Rights, respect, care, support, participation

A Response from Catholic Social Services Victoria to the Productivity Commission Issues Paper on Disability Care and Support

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SUMMARY AND RECOMMENDATIONS

Catholic Social Services Victoria welcomes the Government initiative, and the resulting Productivity Commission Issues Paper, to explore the viability and effectiveness of the National Disability Insurance Scheme.

This response has been developed through consultation with member organisations working in the disability and mental health areas, and family members and carers, and others within the broad network of Catholic social services.

Our response is based on a vision of integral human development that holds as fundamental the inherent dignity of all people, and which derives from a focus on the common good – that no part of society can flourish if other parts of society are unable to achieve their potential. As a body founded on the Gospel-inspired teachings of the Catholic Church, CSSV thus strongly affirms efforts to improve the both the quality and quantity of supports to people with a disability.

These principles also require us, as a society, to promote the rights of people with disabilities, and to admit them to the life of the community. This is fully aligned with the urgings of the UN Convention on the Rights of Persons with Disabilities. A community which values the dignity of all people must reach out with the best and most effective help possible – physically, spiritually, emotionally and materially – and promote the fullest participation by people with disabilities in that community.

Substantial reform to the means of funding and the operation of disability services is much needed and long overdue. Disability services are an essential government responsibility, and one that requires a substantial commitment of resources. We applaud the work that is being done to create a consumer directed and responsive service system, that would address the needs of people with disabilities regardless of how their location or the cause of their disabilities, in the context of an efficient and viable framework for ongoing funding.

Given the breath of the Issues Paper, this submission does not seek to respond to all issues, but rather to highlight some key points, including the areas of concern to member organisations and the carers and family members that were consulted in the development of this response. The following recommendations emerge from an analysis of the Issues Paper and the experience of service providers and family members.

Recommendations:

The following recommendations emerge from the analysis that is presented in this submission:

Scope of the reform:

In order to ensure a comprehensive framework to support and maximise the independence and contribution of people with disabilities, we recommend the approach to reform recommended in the report from the Disability Investment Group, based on the following ‘three pillars’:
• a comprehensive National Disability Insurance Scheme to deliver care and support for life for people with severe and profound disability using an individualised and lifetime approach;
• a strong income support system that facilitates people with disability who cannot support themselves through work, to live in dignity; and
• a range of measures to enable increased private contributions.

That reform should be underpinned by a strategy to enhance community attitudes toward the right to inclusion and support of people with disabilities and their families, so as to sustain the political and economic resolve required for allocation of resources.

The current service system:

a. That the focus remain on a national scheme of person centred support, so that so that current inequities based on the type of disability, how it was acquired, or the geographical location, are not replicated.

b. That a future service system have the capacity to allow families and individuals with a disability with the desire and ability to direct their own service entitlements, to do so, while also providing non-directive support to those who are unable or unwilling to manage their own support needs.

c. That the limitations within the current service system identified in the Issues Paper be addressed in future reform and the design of a new service system.

Whole of life planning:

a. That the foundation of the disability support system for individuals and families be a regularly reviewed ‘whole of life plan,’ taking account of predictable transitions and changing needs. This is particularly important because the uncertainty currently faced by many individuals and families is a major cause of concern for them.

b. That the vulnerability of people with disabilities when transitioning between service systems (such as between early intervention, children’s services and adult services) be recognised and that the systemic issues be addressed so as to ameliorate these difficulties.

c. That the role of family members in planning for future supports be acknowledged.

Eligibility and assessment:

a. That the development of a comprehensive assessment tool to assess eligibility for the scheme and the provision of services be a high priority.

b. The assessments should take account of the full range of disadvantages impacting on level of need. This includes taking into account the gifts and attributes of a person with a disability that need to be nurtured to enable them to fully participate and contribute to the community.

c. That there are clear limits on the caring role expected of families.

d. Those people with mild and moderate disabilities, who may not be eligible for the proposed NDIS, be able to access the services they require outside the scheme.

The needs of carers:

a. The right of family members to maintain a balance between their own needs (and the needs of other family members) while maintaining their caring role should be respected.
b. That specific supports to meet the needs of carers be a legitimate component of the ‘support packages’ provided through the scheme.

Transition to ageing:
   a. A person who has a disability diagnosed before the age of 65 should maintain eligibility for the NDIS disability supports beyond the age of 65, so as to avoid unnecessary transitions to the aged care system.
   b. The availability of age appropriate health care to people within disability accommodation be extended.

Inclusion of mental illness related disability:
   a. The inclusion within the proposed NDIS of people experiencing disability related to mental illness is strongly endorsed.
   b. That the scheme be proactive in contacting people with mental illness who may be eligible for supports.

Service types:
   a. That services under the scheme be flexible and portable, and respond to the individual needs of people with disabilities and their families – rather than restricted to a fixed set of options. The ability to choose fellow-residents is an element in this.
   b. Financial and legal advice for families should be available to assist in setting up supports for a family member with a disability.
   c. Case management and advocacy services should ensure that those people with disabilities requiring such support have their interests protected over the course of their life.

Workforce issues:
   a. A workforce strategy should be viewed as a foundational requirement of a reformed service system.
1. INTRODUCTION

Catholic Social Services Victoria

Catholic Social Services Victoria (CSSV) welcomes the opportunity to respond to the Productivity Commission Issues Paper on Disability Care and Support.

As part of the Catholic Church, CSSV is a peak body for the many Catholic social service agencies that deliver a wide range of social services in Victoria. A list of our member agencies is at Attachment 1 to this submission. Inspired by the life, death and teachings of Jesus Christ, we work with these member agencies to fulfil the gospel imperatives to stand with and serve the poor, disadvantaged and marginalised, and to work for a just, equitable and compassionate society. Further information about Catholic Social Services Victoria can be found on our website: [www.css.org.au](http://www.css.org.au)

Several of our member agencies are engaged in many elements of care and support for people with a disability and with those members of the community experiencing mental illness.

Development of this submission

This submission was developed in consultation with those CSSV members who provide care and support for people with disabilities, and with others from our broad community of support who, through service, experience of family relationships, study and caring responsibilities have been led to reflect on the issues associated with care and support for people with disabilities. The time and effort of all of these is appreciated by the broader network. This involvement has also flowed through to the development of other submissions, thus amplifying the value of the consultations.

Special thanks are due to Helen Burt, who was the principle researcher and writer, and brought to this task many years of professional and personal engagement with the issues that are being addressed. Margaret McCarthy also requires special mention, for the support she provided in reporting and analysis, as well as input as a carer.

Principles

The principles of Catholic social teaching promote the common good - that no part of society can flourish if other parts of society are unable to achieve their potential. Currently many people with a disability and their families do not receive the supports they are entitled to, or require to participate fully in the social and economic life of the community, or systemic issues prevent optimal support. They are therefore unable to achieve their potential, or all too often fail to even reach a decent standard of material, social or emotional life. As a body founded on the teachings of the Catholic Church, CSSV strongly affirms efforts to improve the both the quality and quantity of supports to people with a disability.

The inherent dignity of all people is a fundamental tenet of both Catholic Social Teaching, and from this it follows that, “Since persons with disabilities are subjects with all their rights, they are to be helped to participate in every dimension of family and social life at every level accessible to them and according to their possibilities.”¹ This leads to a broader focus than on care and

the provision of services. It requires us, as a society, to promote the rights of people with disabilities, and to admit them to the life of the community. The UN Convention on the Rights of Persons with Disabilities similarly urges Governments to be proactive in identifying need and establishing more effective social support systems - “Countries that join in the Convention engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination” 2.

A community which values the dignity of all people must reach out with the best and most effective support possible – physically, spiritually, emotionally and materially – and promote the fullest participation by people with disabilities in that community.

**Directions for change**

These principles lead towards some general directions for change:

Work towards providing a coherent and consistent system of support for people with disabilities and their families is strongly commended. The work done through the Productivity Commission and the Disability Investment Group to explore the feasibility and potential operation of a National Disability Insurance Scheme is a very welcome initiative.

Given the essential nature of many disability services, the fundamental shift from a ‘social service’ to an ‘entitlement’ is a necessary and long overdue development. Just as we as a community have come to accept that a universal system of health care as a fundamental right, there needs to be an acceptance of disability related supports as essential to ensure quality of life.

Recognising that a service system, whether provided by government or non-government organisations, cannot provide for all a person’s needs, it is to be expected that the government plays a strong enabling role, acknowledging and supporting community initiatives which promote the dignity of all people. Equally, the government must ensure the rights of people with disabilities are protected and promoted – to guarantee social and economic inclusion, access, education and training and employment. In parallel with a comprehensive system of care and support, these factors will ensure that people with disabilities and their families and carers are not further marginalised within the community, thereby becoming more dependent on the service system.

But beyond anything that can be done by Government, a broader community sensitivity to the needs and to the potential for contribution by people with disabilities is needed. Only this will enable the fullest family and community participation by people with disabilities; and only this will sustain the unpaid and paid carers, workers and volunteers who are needed to underpin this participation and the service and support programs that are needed.

### 2. THE SCOPE OF REFORM

The Terms of Reference for the Productivity Commission are limited to the feasibility and operation of the National Disability Insurance Scheme to deliver care and support for people with disability,

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2 United Nations, Convention on the Rights of Persons with Disabilities, Article 4
and this is reflected in this response. While of course this would of itself be a major reform, it is noted that the report from the Disability Investment Group proposed a three pillar approach to achieve transformational change – “The proposed new policy framework focuses on government and private investment to assist people with disability to manage their own lives and maximise their independence and contribution to the community”\(^3\). These pillars are –

- a comprehensive National Disability Insurance Scheme to deliver care and support for life for people with severe and profound disability using an individualised and lifetime approach;
- a strong income support system that facilitates people with disability who cannot support themselves through work, to live in dignity; and
- a range of measures to enable increased private contributions.

It is important that the overall reform measures include these additional initiatives. While better care and support is crucial for people with disabilities and their families, true inclusion requires the financial security of an enhanced income support system, and the flexibility envisaged by the range of taxation and other reforms. A strong framework to protect the rights and interests in the workplace and the broader community is also essential.

In addition to these structural reforms, full participation by people with disabilities in the life of a community will depend strongly on the support of that community, in a number of ways. Firstly, the provision by Governments of services and their recognition of rights is sustained by the support of the community. Perhaps more importantly, it can only be at the level of families and of local neighbourhoods that people can be invited and enabled to participate in all the dimensions of family and social life, “at every level accessible to them and according to their possibilities”\(^4\). The Productivity Commission enquiry and the broader process of which it is a part can help build this necessary community awareness and support, and can work to encourage others to work to that same end. This is an essential element of reform.

### 3. THE CURRENT SERVICE SYSTEM

The analysis of the current service system and social support for people with a disability and their families/carers contained in the Issues Paper\(^5\) is supported. Despite the intentions of individual organisations providing services and advocacy, the current service system must be described as fragmented, inequitable and crisis driven. The most significant deficiencies identified by those people, families and agencies are:

- The lack of assurance of ongoing support, and the consequent inability to plan for future needs,
- The lack of consumer choice, for both adult individuals and families caring for a child or family member with a disability,
- The limited capacity of the service system to facilitate transitions in an individual’s life,
- The limited and inflexible supports available to carers,

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\(^3\) The way Forward – a New Disability Policy Framework for Australia’

\(^4\) Pontifical Council for Justice and Peace, *ibid*

• The overall lack of resources, which leads (among other things) to allocation of resources
  only when trauma and crisis are affecting a family or individual, scarce services, and
  restricted service models,
• Limited access to aids and equipment,
• Insufficient respite facilities to meet the level of need, and
• The restricted access to early intervention, even when the benefits to the individual (and
cost effectiveness) are clear.

The development of an alternative approach must ensure that another set of inequities (or ‘lotteries’
as they have been aptly described) do not arise. A comprehensive national support system should be
focussed on the needs of people rather than how a disability is acquired, or the where a person
resides.

It has become evident in consultation with member and other organisations that there is a clear
openness (and eagerness) for change. Service providers are all too aware that they operate in a
system that is crisis driven and compromised by a lack of resources in proportion to the level of
need, a lack of certainty from budget cycle to budget cycle, and often with inappropriate service
models. There is little room to tailor services and resources to meet the unique needs of individuals
and their families. While incremental improvements are made to parts of the system, the lack of any
fundamental change to the system means that these improvements may lead to a new set of
inequities or inefficiencies.

For many families and individuals the management of the daily support and decision making is seen
as an additional load, and the involvement of an organisation provides a necessary ‘buffer’ to deal
with this load. Without in any way detracting from the crucial need for choice for people with
disabilities and their families, there is a valid role for agencies in assisting with planning and
facilitation. The success of person centred planning in Victoria, and the capacity of many
organisations to undertake this role in a facilitative and non-directive way, so that people and
families are assisted to see options and make choices, and in turn procure needed services, indicates
a successful model. On the other hand, other individuals and families are extremely willing and able
to direct their own entitlements to service provision. A mature service system should be able to
discern these differing needs and choices.

At their best, organisations have the capacity to be strong advocates for systemic change, provide
enormous support and advice to people with disabilities and their families, and at a practical level
are able to carry risk and capital developments. Unfortunately organisations and the service system
have grown in an ad hoc manner, and with inadequate resourcing. The proposal is an opportunity
for transformation to a planned service response, designed around the individual needs of people
with a disability and their carers.

4. THE IMPORTANCE OF WHOLE OF LIFE PLANNING

CSSV strongly supports the conclusion of the Disability Investment Group (DIG), that while there is
currently a significant allocation of funds to disability support, there is no certainty or guarantee that
there will be continuing access to services for people with disability and their families. The sad
impact of this is that ‘whole of life planning’ is rarely possible. The foundation of the disability
support system should ideally be a full person centred assessment of the impact of disability on the
whole of life of the individual and their family. This could be reviewed at regular points to ensure it
takes into account changing needs and aspirations.
The greatest vulnerability of people with disabilities is at the various transition where there is a move from one service system or provider to another (as currently occurs when a child ‘moves’ from the early intervention system to the broader children’s services, then again when a young person turns eighteen and moves to the adult service system, usually including a transition from a special school to a day program, and possibly upon the ill health or death of primary carers, and with a further transition to the aged care system at 65). Combined with the sometimes predictable events related to the person’s condition, and the different aspirations a person and his/ her carers may have at different life stages, it is clear that planning (with a level of certainty about the availability of resources) can avoid much of the trauma and dislocation of transition.

As also pointed out in the DIG report, the NDIS would enhance this planning and early intervention, because the scheme would have “clear incentives in the service system to invest in timely interventions that promote independence and produce long term benefits”.

At the other extreme, support options put in place within the context of a crisis are unlikely to provide a ‘best option’ for the person involved.

The current lack of capacity for whole of life planning and future assurances of support are a significant contributor to the stress felt by families, particularly parents. Much of the concern expressed by parents as they age is about the future care and support of their (adult) child, particularly when their daughter or son is unable to advocate on their own behalf.

5. Eligibility and Assessment

The criteria for eligibility for the NDIS will be crucial on many levels – equity, financial viability and effective operation.

The principles for establishing eligibility criteria for the scheme should -

- Be transparent and based on a nationally consistent assessment process.
- Be person-centred, based on the needs and choices of the person with a disability and their family.
- Take a ‘whole of life perspective’, focussed on early intervention, long term outcomes and maximising opportunities for participation and productivity.
- Take account of the gifts and unique attributes of the person with a disability.

The limit of eligibility to those with severe and profound disability is generally supported as the most effective way to balance the need for equity and financial viability of the overall scheme. While this criterion would include most people with a significant level of need for daily support and assistance, it is recommended that a sophisticated assessment tool will be essential to the effective/ equitable operation of the scheme. This is important for both eligibility and determining the actual services to be provided.

The basis of most definitions of ‘severe and profound disability’ focus predominately on the person’s capacity to function in the areas of self-care, mobility, and communication.


7 World Health Organisation International Classification of Functioning, Disability and Health (ICF) www.who.int/classification/icf/en
are crucial domains, most people with experience in the field are aware that assessing a person’s level of need for support requires taking into account many more factors – the person’s need is often related to the interaction between their disability and various personal and social factors.

The assessment would also require the capacity to take into account the many nuances of disadvantage which may impact on a person’s level of need. Examples of necessary distinctions would be –

- Socio-economic disadvantage
- Capacity to utilise social supports
- Geographical isolation
- The interaction of dual or multiple disabilities
- The known value of early intervention.

A well-constructed Assessment Tool must be able to evaluate these factors so as to avoid further inequities. It must also be able to take into account the gifts and attributes of a person with a disability that need to be nurtured to enable them to fully partake and contribute to the community.

While the lack of family and community support should be a factor in any assessment, there should clear limits on the role expected of family members and carers. For example, parents and their adult children may find the expectation that parents provide personal care inappropriate. The right of people with disabilities to move through normal stages of independence from their families should also be respected.

If the eligibility is limited to those with a severe or profound disability transition arrangements should ensure that those people with mild and moderate disability, are able to access services they require outside the NDIS. For example, the impact of a mild intellectual disability can be very significant for a young person moving into adulthood, and may require specific long or short term supports. As a general principle existing service provision / eligibility for services should be maintained for those with mild and moderate disabilities, who have a clear need for ongoing or episodic support.

6. THE NEEDS OF CARERS

The vast majority of people with severe and profound disabilities are cared for in informal family situations, so that the majority of their day to day is outside the funded service system. The experience of carers is well documented8 -. These include -

- ‘Extraordinary’ levels of depression, significantly higher than the general population,
- High degrees of physical exhaustion,
- An often high degree of concern for the future of a son or daughter, because of the difficulties of planning for future care, or even to have an optimism about appropriate care being available in the future,
- Social exclusion because of the time commitment to caring, and difficulties of integrating the person with a disability into community activities,
- Financial constraints related to the costs of caring, and the limitations placed on their capacity to work.

8 ‘SHUT OUT: the Experience of People with Disabilities and Their Families in Australia’
The wellbeing of carers is of great concern, and inevitably this will impact on the wellbeing of the individual with a disability. Carers may be across the gamut of age groups – of notable concern are young carers - the children of parents with psychiatric or chronic illness who become the ‘parent’ within the family – and ageing parents who have maintained day to day support of their adult children, and now carry an unacceptable burden of caring (for example, because of their own physical capabilities) combined with the stress of being unable to plan for the future of their daughter or son.

The right of carers to maintain a balance with their own needs (and the needs of other family members) while maintaining their caring role should be respected. Many carers report the disruption of their careers and an inability to follow their own aspirations, or even meet their own needs.

The limitations of the current service system are all too often reflected in the distress and burdens ‘shouldered’ by carers, who will compensate for the inadequacies with their own time and resources, and must live with the fears for the future of their family member resulting from the lack of ‘whole of life planning’ and assurances of ongoing support.

A significant dimension of this concern for the future relates to concern about the type of accommodation that will be available, and who the fellow residents will be, and what spiritual support will be available. A greater flexibility for carers and residents to choose fellow residents would go someway towards alleviating this pressure.

7. TRANSITION TO AGEING

The shift of an individual to aged services cannot be seen merely as an administrative issue, related to funding sources and responsible government departments. The impact of a change in accommodation and/ or supports can be extremely significant for an individual, affecting continuity of care, proximity to familiar surrounds and social networks.

A recent study on intellectual disability and ageing raises concern about the way decisions about major life transitions are made for some older group home residents. It found that people with an intellectual disability prematurely move to aged care because of health related issues. With greater attention on prevention and intervention, and by providing appropriate training and support to group home staff many of these moves could have been postponed or averted. ⁹ ¹⁰

It was found that upon transition to aged services, while physical wellbeing tended to increase, the social well-being of participants in the study decreased. This research indicates both the inappropriateness of many aged care settings for people with an intellectual disability, and the lack of age appropriate medical care within disability accommodation.

There is little rationale for moving people who are settled into a disability accommodation service into an aged care service, merely because their chronological age makes them eligible for a different

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funding source – a more lateral and person centred solution would be to increase the availability of age related supports able to link with disability services.

8. INCLUSION OF MENTAL ILLNESS

The inclusion of people with mental illness as potential ‘beneficiaries’ of the NDIS, and the recognition of the disabling effects of long term mental illness, has the potential to transform the lives of many people diagnosed with serious mental illness. This would allow an entitlement to appropriate early interventions and services, filling a major gap in service provision.

CSSV shares the optimism of the Issues Paper, that the coverage of people with serious mental illness within the NDIS, should diminish the currently unacceptable outcomes for people experiencing serious and long term mental illness.

As many people with severe mental illness are currently outside the mainstream disability support system and (for example) may be receiving support through homelessness services, it is proposed that the NDIS should be proactive in reaching people and ensuring that they receive optimum supports through the system.

9. SERVICE TYPES

As a person centred system, the services provided through a NDIS should be flexible and portable, and most importantly reflect the individual needs and preferences of people with disabilities and their families. The system should not be limited to a finite set of service types, but seek to respond flexibly to the funding of solutions assessed as effective to meet the needs of eligible people.

In addition to the service types listed in the Issues paper, specific services mentioned in our consultations included –

- Financial and legal advice for families to establish trusts or other vehicles for the support of a family member,
- Case management and advocacy, to ensure that people (especially those with cognitive disabilities) have their interests protected over the course of their life.
- Supports targeted directly to carers, to relieve stress and social isolation, or create opportunities where life chances

10. WORKFORCE ISSUES

Ultimately a service system can only be as good as the staff employed within it – this is particularly the case in a human service industry where the quality of the interaction between direct care staff (social/case workers and personal care staff) is the greatest indicator of quality as experienced by the client.

For carers and people with a disability it is the qualities and expertise of these staff which is of greatest concern. For service providers it is also their capacity to recruit and maintain such staff. A comprehensive workforce strategy is required, if the quality of the service system is to be enhanced. Such a strategy will have many elements, including ‘better pay, better qualifications’. A workforce
strategy would also intersect with a strategy to improve the position of people with disabilities in the community, as the status of support staff and their work would increase as a consequence.

Such a workforce strategy should be the foundation of a reformed service system.

11. IMPLEMENTATION

Given the scale of the reform that is required, it is unlikely that incremental reform will be sufficient to achieve the aspirations of the NDIS. It is also important that the success of the scheme not be compromised by partial implementation.

There will inevitably be dislocation in such major reform, and it will be important that the lives of vulnerable people are not disrupted. The implementation will therefore require a clear and sensitive blend of business acumen and capacity to respond sensitively to the needs of the many individuals and families who will benefit from the reforms.

It will be crucial that a ‘no disadvantage’ approach to current recipients of disability services be established. One of the greatest challenges of bringing to fruition this far reaching reform will be to ensure that it does not create a new range of inequities.
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<td>Don Bosco Youth Centre and Hostel</td>
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<td>Jesuit Social Services</td>
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<td>John Pierce Centre for Deaf Ministry</td>
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<td>Justice and Peace Unit, Archdiocese of Melbourne</td>
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