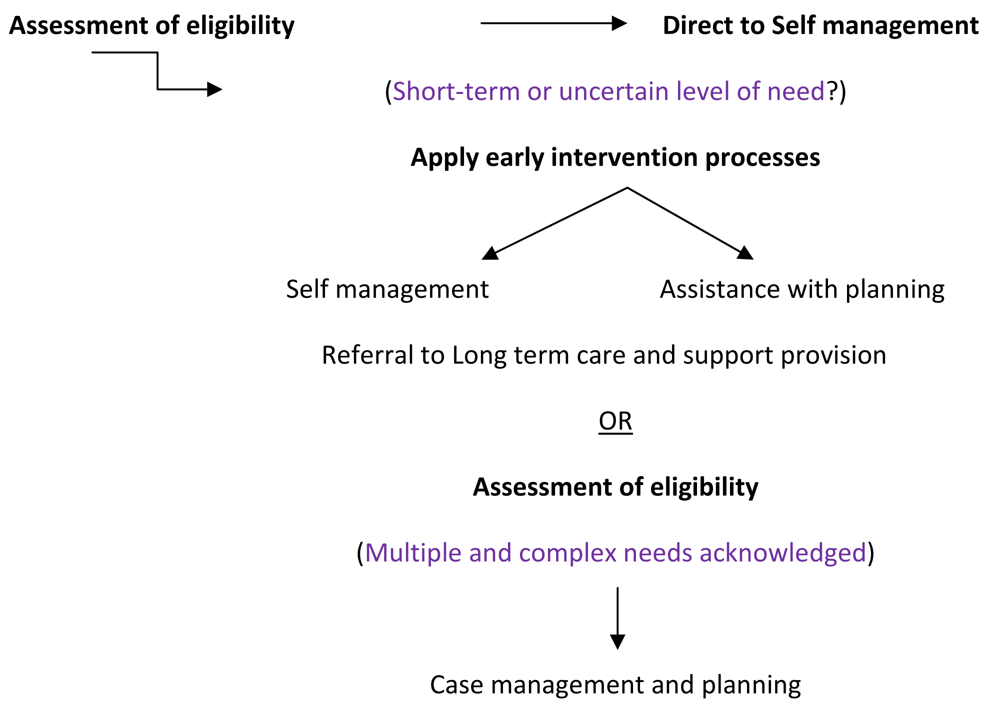
The benefit of having all of these streams coordinated under the one system is that the problems of system interface and silo mentality can be reduced. There will still need to be partnerships and coordination across sectors, with the education, health, justice, employment, housing and community care sectors in particular, frequently involved in the lives of those with complex disabilities.

There has been an artificial separation between the systems for people with disabilities that are the result of compensable accident or injury, and for those where there is no insurance. Similarly artificial is the separation of streams for those with traumatic injuries from other non-traumatic injuries. The resulting support needs are similar but the separation has introduced significant unfairness into the community response, particularly with the huge differences in access to resources.

Melbourne Citymission rejects any proposal to continue the separation of insurance and compensation schemes both because of the resulting unfairness, but also because separation has mostly thwarted the development of joint initiatives in housing, support and management with the public sector.

The retaining of the option of common law claims where there is clear liability should not prevent the development of a universal system for care and support.

Possible streaming model:



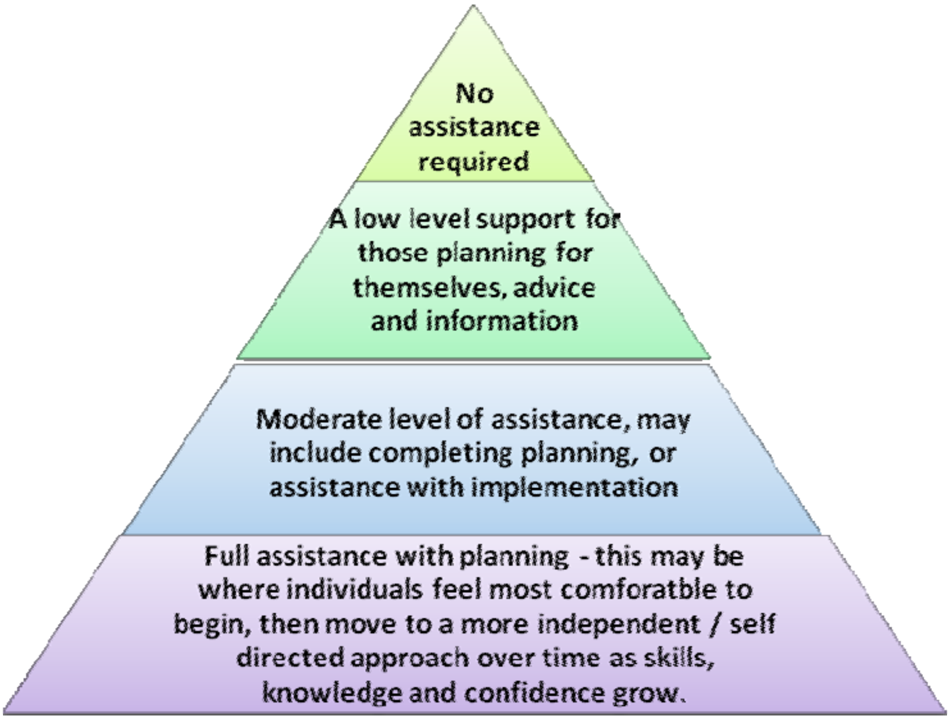
An appropriate planning and implementation framework

With the introduction of the Victorian Disability Act 2006, the goal of self-directed approaches to the provision of disability services has been significantly advanced. There are ethical as well as practical reasons for privileging self-direction as a key plank in any disability system. **Individuals who can clearly identify, engage, monitor and review the services they need should not be subject to the direction or mediation of a service provider in determining their care and support requirements.** There is clear indication from those bodies representing people with a disability that this approach is essential to the dignity and citizenship of people with a disability.

The essential focus of self directed approaches to care and support should not be the administrative tasks involved with funds management. Directing how funds are used should be distinguished from the administrative task of managing funds. There should be administrative mechanisms for people who want to directly manage their own funds, with appropriate levels of accountability in keeping with the scale of packages. Alternatives are needed for the estimated to be large group who don’t want to, or can’t directly manage funds but are keen and able to direct how those funds are used. This is not inconsistent with a system promoting self directed funding.

There is also a group who have limited capacity to direct and manage services and funding, who need assistance or want guidance but who wish to retain or develop this capacity, perhaps expanding it over time. **The back-up of skilled and experienced planners, along with a system of case management that can provide the building of capacity in readiness for planning future care and support, is necessary to ensure individuals and families are not subjected to a framework they are currently unable to manage.**

In the recent report developed through consultation with people with disabilities and their carers, developed for the Case Management Action Group (CMAG)[9], feedback on the process of planning for services indicated a spread of desire for engagement in the process of planning, summarized in the following diagram:



Whilst it is generally agreed that planning involves a range of tasks and activities, it is evident there is often no clear and defined boundary. The report states that people commonly need three kinds of support:
i) Advice to create their plan – informally through family and friends, and formally through professionals;
ii) Personal and general support from those in a trusted role (case manager/support worker); and
iii) Specialist skills.

Participants commented on the benefit of having a skilled planner involved to provide assistance with planning - there is a degree of flexibility in the role to 'fill the gap' when and how it is required. Therefore it would seem some value may be lost if we too clearly define the range of assistance and support associated with the planning role. It is crucial to maintain the role of planning. People commented that regardless of their confidence in undertaking their own planning, they felt it was advantageous to have the support of someone in a planning role. Whilst many participants are able and willing to take on their own planning, most comment that they still require a level of assistance[10]

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[9] CMAG is a collective of disability case management agencies operating in the North and West Metropolitan Region of Melbourne. It is auspiced by Melbourne Citymission.

[10] CMAG *Self Directed Approaches* 2010 http://www.cmag.org.au/assets/files/%20SDS/Part%20Two%20Consumer%20Experience%20Final%20Version.pdf

Individualised approaches to funding

Melbourne Citymission continues to support reorientation of the disability sector to create individualised approaches to service delivery. In the past disability services has been structured to mediate the needs of many people with a disability where that has been unnecessary, because they are perfectly capable of managing their own affairs, including financial and contracting arrangements. However, the current situation in Victoria, where there are problems with meeting the demand for disability supports in a rationed system, a wholesale reorientation to this approach has shown to be problematic.

Additionally, the high support needs of a significant number of people with disability to whom Melbourne Citymission provides services, indicates that individualized funding and the expectations associated with that approach, is not always an option. Two circumstances illustrate this quite clearly – where the disability has significant cognitive aspects, affecting the ability to plan, to manage 'executive' functions such as personal organisation, and where insight and motivation are damaged, and secondly where trauma has left individuals and families currently unable to function as effectively as they would normally.

Melbourne Citymission supports a proposal for individualised funding where there is also concurrent service opportunities that suitably offer alternative mechanisms for funding. The overall direction in these services should be geared to the possibility of a transfer to individualised approaches when possible, but without the expectation that it needs to occur when individuals and families are not able to cope.

There are also key additional needs in an effective disability service provision system for innovation, research and community capacity building, flexibility and trialing of new and yet to be scientifically 'proven' approaches. We have seen in Victoria that supporting the re-orientation of existing service types to an individualised approach has already reduced opportunities in these crucial areas.

Providing people with disabilities and their families/carers more power to make their own decisions does not mean the scheme needs to be based entirely upon an individualised approach to funding. This is one mechanism that is essential to a disability system, but it has not proven to be a complete solution to the support needs of all people with a disability and their families/carers. A purely individualised approach also can endanger existing opportunities for collective or joined-up care and support, and miss opportunities for new coordinated ideas as these systems privilege pre-planned contracting of services to individuals sometimes to the detriment of important alternatives.

It is clear that there are problems associated with some traditional location based services, where expectations of the service provider can outweigh those of the participants. However, they have also provided opportunities for informal communication and engagement, as well as the development of identity in relationship to others, and this also brings benefits to many people with disabilities, particularly where isolation and marginalisation has been the experience. **A new scheme would need to**

ensure opportunities for collective services and supports can be sustained, alongside individualised approaches.

Case study – Compass Clubhouse

Melbourne Citymission's pilot project for the ABI Clubhouse commenced in January 2008 The *Compass Clubhouse* is a member driven community of adults who have experienced an ABI and are working towards a fulfilling life after brain injury and reintegration back into their community. For many members this will include both social and economic participation through a return to work, or to training for employment. Close connections with the local community and clear pathways for people into employment, support, education, training and / or community activities are developed.

The Clubhouse model fills the gap between formal rehabilitation and returning to work. It also links with or modifies existing community supports and services.

Clubhouse members are responsible for completing the work of the Clubhouse, which is functionally related to member goals and to program operations. The Clubhouse model encourages members to have a greater awareness of themselves and their skills and strengths, and to be future focused. Members gain confidence and skills which facilitate their reengagement in the broader community. The model of the Clubhouse allows members to develop pre-employment and employment skills in a safe and supportive environment. For example, the Clubhouse has a work-ordered day, typically 9-5pm Monday – Friday, and members work alongside staff to make decisions and to do the work of the Clubhouse. Within a Clubhouse, people focus on practical skills that relate to daily life. Members learn experientially through daily activities and numerous opportunities for feedback and repetition. Utilising current knowledge and skills of the members is another essential ingredient to the success of the Clubhouse.

Clubhouse members are members for life. This does not mean that they will remain active in the Clubhouse all their life but that they can return at any stage during their journey to seek support, advice and guidance or to provide this support as a mentor for other members.

Clubhouse members say:

'In my life I have experienced an acquired brain injury. After spending a period of time in rehabilitation people tend to lose touch with their employment skills. This model works with the person to set achievable work structured goals'.

'… coming here opens you up so you can go forwards, not backwards'

'… I have gained confidence that I had completely lost, just even living.'

These comments indicate the lengthy process of recovery and the need for a supportive environment for people with an ABI to relearn skills for economic and social participation.

Melbourne Citymission is currently seeking funding to sustain this important initiative in employment readiness for people with an ABI. Current policy is a barrier to this outcome, because the model is seen as a 'segregated' approach, and not in keeping with the integrated approach required under the Disablity Act 2006.

A similar hurdle would be in place for a social group for the hearing impaired, whose preference would be limited to people who can sign. People who elect to prefer a group approach to a service need, and/or whose specialist needs have limited general community skill or understanding, can face the double-jeopardy of unnecessary policy barriers which prevent funding being accessable.

Specialist and generalist approaches to disability service provision

The Victorian experience of the Disability State Plan 2002-2012, and Disability Act 2006, which expanded the definition of 'disability' to include all disabilities has brought many advantages. There have also been significant lessons learnt about the provision of care and support, with the reorientation of the disability service sector under the Act.

Under this Act a new service access approach has been defined: *'The Act changes the way people access disability services, by allowing for a simpler and more consistent system for all people with a disability'*[11] The stated policy aim is *to ensure that the process for making a decision in response to a request for disability services is consistent across all disability service providers.* One outcome of this goal has been the creation of a more 'generic' approach to some disability service types, such as Individualised Support Packages. Under this system assessment of need is undertaken through generalist planning teams, without streaming based on disability type.

The Melbourne Citymission experience suggests that **this generalist approach has achieved significant additional outcomes, as it is addressing support needs common across disability types, and can streamline access to common service options.**

There is equally a need to support specialist and targeted approaches for specific disabilities, where the specific skills and experience located in robust services can provide both targeted services and consultations to generalist providers about the particular approaches that are successful (eg. behavior management support and case management for people with complex cognitive disability, autism or injuries such as acquired brain injury).

The provision of both specialist and generalist disability providers allows for choice by the service users, and offers a source of specialist support and secondary consultation where complexities exist.

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[11] Access to Services policy framework under the Victorian Disability Services Act 2006 http://www.dhs.vic.gov.au/disability/improving_supports/disability_act_2006/access_to_services

Case Study – Specialist secondary consultation approach: Statewide Acquired Brain Injury Paediatric team

The Statewide Acquired Brain Injury Paediatric Consultancy (SAPC) works with people living or working with children and young people with an Acquired Brain Injury (ABI) (who do not receive compensation). It has been very effective based on a secondary consultation model. SAPC undertakes to:

- **Provide information about paediatric ABI**
- **Link people to workplace training about ABI**
- **Provide one-to-one mentoring with a case manager or worker**
- **Provide resources**
- **Assist the worker to find suitable case management services, funding packages, behaviour management, education and training, doctors and specialists**
- **Go to meetings where the child's situation or program will be discussed, for example, school support groups, clinical team meetings.**

Behaviour intervention support worker emailed.... ***I want to compliment you again for your effort on Tuesday. You were able to let the family see some hope when for a long time they could not.***

SAPC mentored Youth Justice worker reported: ***I feel confident to discuss (client's) ABI and some strategies with his Dad now that I have met with you.***

Teacher Aide: ***Thank you for all your help over the last 2 years that I have been involved with (client). Being able to contact you and discuss things and all your efforts to help with (client) has been fantastic. Not only has it helped me to learn more about (client) but gain knowledge to use with other students that require aiding.***

Youth at Risk worker: ***I have learnt a lot about ABI and you have shown me some signs to look for and ways to work with and understand ABIs***

6. Who should be eligible?

Eligibility and entitlement

There are practical and ethical reasons for a broad inclusion of all experiences of disability, rather than limiting this proposed scheme to only 'severe or profound' in the design of a disability care and support system for Australia.

Eligibility should be based upon the effect that disabling conditions have on lives, rather than trying to draw a line against a scale of disability. Mild, moderate, severe and profound classifications are difficult to define, and do not align directly with the level of effect they have on functioning in community.

The issue of entitlements provided by the scheme, and the design of appropriate responses to address the particular needs of people with a disability/ disabilities will need to be streamed according to circumstances to be most effective. Many people with a disability have life-long needs, but require access to supports intermittently rather than continuously. The capacity for a scheme to address needs in a timely way should also mean that people with a disability can confidently access supports through this scheme when required, and not be confined by 'long-term or nothing' thinking which is a feature of current disability systems.

It is clear from the work Melbourne Citymission has done in providing community services (across many domains including disability) that **any goal of improving inclusion of people with disability into the Australian community needs to also consider the interactive nature of disability with other factors.** Issues of marginalisation, locational disadvantage, cultural and language proficiency and family context, as well as co-morbidities such as alcohol and other drug use, mental illness and medical health, all impact on the success of interventions in disability.

Age limits on access to disability supports can also be problematic. While there is a clear need to separate interventions that are more appropriate to a response from the Aged Care system, the practicalities of defining a 'disability which is part of the natural process of ageing' will be difficult.

There are people over 64 years of age whose primary need is for disability support services. Currently the Transport Accident Commission recognises its responsibility for the supports required after a motor vehicle accident without age limits. However, recognition of the expertise of the aged care system in being able to provide services in an appropriate way to their target group means that a disability care and support scheme should be designed to complement, rather than replace entitlements already in place for those over 64. A partnership approach with Residential Aged Care has proven effective in some circumstances, in providing appropriate response to people who have concurrent disability and age-related requirements.

Case study – *My Future My Choice*

A key plank of the Victorian response to the National Younger People in Residential Aged Care initiative by the Council of Australian Governments (COAG) in March 2006, has been the development of 'enhancement' packages for those wishing to remain in Residential Aged Care. These packages have provided access for young people to the disability support system, importantly in many cases supporting their participation in specialist disability programs or facilitating community access where that has not been achievable through the resources available in their aged care setting.

This partnership approach to the needs of younger people with high level support needs has provided an avenue to start to address the significantly inappropriate service response of sending young people into aged care facilities because there is no other option available.

Determining which aspects of care and support are most appropriately supported through each system's contribution requires continuing work. However the exclusion of people over 65 to this proposed scheme would seem to limit effective outcomes and over-burden an aged care system that is already struggling to cope with demand. There may be more value in limiting entitlements where the aged care system's contribution is available.

There is an increasing concern about the issue of ageing in place for people with disabilities. Advances in the technologies supporting people with a disability, as well as the greater skills and understanding that is in place in disability services and across the wider community, has meant that issues of retirement and ageing with a disability are now very real. **The needs of people with a disability do not vanish with age, and Melbourne Citymission supports that eligibility, for those in receipt of disability care and support, should continue beyond the age of 64**. That includes the need for continuing access to existing accommodation that is now 'home' as people age.

Who is in the scheme?

Melbourne Citymission acknowledges the complexity of maintaining the balance between providing comprehensive access to a national disability system for those who require specialist care and support, while also the need to ensure public value from the scheme and keeping it fully funded within the available revenue base.

However, there are complexities in providing this scheme only for those with 'severe or profound disability' that Melbourne Citymission considers will be both impractical to implement and also financially self-defeating.

Eligibility should be based upon the effect that disability and impairments have on lives, rather than trying to draw a line against a scale of disability (mild, moderate, severe and profound classifications are difficult to define, and do not align directly with the level of effect they have on functioning in community).

What entitlements should be offered?

With the application of a social insurance approach to funding this scheme, there are implied associated universal benefits such as entitlement to access this scheme by all citizens when they need it.

Melbourne Citymission's experience suggests that a high percentage of people experiencing disability require financial support to get their needs met, and that the level of private income is not an adequate measure of the need for this support. There are always options for private payments for services by those with higher levels of income or wealth. However unless there are quality services available (and these are classically 'merit goods' in an area of 'market failure') then even the capacity to pay privately may not result in adequate outcomes.

Further, those people who require disability services at Melbourne Citymission are mostly on limited incomes, often with only the Disability Support Pension as income, and their capacity to contribute to their own care and support needs is minimal.

Additionally, there is a clear link (at least under the present systems) between developing poverty and the onset of disability into a person's or a family's life[12]. Therefore the possibility of such measures as means testing of entitlements may be more problematic and costly than is warranted.

7. Who makes the decisions?

The majority of needs in the disability sector are relatively easily assessable, and so a system design principle that enables a fast and efficient way of streaming these into a process of access to appropriate services is essential. In the current rationed systems across Australia, a significant amount of effort and resourcing is swallowed up in the work of determining eligibility through prioritisation and comparative need, according to an ever changing set of policies. All these are in place largely because there are inadequate resources to meet demand.

There are also a smaller number of people who already present to disability services with multiple and complex needs. It is frequently not clear that their need is associated primarily with their disability, what the most appropriate disability service response will be, or where the presentation is complex and a multi-sectorial assessment is required (eg. People with disability, alcohol or drug use, family crisis etc all at once). These people will require a more detailed assessment response and will require additional

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[12] See for example: Bradbury et al, *Socio-Economic Disadvantage and the Prevalence of Disability.* Social Policy Research Centre, University of NSW, SPRC Report1/01 [2001]; Australian Institute of Health and Welfare[AIHW], *Children with disabilities in Australia,* AIHW cat no Canberra:AIHW,[2004]

specialist knowledge and management skills in the decision making about how to most effectively address their needs.

Melbourne Citymission's Community Integration and Accommodation Option's program was approached to provide service and supports to a client with Multiple and Complex Needs (MACN). The referring/funding service believed the youth service model would meet the needs of a group of eligible clients aged eighteen to twenty years old.

One referred client was in his early twenties and had an ABI and a disability diagnosis at age thirteen. The individual was not assessed as eligible for complex needs services and supports until age twenty as he did not meet the eligibility criteria or was not referred to the *MACN* initiative. The service systems at that time did not offer a coordinated approach of service delivery.

A comprehensive assessment of the client needs was provided, which included a history of services provided by Mental Health, Acquired Brain Injury, Disability, Drug and Alcohol, Criminal Justice and other services. A care plan was developed using the assessment which provided a framework for the development of an enhanced model of service tailored to meet the needs of the individual. The referring service coordinated a care team of practitioners from all of the services involved, both disability specific and others. The care team model approach was developmental and highly effective in addressing the issues and need presented.

Earlier intervention and systems coordination may have assisted our client and prevented the need for multiple and ongoing specialist response. The impact on our client is severe and has resulted in mental health issues, recurrent homelessness, imprisonment, disconnection from family and community and negligible employment opportunities. Our client may have benefited from mainstream service and supports had they also been available and accessible.

It would be appropriate to design a system where the need for a delayed and detailed decision about entry to the scheme is really restricted only to those whose needs are complex to assess, and to ensure that access for the majority is streamlined. Procedures that allow access through an administrative process governed by clear policy where there is no issue with the eligibility for disability care and support should be delineated from those who require specialist response. This can introduce significant efficiency into a national scheme.

8. The nature of services

One of the main features of the needs of people with a Disability that underlies the issue of assessment is that they are varied and often multi-faceted. **People with a disability come with a wide range of presentations, and concurrently have other needs that can interact with their disability, often to their disadvantage.**

However, there is also a need to ensure that any system that is set up to address the care and support requirements of those with a disability and their families/carers is not hampered by unnecessary administrative and bureaucratic requirements for assessment. In a significant number of cases, the need for supports will be straight-forward, and while the refinement of what may be most useful in terms of services may be more complex, the essential need is for timely and early intervention to prevent further escalation of the need or deterioration of the person's situation.

In light of this, **the hurdles for eligibility for this scheme need to be minimised, and the use of assessment material from the adult and pediatric health and primary care systems can often be the basis for establishing eligibility.** The use of existing universal tools that means people do not need to repeatedly provide basic information at each access point needs to be recognised in this proposed scheme. If there is a record-keeping system that can track with the person themselves, then this can also be empowering and add efficiency.

There are, however, a number of people whose presentation makes the assessment of their needs more complex. In these situations, there will need to be a more detailed approach to determining eligibility, and the use of a secondary streaming in these situations will be required. Access to specialist skills and knowledge will be needed and there are examples of this streaming that have proven successful – the engagement of specialist panels through the Multiple and Complex Needs Initiative (MACNI) in Victoria to oversee highly complex situations, and the use of a dual streaming for the ABI Slow To Recover program are examples of how to effectively deal with the varied types of demand for a disability service response.

11. Workforce issues

Broad trends have been identified in relation to the size and composition of the Disability Services workforce in the non-government sector[13]:

An ageing workforce

This table represents the percentage of 45+ year old workers by aggregated services types. Percentages given are calculated as a percentage of the total for that gender in that aggregated service type.

	Accommodation	Day Programs	In Home Support

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[13] Data from Victorian Disability NGO Workforce Analysis Project © Copyright VICRAID, 2003

% of females over 45	43%	40%	40%
% of males over 45	41%	42%	34%

Gender imbalance

Women make up 75% of the workforce. The 3 to 1 ratio of women to men is fairly consistent across all service types.

Length of time with current employer:

17.2% of people working in accommodation services have been with their current employer for less than 12 months. 16.3% of those working in day programs have joined their employer within the last year while the comparable figure for in-home support is 25.4%.

Length of time in the sector:

Approximately one third have been working in the sector for more than ten years, with 9% of them involved for more than twenty years. Almost 20% have been working in the field for less than two years.

Employment status

The data indicates that Day programs employ significantly more full-time staff than the other two main services areas. By contrast In-home support relies heavily on a part-time and casual workforce. Accommodation services have more than four times more part-time staff than full-time or casual staff.

These trends are noted for three key high-employment activities in the disability services sector. There are similar concerns emerging in the areas of case management, planning and service coordination as well as in the administration of non-government disability service provision.

The individualised approach to service delivery, along with the recognition of the specialist needs of a wider group of people with disability has challenged the current workforce capacity and requires a much wider skill set.

There is a need to advance the recruitment and retention rates of those within the sector. Skills and experience need to be developed and recognized to support the worker moving into more specialist and senior levels. The trend to simplify disability service provision through competency based training is not keeping abreast of the workforce support needs of people with a disability.

12. Governance and Infrastructure

‘Consumer’ led policy

There is currently a lot of debate in the disability system about problems that have occurred with disability support agencies, and particularly the unfair control agencies have had over the lives of people with disabilities. **The voice of people with a disability has emerged now as a key driver in the policy direction of the disability care and support system. This voice continues to develop and Melbourne Citymission applauds the work already done, and supports expansion of resources to assist in this process.** A significant quality improvement goal for all funded disability services, now embedded in the quality framework in Victoria, is the necessity of ‘consumer’ feedback as part of service delivery.

There is a continuing need to further develop the capacity of all people with a disability to have a say in their services. The level of opportunity for people to learn about self-management processes and to have access to the information that exists within the disability system remains very poor. **An expansion of learning opportunities needs to be embedded in the new scheme, so that individuals with disabilities and their families can engage in directing disability supports more actively.**

There is complexity in this process, and the number of ‘voiceless’ still remains high, particularly where the disability involves limitation to communication or cognitive impairments. There is also the additional complexity of the trauma and distress that individuals and families experience in dealing with the onset of disability, and the burden on lives that occurs in dealing with a set of needs and service options that can be confusing and difficult.

While the proposed National Care and Support scheme will go some distance in resolving unnecessary aspects of this complexity, the experience at Melbourne Citymission suggests that many aspects of the existing ‘industry’ will continue to be required.

Industry development

The non-government and charitable sector has been providing disability services for a long time, and there is a body of specialist experience, skills and knowledge in the delivery of efficient and effective services already in place. There is also a history of contracting and policy development that has framed the delivery of services to ensure that public expectations are being met in the disability field. There are some continuing issues that require addressing in this industry, though. Workforce development remains one of the most pressing issues, with problems having been documented in detail through the recent Price Waterhouse Cooper report to the Victorian Government.

Despite the current flavor of some public debate that suggests that disability agencies are ‘feathering their own nests’ with public resources more appropriately channeled directly to those with disability and the families/carers, our experience at Melbourne Citymission indicates that **there remains a need for a level of funding essential to support infrastructure so that viability of specialist disability supports can be retained.**

The open market has not proven to be effective in the provision of services where there is limited competition and where the incentive of profit does not exist. This does not have to contradict the essential move to the provision of more self-determining and individualised approaches in the proposed scheme, but is complementary.

Support for an industry where there are specialised skills, experience and knowledge will ensure that where individuals and families are not able to assume the full responsibility for identifying appropriate supports and services, there is the capacity to provide them while external support is required. The policy goal remains that a move to self-direction and self-management should be embedded in these agencies, when that option is timely and chosen.

Transition issues

There have been significant lessons learnt from the recent changes in the disability support system in Victoria, with the introduction of the Disability Act 2006. Within the context of rationing and un-met demand, the reorientation of services to provide an individualised approach has meant that additional funds flowing into the system have all been channeled through the planning process into individualised packages. This has certainly been a welcome outcome for those who have benefitted, but there remains a significant unmet demand for other services as well, and these have not kept pace with demand.

Assuming that available resources through a social insurance scheme will steadily increase over the initial implementation stages until it is fully funded, the need to address the significant unmet demand as a first priority would seem appropriate. This should be done prior to implementing further reorientation of existing services that (while there may be flaws in their design) are relied upon significantly by individuals and families.

Recent experience in Victoria indicates that the desire to achieve service reorientation, with the understandable and well-supported policy goal of creating greater access to individualised packaging of resources, has resulted in greater administrative burdens, an increase in delays in processing applications for funding, centralisation of flexible funding pools, and a lack of growth in community building and innovation activities. Hopes have been raised but the capacity to deliver results overall has diminished.

Solving the unmet demand problem is perhaps the greatest priority we face across the disability community, and any increased capacity should not disadvantage those in receipt of existing services. While new resources should be directed to the policy goals of self-determination and greater flexibility, a staged transition to a new scheme should be adopted, identifying priority targets as the scheme gets to maturity. Service reorientation will continue to be required as evaluations of service models reveal how alignment to the policy goals of the scheme is progressing.

13. Appraising costs, risks and benefits

The demand for disability services continues to grow. Growth in Melbourne Citymission services over the last decade has been significant, responding to the identification of gaps requiring new service responses, and increase in demand for our existing service types. Wait lists feature in many of our services and despite effort to respond in a timely way to the needs of people with a disability and their families, this unavoidable delay in response time is noted across the disability sector, as well as internally, because of the rationing of disability resources.

The social cost of an inadequately resourced disability care and support system grows as well, both for the individuals directly affected, and also because of the 'opportunity costs' we incur as a community when the potential for individuals to contribute both financially and in broader terms to the welfare of our Australian community, is lost through lack of timely opportunity to access care and support services.

Melbourne Citymission has a strong focus on outcomes evaluation of its initiatives. **The implementation of a new national scheme will need to ensure that evaluation methods, based on outcomes rather than outputs, should be in place right from the beginning.** Melbourne Citymission employs a specific framework, the *Measuring Outcomes and Results Framework (MORF)* which has been developed and refined specifically to provide a disciplined and robust measurement system for measuring outcomes for our clients and ourselves. Adopting a social insurance model where there is a universal contribution to a national care and support scheme will demand an effective evaluation model to ensure best use of this public resource.

Conclusion

The opportunity to design and develop a new scheme for Disability Care and Support has proved a significant challenge. Working with people with a disability and their families, in an environment of rationed resources, where demand continues to outstrip capacity to respond, means the identification of gaps can be constant, and the emotional support required for those unable to get access to what they need is often frustrating.

There are many issues identified in the Productivity Commission Issues paper, and the questions these lead to are difficult to easily answer. Melbourne Citymission has been impressed with the scope of what has already been canvassed in that paper, and commends those involved in this work already. We hope that this contribution will be valuable to the development of a firm proposal that can more satisfactorily address the needs of those with a disability in our community. We look forward to further involvement.