Productivity Commission Inquiry:
“Disability Care and Support”

Draft Submission

Disability Council of NSW

About the Disability Council of NSW

The Disability Council of NSW was established under the terms of Section 16 of the Community Welfare Act 1987 as the official advisory body to Government in NSW on issues affecting people with disability and their families. We also give advice to the Australian Government on the effect of policy on people with disability living in NSW.

Council members are appointed by the NSW Governor on the recommendation of the Minister for Disability Services. Members are selected on the basis of their experience of disability and their understanding of issues, their knowledge of service delivery and their ability to reflect and advise on government policy. The majority of Council members are people with disability.

General observations

We agree with the Productivity Commission observation in its key questions paper.

> *The key question for the Commission is not how bad the current system is — nearly everyone thinks it needs to be overhauled. What we want to know is how to build a good system.*

People with disability and those closest to them deserve a better system of support. We believe they deserve the best system possible. Currently that’s not available to them, although there are pockets of excellence and much more that could be described as good practice in the current system. Everyone recognises, however, that the current arrangements are inadequate (sometimes woefully so) and unsustainable.

The status quo is not acceptable. We know of no one who argues that it is. We need a disability support system (not a disability services system) that is culturally, operationally and financially resourced for the needs of the 21st Century.

As we set out in some detail below, we believe that people with disability are citizens with rights, and welcome the development of systems of support which recognise and support their full citizenship. Current charity, institutional and bureaucratic models of service to people with disability have been acknowledged both by the Productivity Commission and widely in the disability sector as inadequate. These outdated models cannot be the pillars upon which we build a contemporary, relevant and cost-effective system of support in the decades ahead.

It is time for change. Indeed, fundamental change is long overdue. Parts of the current disability services system have their origins in 19th Century practices of institutionalisation. Although most of the Dickensian connotations of institutional living have been eradicated a legacy remains even today in the dominance of service structures, policies and programs over people's individual choices and aspirations. Some of what we can achieve by transforming the support system from a facilities and programme basis to the resourcing of people as authors of their own life stories will be to make an irrevocable break with an institutionalising past whose day is done.

Like many stakeholders we favour a new, unified national system. It would pool resources from across the country and establish a new fund for support. We believe that new fund should be created by means of a hypothecated tax collected as an enhancement of the existing Medicare levy. The fund would grow and be managed centrally. Access to and support through the fund would be administered and provided locally. The levy should be set sufficiently high from the outset to 'fully fund' the needs of all people with disability eligible for support.

Finally, in this general introduction, we wish to endorse an observation about nomenclature made by the NSW Disability Discrimination Legal Centre. Words, language and names matter. *"Disability Care and Support"* occupies a place in the traditional, welfare paternalistic landscape of disability as deficit. We contrast its subliminal message with, for example, the nation's *"Future Fund"* (one possible model for the structure of the new disability support fund). *"Future Fund"* has a 'ring' to it. It's forward looking, optimistic and dynamic in tone. Who would not want to be associated with a fund for the future?

We do not immediately have any suggestions for a 'brand', name or mobilising tag line. We hope this much, though: When this discussion is over and Parliament votes to establish a fund that will finance a new, contemporary framework for support whatever it's called the new system and associated agencies operate under a banner that empowers, encourages and supports people with disability as much as will the funds and new opportunities they will have access to.

Recommendations by the Disability Council of NSW

Recommendation 1: Any person with disability (below retirement age at the point of application to the scheme) who requires support to live in the community should be eligible for assistance from the new scheme. The level of support should be determined by and provided up to the level of the assessed need of each person with disability.

Recommendation 2: An assessment tool that is consistent with the World Health Organisation International Classification of Function, Disability and Health should be used to determine eligibility.

Recommendation 3: We believe that the new scheme's arrangements for determining eligibility should acknowledge the existence of clinically well-recognised disabling conditions.

Recommendation 4: The people given responsibility for assessing eligibility, individual need and levels of support required should be adequately trained in the legislative context of the rights based framework within which the new scheme will operate and in the use of assessment tools that are consistent with the WHO ICF.

Recommendation 5: Any new national system of *"disability care and support"* must be based on meeting the individually assessed needs of people with disability who require support.

Recommendation 6: There should be a network of locally based advice, support, facilitation and / or brokerage agencies developed to support scheme participants to reach decisions about the support arrangements best suited to their individual needs and to provide training in skills essential to making informed choice and decisions.

Recommendation 7: The new scheme should be operated by a new, national, autonomous agency that is entirely separate from any direct disability service provision to scheme participants.

Recommendation 8: The key requirement is to create, develop and maintain locally based support, brokerage and / or training / capacity building services that assist individual people with disability and those closest to them to make informed choices and reach decisions about the network of supports that best suit their individual needs.

Recommendation 9: The Disability Council of NSW supports a hypothecated tax or levy payable by everyone as a form of social insurance. We want the smallest portion possible of the funds to be lost to collection and administration. For that reason we favour a link to an existing, universally applied levy such as Medicare.

The context of the current agenda for major reform

The Australian Parliament ratified the United Nations Convention on the Rights of Persons With Disabilities in 2008. That Convention is rapidly becoming the key driver of policy development in Australia with regard to people with disability.

Article 1 of the Convention states:

> *The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

Article 3 - General principles, states:

> *The principles of the present Convention shall be:*
> - *a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;*
> - *b. Non-discrimination;*
> - *c. Full and effective participation and inclusion in society;*
> - *d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;*
> - *e. Equality of opportunity;*
> - *f. Accessibility;*
> - *g. Equality between men and women;*
> - *h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

Article 4 - General obligations, states:

1. *States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.*

Article 19 - Living independently and being included in the community, states:

> *States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*
> - *a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
> - *b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
> - *c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

The principles of the United Nations Convention are beginning to directly and profoundly underpin the development of policy with regard to people with disability in Australia. The Australian Government released its draft National Disability Strategy on the 29th July 2008. (Importantly for the Disability Council of NSW) the Premier of NSW indicated that the NSW Government will endorse the draft when it is formally presented to the Council of Australian Governments (COAG).

The draft National Disability Strategy states (emphasis is that of the NDS):

> *The shared vision is for* ***an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.***

The draft National Disability Strategy continues:

> *The Strategy will play an important role in protecting, promoting and fulfilling the human rights of people with disability. It will help ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disability, their families and carers.*

And (in an observation with profoundly important consequences for the current discussions about the potential for and of a national system of disability support and care) the National Disability Strategy further states:

> *People with disability are citizens with rights, not objects of charity.*

The Disability Council of NSW welcomes the approach taken by the draft National Disability Strategy. It correctly locates the future development of disability policy in Australia within the rights-based framework of the United Nations Convention.

Answering the Productivity Commission's "Key Questions"

Who should be eligible?

Who should be in the new scheme?

Recommendation 1: Any person with disability (below retirement age at the point of application to the scheme) who requires support to live in the community should be eligible for assistance from the new scheme. The level of support should be determined by and provided up to the level of the assessed need of each person with disability.

Considered together, The UN Convention and the draft National Disability Strategy provide a helpful focus.

The draft NDS sets out its intentions with regard to understanding who it means when discussing people with disability. The draft strategy states;

> *… the term 'people with disability' refers to people with all kinds of impairment from birth or acquired through illness, accident or the aging process. It includes cognitive impairment as well as physical, sensory and psycho-social disability. There is a more detailed definition of disability in the Disability Discrimination Act 1992 (Cwlth).*

Article 19 of the UN Convention requires that

> *States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right…*

Taken together, we believe that the new national system for providing *"disability care and support"* should be open to all people with disability (as defined by the Disability Discrimination Act 1992) who,

a) require support to realise their rights under Article 19 of the UN Convention and
b) are below the national retirement age (currently 65 years of age for most Australians) at the point of application to the new national system.

The Disability Council of NSW recognises the key differentiation made in Australian social welfare systems between pre- and post-retirement age. We cannot foresee any fundamental change in that age-related split in the near to medium term future. We believe, therefore, that responsibility for funding the support required by any person with disability should be determined by the age of the person requiring support at the point of their first application to the appropriate funding agency.

For us this means that a person with disability applying to or receiving support from the national system for *"disability care and support"* before retirement age would continue to be supported from that source beyond retirement age for their disability-related support needs. Anyone applying for disability-related support for the first time after retirement age would continue to be supported through the *'aged-care system'* of the day, as is currently the case.

How could people who are eligible for support be practically and reliably identified?

Recommendation 2: An assessment tool that is consistent with the World Health Organisation International Classification of Function, Disability and Health should be used to determine eligibility.

We see no reason to re-invent wheels. The World Health Organisation International Classification of Functioning, Disability and Health (ICF) already exists. Australia is a member of the World Health Organisation (WHO).

The WHO web site notes:

> *The ICF is WHO's framework for measuring health and disability at both individual and population levels. The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001(resolution WHA 54.21). Unlike its predecessor, which was endorsed for field trail purposes only, the ICF was endorsed for use in Member States as the international standard to describe and measure health and disability.*
> (source: http://www.who.int/classifications/icf/en)

The WHO ICF has developed its own ICF application and training tools. These include the ICF checklist, which the WHO describes as a,

> *… user–friendly display of the most relevant ICF categories for clinical purposes. The checklist allows the user to identify and qualify the individuals functioning profile in a simple and time efficient manner.*
> (source: http://www.who.int/classifications/icf/icfapptraining/en/index.html)

We do not suggest here and now that the ICF checklist is the only instrument that could or should be used to identify people with disability who would be eligible to be supported and / or entitled to support. It does indicate, however, both the approach that must be taken and the kind of factors that must be considered. Whatever tools, instruments, assessment methodologies and the like are developed to identify scheme participants should be consistent with the ICF and incorporate its multi-dimensional approach to key factors.

We would summarise its attributes as follows:

i. The tool used considers people as individuals (not as members of groups or categories) but allows the collection of consistent aggregated data.
ii. The tool is about more than functional ability but recognises that functional ability has a part to play in determining support needs.
iii. The tool is multi-dimensional, addressing
    a. Health / disability factors
        i. *"disease, disorder, injury"*
    b. Contextual factors
        i. Environmental factors such as social attitudes, legal structures, the built environment, location, etc.
        ii. Personal factors such as age, gender, family circumstances, education, etc
iv. The tool is fair, can be applied consistently in any location and is neither too brief as to provide little useful information nor too long as to be cumbersome.

Recommendation 3: We believe that the new scheme's arrangements for determining eligibility should acknowledge the existence of clinically well-recognised disabling conditions.

One of the problems in the existing disability services system is that people with disability can be required to 'prove' their disability or eligibility again and again as they attempt to construct packages of support from more than one provider or programme. Different service providers and different programmes within the same service provider sometimes require applicants to start from the beginning, repeating information already given by them elsewhere in the service system. This can be stressful for the individual concerned and for family members as well as wasteful of time and resources.

The new scheme should allow for clinically well-recognised disabling conditions as part of a simplifying process for determining eligibility. Centrelink and the Roads and Traffic Authority of NSW are among the agencies that utilise such an approach.

Clinically well-recognised disabling conditions should not be used to assess need or levels of support required. Those matters must always be the outcome of individual, person-centred assessments.

Recommendation 4: The people given responsibility for assessing eligibility, individual need and levels of support required should be adequately trained in the legislative context of the rights based framework within which the new

scheme will operate and in the use of assessment tools that are consistent with the WHO ICF.

Which groups are most in need of additional support and help?

Recommendation 5: Any new national system of *"disability care and support"* must be based on meeting the individually assessed needs of people with disability who require support.

People with disability are individual citizens with rights. That is what the UN Convention tells us and the draft National Disability Strategy confirms.

Australia's social welfare and State-based disability systems must learn to stop thinking of people with disability in group or category terms. It leads to group and category responses, which is a key problem with traditional approaches to disability service provision.

Any new national system of *"disability care and support"* must be based on meeting the needs of individuals who require support. If such a need for support is identified using an assessment tool consistent with the WHO ICF, we argue that the assessed level of support required should be provided as an entitlement. Different people will require varying degrees and types of support.

It helps no one – not the person with disability, family member, support provider or government – to attempt to squeeze individuals with disability into pre-determined, somewhat arbitrary and ultimately questionable groups or categories such as mild, moderate, profound and severe. Even if those labels served a purpose in the real world (and we contend they do not) their purpose would at best approximate to a very limited understanding of a single dimension of 'disability' – bodily functioning within a medical model. We have moved beyond such constraints.

It will be necessary, of course, for any new system to acknowledge, deal sensitively with and respond to the particular circumstances of different individuals. For example:

- Two people with identical disabling conditions (if such a thing were possible) but living in urban and rural or remote locations may require different levels of support to realise the same rights to participate on consistent and equal terms.

- Aboriginal people with disability or people with disability from non-English speaking backgrounds may require additional or particular (culturally specific) types of support because of the additional barriers to inclusion created by racial and disability discrimination's combined effects.

- Some people with disability have multiple and complex disabling conditions which, when taken together and considered holistically, result in levels of support need that exceed that which might typically be associated with any single disabling condition if viewed in isolation from others.

We acknowledge that in the current system of sometimes rationed access to disability services people with disability may have urgent need for immediate access to support. This may result from a change in family circumstances (e.g. the illness or death of a family member) or a change in the functional capability of the individual scheme participant (e.g. as a consequence of a degenerative disabling condition). A combination of person-centred approaches and early intervention is essential to ensure that changing levels of need for support can be identified and responded to in a timely manner.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

The Disability Council of NSW agrees that any new system needs to be fair and to be seen to be fair. We should note, of course, that the current patchwork quilt of service systems is neither fair nor consistent. As examples:

- It ought not to be permissible or possible that three different young men with essentially the same levels of quadriplegia receive different levels of support because of where they happened to be at the time of injury: at work, at the beach or in a motor vehicle on a NSW road.

- It is unfair that two ‘middle-aged’ women with essentially the same functional abilities resulting from acquired brain injury have different types and levels of support because one lives at home and the other lives in an aged-care residential facility because no other option existed at the time of discharge from hospital.

- A six year old girl with intellectual disability living in Broken Hill ought to have the same, timely access to speech therapy support as a six year old boy living in North Ryde, Sydney but that’s not what happens.

We note once more that the Productivity Commission itself acknowledges the current dilemma when it affirms that the *“key question for the Commission is not how bad the current system is — nearly everyone thinks it needs to be overhauled.”*

The Disability Council of NSW suggests that any new national system must be able to demonstrate the following minimum set of characteristics.

- There is a single set of nationally determined eligibility and resource allocation criteria, which remains sensitive to regional variation and cultural diversity.
- System guidelines / policies / operating protocols are subject to external consultation (and revision) prior to formal approval / gazetting.
- Decision-making on systemic matters is transparent, publicly accountable and subject to review.
- Decision-makers on systemic matters are accountable for their decisions and (at Board / Council / Authority level) required to serve fixed terms, which may be renewed.
- Individual participants have a right to know about any decisions taken about their personal circumstances.

- Personalised budgets, which allow but do not require direct payments, for all system participants.
- Feedback, complaints and appeals mechanisms that give confidence to scheme participants that their concerns will be heard, acted upon and addressed without risk of adverse consequence. Ideally, complaints mechanisms should be wholly independent of eligibility, assessment and administrative processes of the scheme. As an absolute minimum there must be unbreakable 'firewalls' separating complaints processes from operational arrangements within the scheme. Complaints mechanisms must protect confidentiality.
- Decision-making about resources to be allocated to or in the name of any individual person with disability should be based on what In Control UK calls the *"Resource Allocation System"* with 12 components:
    1. Control ... the allocation decision gives the person needing support or those closest to them genuine control of the money allocated
    2. Transparency ...makes it easy for those administering the system and those using a personal budget to make decisions
    3. Efficiency ...runs smoothly, is easy to use and requires the minimum resources possible to administer
    4. Innovation ...encourages people to use resources flexibly and find the best possible means of meeting their needs
    5. Collaboration ...encourages those administering the system and those needing support to work together productively
    6. Equity ...treats all individuals fairly, respecting relevant individual needs and circumstances.
    7. Integrated ...operates as an integral part of a wider system of self-directed support
    8. Realism ...reflects the local economic situation, local prices and changes over time
    9. Contribution ...avoids creating poverty traps and encourages people to earn, save and build social capital
    10. Portability ...lets people who need support move home without undue cost, complication or uncertainty
    11. Prevention ...allocates resources at the right time and minimises the risk of people coming into crisis.
    12. Citizenship ...recognises and defines needs in the terms of rights and entitlements.

    (source: http://www.in-control.org.uk *Fairness Requires Transparency*)

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

Recommendation 6: There should be a network of locally based advice, support, facilitation and / or brokerage agencies developed to support scheme participants to reach decisions about the support arrangements best suited to their individual needs and to provide training in skills essential to making informed choice and decisions.

Any new system of *'disability care and support"* must result in people with disability and those closest to them (as required by the circumstances of the person with disability) being in control of the support network that enables them to participate in the community. The new system must ensure that scheme participants have the power, authority and means to make decisions about their own lives. Sometimes, some people with disability may require assistance to make key life-decisions. The new system should enable assisted decision making where that is required.

Currently, people with disability and those closest to them (often family members constituting 'the informal network of care') can often have nothing or very little to do with determining what services are developed, delivered and allocated in any given location at any point in time. People are sometimes / often made to fit into a limited set of traditionally organised service types often known as 'day services', supported accommodation' respite', etc.

The Disability Council of NSW strongly favours a fundamental shift in the relations that would drive forward any new national system of *"disability care and support"*. We believe that the disability system should resource / fund individuals with disability through the mechanism of personalised budgets (which would allow but not require direct payments). These arrangements should be funded by means of hypothecated taxation or levy on all taxpayers.

The current system of disability services is built upon two pillars neither of which directly support / empower individuals with disability. Government, using tax generated income, either funds its own agencies to be a direct provider of disability services or (increasingly) funds non-government agencies on a contracted or grant-aided basis to provide pre-determined types of services at agreed rates.

Politicians, senior public servants and non-government sector leaders are, however, increasingly considering the policy, funding and operational consequences of 'placing people with disability and their families at the centre of decision-making'. That is a welcome development. There is a risk, however, that the statement could be used as a rhetorical device to mask continuation of existing arrangements and current practices.

We favour an approach that looks something like this:

1. A single, national system or framework of *"disability care and support"*.
2. A mechanism such as a Medicare levy enhancement to provide a hypothecated and ring-fenced national pool of funds.
3. Personalised budgets for all participants. This creates a direct relationship between the funding agency and the system's intended beneficiaries, people with disability and those closest to them. This would have the effect of fundamentally altering the nature of the relationship between people with disability equipped with personal budgets and non-government service providers (some of which would be existing agencies and some would be new).
4. Personalised budgets based on principles of self-directed support. Such arrangements would allow but not require direct payments to participants (see the NSW Attendant Care Programme as an example). In Control UK describe the principles of self-directed support in these terms:
    a. **Right to Independent Living** - I can get the support I need to be an independent citizen.

   b. **Right to a personal budget** - I know how much money I can use for my support.
   c. **Right to Self-Determination** - I have the authority, support or representation to make my own decisions.
   d. **Right to Accessibility** - I can understand the rules and systems and be able to get help easily.
   e. **Right to Flexible Funding** - I can use my money flexibly and creatively.
   f. **Accountability Principle**- I should tell people how I used my money and anything I've learnt.
   g. **Capacity Principle** - Give me enough help, but not too much; I've got something to contribute.

   (source: http://www.in-control.org.uk *Fairness Requires Transparency*)

5. Contracts between participants (people with disability) and service providers setting out the particulars of services (type, quantum, location, duration, etc) as well as roles, responsibilities and review mechanisms.
6. Timely access for participants or their representatives (particularly for people with cognitive or developmental disability) to independent advice about building and sustaining relationships with and support from service providers. We note that such services would be wholly consistent with Article 12 (Equal Recognition Before The Law) of the UN Convention on the Rights of Persons with Disabilities.
7. Strong, sustainable and autonomous individual and systemic advocacy.

How should the amount of financial support and service entitlements of people be decided (and by whom)?

Recommendation 7: The new scheme should be operated by a new, national, autonomous agency that is entirely separate from any direct disability service provision to scheme participants.

We will begin to answer by addressing "by whom?" The Lifetime Care and Support Authority of NSW (LTCSA) is a model worth investigating in depth. Similarly, the Future Fund Board of Guardians and the Future Fund Management Agency may be of particular interest.

We support the creation of a new, national autonomous statutory agency that would hold and dispense the funds of the new national scheme, generated from a new hypothecated stream of revenue raising. We favour an enhancement of the Medicare levy but are open to better suggestions if they emerge.

Like the NSW LTCSA and not dissimilar to the Future Fund, the new national agency would have three components. These would be.

- A policy Council responsible for determining the breadth and scope of the system including policies and guidelines in accordance with the intentions of the legislation establishing the new system and agency. The majority of the members of the policy Council would be people with disability eligible for support through the new framework / system and / or nominated by representative organisations of people with disability. Council members would be appointed for (renewable) fixed terms by the appropriate Commonwealth Government Minister.

- A financial Board responsible for overseeing and developing a pool of funds sustainable over the long term that would be used to support scheme participants within the policy Council's guidelines and in accordance with the Act establishing the new arrangements. The Board would be comprised of individuals capable of managing, developing and sustaining a very large pool of funds and be appointed by the appropriate Minister of the Commonwealth.

- An new national Authority or Agency with a comparatively small central unit (policy, finance, administration, quality, complaints and appeals) and a much larger locally based network of information, assessment and advice professional staff (perhaps based initially on reformed structures of existing State and Territory Government disability support agencies).

At the level of individual allocation of resources within the entitlement based model we envisage there would be mechanisms / professional staff to enable the following arrangements to operate. (NB eligibility / assessment / allocation decisions would be reached through process that would be wholly separate from any support providing agency to minimise or eradicate potential conflicts of interest).

- Eligibility for support and entitlement to receive an assessed allocation of resources from the pool (either directly, in one's name or through a third-party fund holder who could not also be a service / support provider) would be determined using a tool consistent with the WHO ICF.

- Decisions about the amount of funding support would be made using something like the In Control UK *Resource Allocation System*, incorporating their *Principles of Self-directed Support.*

- The outcomes to be supported would be set out in a personal plan for each individual scheme participant. Such plans could not be at variance with the intentions of the Act establishing the system and the policies of the Council charged with realising the Act's purposes.

- Personal plans and resource allocations would constitute a contract between the Authority and the intended beneficiary (the person with disability).

What kinds of services particularly need to be increased or created?

Recommendation 8: The key requirement is to create, develop and maintain locally based support, brokerage and / or training / capacity building services that assist individual people with disability and those closest to them to make informed choices and reach decisions about the network of supports that best suit their individual needs.

Working within the current paradigm leads to well-intentioned but ultimately redundant shopping lists of traditional service types. The question, as framed, begs familiar answers: 'more accommodation places', more respite', 'more day time activities', 'more out-of-hours back up' or 'more innovation' (an often expressed idea that few people can actually define).

If this debate were simply about more (or less of traditional models such as congregate care) we wouldn't need a Productivity Commission Inquiry. Increased funding is a necessary outcome of the current debate but it is not a sufficient outcome.

More of the same 'service system' discourse no longer serves the needs of people with disability and their families who have been carrying the weight of unmet need for too long. We must all be bolder and more imaginative in our thinking if we are to rise to the challenges of the 21st Century agenda favouring rights. Initiatives such as the NSW Industry Development Fund suggest that the urgency of the need for genuinely systemic change has been recognised and is beginning to be addressed.

Any new system must not replicate the traditional service oriented approaches which are acknowledged by many elements of the disability sector and the Productivity Commission as inadequate in form and structure and lacking in responsiveness and flexibility. The new system should resource and empower individual people with disability and those closest to them and support them to take increasing control of their own lives through formal and informal arrangements.

Some of that determination of need will lead to contact with and support from 'traditional' models of disability service support. And where an existing service is working well to meet the individual needs of a scheme participant its costs should be factored in to the assessed level of need the new scheme will support and allocate to the participant's personalised budget. Some will lead to entirely new forms of self-directed support and community engagement, most of which (we hope) will be arranged through reformed and increasingly diverse and inclusive 'mainstream' community organisations.

We foresee a need for planning, brokerage, training organisations to support people to participate in the community. It is unrealistic to imagine that most people could immediately move from the traditional, passive model of service provision to the new model of self-direction and active engagement without support to understand and make the transition. But such new forms of support are feasible and, we note, already operating (sometimes as pilot programmes that should become industry-wide standard practice). As NSW examples of existing models of self-directed support built upon personalised budgets we refer the Productivity Commission to the following schemes:

- The NSW Attendant Care Programme, including its direct funding pilot programme (funded by NSW Department of Human Services Ageing Disability & Home Care, known as AHDC).

- *"My Life, My Choice"* self-directed community participation pilot programme utilising a direct payment mechanism (funded by ADHC).

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

We have already proposed (Recommendation 8) that any new system must build the capacity of service users (people with disability) to make informed choices. The new arrangements for *‘Disability Care and Support”* must resource and empower people with disability and those closest to them to establish, develop and / or maintain sustainable networks of formal and informal support.

A crucial component of any new system would be the development of a network of well-resourced, readily accessible and highly skilled Local Area Co-ordinators. They would act as brokers, assisting people with disability to reach informed decisions about support options and, where required, assist people to negotiate and organise their networks of support in accordance with person-centred, individual plans.

We refer the Productivity Commission to three models of Local Area Co-ordination (LAC) in particular.

- Western Australia introduced its highly-regarded LAC network in the early 1990s.
- Queensland introduced LAC in 1999.
- Most recently, the New Zealand Government has proposed a national roll-out of LAC following evaluation of its current demonstration projects.

We cite these models because of their flexibility, genuinely local characteristics and potential to provide the template for LAC within the new system of *“disability care and support”* which we believe will be required.

We would also expect the new system to allocate funds to (and replicate across Australia) sector reform strategies such as the NSW Industry Development Fund, jointly co-ordinated by the State Government’s disability services department and National Disability Services NSW (NDS). We believe that the tradition service system must change and modernise if it is to become responsive to the demands of 21st Century service provision. We recognise that cultural and organisational changes will need to be supported by some kind of transition and / or development fund.

Releasing the NSW Industry Development Fund Report, NDS described the Fund in these terms:

> *The NSW budget for 2009-10 announced $17 million to establish an Industry Development Fund (IDF) to be used by the sector to build the capacity and sustainability of services and to revolutionise the way in which services are accessed by, and provided to people with disability.*
>
> *In late 2009 National Disability Services NSW in partnership with Ageing, Disability and Home Care, Department of Human Services brought together advocates, peak bodies, service providers and policy makers to develop a vision and direction for disability services into the future.*
>
> *This report is the first step in setting out a truly strategic focus for the sector in collaboration with the NSW Government, moving us beyond the funding relationship into a partnership that is focused on supporting people with a*

> *disability, their families and carers, and placing them firmly at the centre of service delivery.*
>
> *It sets out a vision for the sector, by the sector.*
>
> *The report highlights six areas of focus:*
>
> - *People with disability at the centre of service delivery*
> - *People with disability have access to the information and range of supports they need to live the lives they choose*
> - *High-performing organisations achieving real outcomes for people with disability*
> - *Robust planning and resource allocation decisions based on accurate data and evidence*
> - *Effective governance, leadership and management of the sector*
> - *The workforce is skilled, capable and focused on people with disability*
>
> (source: http://www.nds.org.au/news/article/780)

The Fund is tangible evidence that the State Government and the non-government disability sector's leading agencies recognise that the status quo of service provision is neither desirable nor sustainable. The creation of the Fund recognises, however, that organisational transition through cultural and operational reform requires a solid resource base to encourage and lead the reform agenda.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

The Disability Council supports early intervention for all age groups, as near to the onset of a disabling condition as possible (post-natal, accident, injury or disease) to promote positive outcomes for the individual. It produces potential returns on public investment. Early intervention should also be provided in advance of foreseeable and planned stages of transition (eg preschool to school, school to young adulthood). Planned and co-ordinated transitions require the skill of experienced practitioners within the disability sector and universal, community-based services. We note that early intervention is an operating principle assumed within the *Resource Allocation System* promoted by In Control UK to which we refer earlier in this submission.

For young children with disability or developmental delays, early diagnosis, provision of early childhood intervention services and access to 'mainstream' early childhood settings vary across Australia. In many cases a delay and/or disability is not evident at birth, which highlights the need for collaboration between health, education and early childhood intervention service sectors. While such collaborations currently assist with the identification process, some children remain unidentified until pre-school or even school entry age. As a result, there is a critical need for readily accessible identification, assessment and diagnosis options, both formal and informal.

In the UK, these issues have been addressed by the introduction of a universal 'hub' approach. 3,500 Sure Start Children's Centres bring together early education, child care, health and family support to deliver the best start for all children. Currently, no such system operates nationally in Australia.

The UK's early childhood intervention strategy known as *Every Child Matters* and the associated Surestart Centres (3,500 by 2010) offer an interesting, inclusive model of support for children and young people.

- See http://www.dcsf.gov.uk/everychildmatters

We believe that resourcing, empowering and supporting people with disability and their closest associates (often but not always their immediate family) will foster a culture of informed choice, greater autonomy and enhanced skills. Nothing is more cost-effective and productive than developing informed service users.

Timely assessment, rapid resource allocation measures and personal plans (capable of sensitive and timely revision as needs change) promote effective early intervention.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

The new scheme should promote and support change in two realms:

- People with disability must be resourced and assisted to make choices that result in the development of networks of formal and informal support that result in greater confidence and more opportunities to participate. For example:
  - Supporting skills acquisition in developing and reviewing realisable personal plans that would be funded through the new scheme.
  - Facilitating mentoring programmes and peer support networks.
  - The new, national agency that will manage the new arrangements would understand and promote best practice. It could act as a national clearing house of innovation, good practice and evaluation.

- The 'mainstream' community – from the built environment through to inclusive employment practices – must be encouraged to accept its responsibility to eradicate systemic and attitudinal barriers to participation. For example, the new, national agency could promote inclusion by:
  - Identifying and resourcing inclusion 'ambassadors' who would draw on their personal experience to encourage others as well as address attitudinal barriers in the wider community.
  - Funding and promoting community awareness and inclusion campaigns, perhaps aligned with the United Nations International Day of Persons With Disabilities.
  - Acting as a catalyst for co-ordinated, whole of Government initiatives to promote access, inclusion and participation.

The arrangements we envisage are intended to build the sustainable engagement and inclusion of people with disability across the 'normal' range of human activities through networks of support, some of which will be formal and some informal. Socially engaged and included individuals, supported by networks of paid and unpaid contributors who actively wish to be involved with the person they support, build platforms from which people with disability are better able to make, develop and sustain natural connections that lead to better social, educational, training and / or work related outcomes.

Personalised budgets and self-directed support arrangements lead to greater social inclusion and a more diverse and complex set of personal networks for people with disability. An example of the success of such schemes is available in the published report of the City of London's implementation of self-directed support. In the introduction to the pilot scheme's report (October 2008), the City of London's Adult Services Director wrote as follows;

> *" … the City's pilot personal budget scheme was set up with the intention of exploring not only whether this approach could work for people with learning disabilities, as pilot schemes in other local authorities have tested, but also for people from other social care groups.*
>
> *In considering this report I think it is quite evident that, by offering users from all social care groups a personal budget, we have found a way of providing services to local people in the way that they would choose."*

The full report can be downloaded from this web site location:

- http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=1107&cc=GB

We also refer The Productivity Commission to the successful pilots operated in NSW by Ageing Disability & Home Care with regard to 'self directed Community Participation' and the Attendant Care Programme, particularly its direct payments pilot (externally evaluated).

How can a new system ensure that any good aspects of current approaches are preserved?

Good governance of the scheme with people with disability at the centre of policy making. We see a need for research into and evaluation of best practice arrangements that promote and maintain sustainable networks of formal and informal support. Further development of quality assurance regimes (e.g. the Australian Attendant Care Industry's accreditation model), robust feedback loops (including complaints mechanisms) and workforce development programmes (such as the NSW Care Career strategy) will be essential to transforming best practice into standard practice.

By resourcing individuals through personal budgets based on self-directed support the new system will encourage, favour and require flexibility, responsive, person-centred approached to meeting the needs of individual people with disability. Innovative providers are already shifting their practice in response to and in anticipation of the developing trend in favour of greater autonomy, self-direction and personalisation of arrangements. That trend will deepen and accelerate.

We believe that responsiveness to the expressed choices, needs, aspirations of people with disability should mean that the current good aspects are maintained, because that is what people will want to keep when they are able to make a much wider choice.

What should be done in rural and remote areas where it is harder to get services?

It is in rural and remote areas, perhaps, that personalised budgets and self-directed support may have the greatest potential to transform lives. Traditional forms of specialist disability services provision benefit most from large populations, critical masses of categorised service users and ready access to new entrants to the workforce in an industry with an above average turnover of staff (particularly at entry grade levels). For reasons that are obvious rural and remote communities beyond regional centres do not lend themselves to specialist service development.

By building the capacity of individuals with disability and their families to develop sustainable networks of formal and informal support people in smaller, more remote communities have the potential to become ‘community builders’. Instead of trying to contort their lives to fit distant or difficult / costly to get to specialist service, people benefiting from self-directed support have the potential to identify local, probably generic or ‘mainstream’ community services to their own advantage and that of the communities in which they live.

Crucial to realising that potential would be the presence (on a regional, peripatetic basis) of skilled brokers or co-ordinators who could advise people with disability and assist with the ‘how’ of building sustainable connections. The Local Area Co-ordinator network of West Australia is probably the best example of an approach that works in often very remote settings.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?

An immediate and clear benefit of the new model of support that we favour is that only one assessment of eligibility is required. We believe there are many benefits to resourcing individual people with disability. Reducing application and assessment overkill is high on the list of benefits.

The traditionally organised disability services system is held back by its framework of policy and programme silo operations. It is understandable that non-government organisations and services have evolved into the programmatic, category specific, vertically-structured agencies that many have turned into.

Many NGO were established by concerned groups (often parents and family members) connected to people with particular disabling conditions. We understand the processes (often involving perceptions of gaps in formal service provision) that result in these kinds of responses: *‘let’s set up a self-help group for our kids with x condition’; ‘what we need is a group home for adults with y disease like they have in the next town’; ‘we need to lobby the State Government for a respite service for people with z’.*

The non-government and government disability services industry has grown (in NSW the Government now invests $2 Billion annually in the industry) and become more diverse and, at times, more specialised and programmatic. Target groups, eligibility criteria, programme guidelines and other administrative boundaries were placed around many services (partly in response to funding rules, partly as a tool to ration scarce resources, partly because decision-makers thought or think that to do so is the correct stance).

As the sector has matured and grown it has become quite common for some service users to construct packages of support from several providers with different policies, eligibility, guidelines, protocols, assessment instruments and application rules. An unintended consequence of this pattern of service development has been to create hoops through which potential clients must jump and gates with gatekeepers asking questions already answered for other gatekeepers. Personalised budgets and self-directed support have real potential to slice through this administrative Gordian knot, which no one believes assists us.

The NSW Government's Ageing Disability & Home Care agency has commenced work on reforming and simplifying client-based administration. Any improvement will be welcomed by service users.

How should a new scheme be financed?

Recommendation 9: The Disability Council of NSW supports a hypothecated tax or levy payable by everyone as a form of social insurance. We want the smallest portion possible of the funds to be lost to collection and administration. For that reason we favour a link to an existing, universally applied levy such as Medicare.

The funds generated from a Medicare-levy enhancement must be ring-fenced for investment only in the national system of *"disability care and support"*.

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

We need to commit to a reasonable period of staged transition from the current arrangements to a new national framework. For a few years the new (national) and existing (State & Territory) systems would run side by side, converging at an agreed date in the future (between 5 and 10 years from enactment of the enabling legislation that establishes the new framework and levy).

The dates here are mostly indicative of the pace / staging of transition, not targets.

Stage 1: Productivity Commission final report goes to Government (July 2011). We assume that the final report will contain a cost / benefits options report giving indications of the spread of potential system investment needs from minimalist to fully-funded (we favour the latter, although we acknowledge that "fully-funded" is an imprecise and debatable concept).

Stage 2: Commencing July 2012 personalised budgets would be established for all existing clients of State and Territory disability specialist services. Initially this would mean that every person in receipt of any taxpayer-funded disability service would know how much money (from all taxpayer funded sources) had been allocated in their name / for the services they receive. The Government of Victoria has recently enacted such a right to know the level of funding allocated in one's name. This approach should become standard practice.

Existing pilots / programmes in self-directed support (e.g, the NSW Attendant Care Programme, self-managed Community Participation, direct payments pilots) would be expanded and offered to a broader pool of people with disability in need of support. New self-directed schemes would be developed in programme areas and jurisdictions where none exist. (To some degree this process is already underway).

Stage 3: In 2013, Parliament approves legislation to enable a COAG backed initiative to establish a national system of *"disability care and support"* with effect from July 2015.

Existing disability services are given two years notice that from July 2015 all existing personalised budgets will become portable. Clients will be empowered and supported in the lead-up to portability to prepare self-directed support plans, which allow clients to continue with existing arrangements or enter wholly new arrangement with existing or new providers or construct so.

All existing disability services spending is notionally pooled as a preparation for wholesale transfer to the new national disability support fund, which would become operational from July 2015.

Stage 4: The new, unified national fund commences operations from 1st July 2015. New clients begin to take up funds generated by the levy (which could be collected from 2014 but not disbursed until it had one-year's tax take. An alternative, like the NSW LTCSA, would be to stage access, beginning with under-fives.) Existing clients would be transferred administratively to the national agency. Applications, assessment, quality assurance and complaints would remain local.

All notionally pooled disability services funds are actually transferred to the national fund. (July 2015)

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

How long would be needed to start a new scheme, and what should happen in the interim?

We've answered these questions in the preceding 20 pages.

Disability Council of NSW
23rd August 2010