

27 August 2010

Disability Care and Support
Productivity Commission
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Dear Commissioners Scott, Kalisch and Walsh

Re: Productivity Commission's Research into Disability Support and Care

On behalf of Cerebral Palsy League of Queensland (CPL), I thank you for the opportunity to provide feedback to assist in disability sector reform.

The Cerebral Palsy League of Queensland gives permission for this submission to be posted on your website.

Should you have any enquiries please do not hesitate to contact me via the details outlined below.

Yours Sincerely

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Productivity Commission
SUBMISSION COVER SHEET
(not for publication)
Disability Care and Support

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**SUBMISSION TO THE PRODUCTIVITY COMMISSION
DISABILITY CARE AND SUPPORT
AUGUST 2010**

ORGANISATION AT A GLANCE

The Cerebral Palsy League (CPL) is the largest non-government service provider for Queenslanders who have a physical disability and provides a broad range of services throughout the state.

The vision of CPL is:

A community which actively seeks and supports the contribution of people with a disability.

The organisation has grown, from its humble beginnings in 1948 led by a group of parents of children and concerned citizens to one - sixty two years on - that provides over \$50m of support services to assist 3,500 Queenslanders with cerebral palsy and related disabilities and their families/carers to achieve their life goals.

CPL provides a broad range of support services, the majority supported by government funding, some fee-paying services and some services supported through corporate and community sponsorship and donations.

CPL groups its services to individuals and families under five areas:

1. **My Service Options** – where we discuss people’s goals and work with them to identify options for support both within and outside the organisation.
2. **My Support at Home** – providing a range of support services to adults with a disability and families of children with a disability in their homes.
3. **My Support in the Community** – assisting adults, children and families access and participate in their communities through services such as community access, life skills development, recreation and leisure support, outside schools hours and vacation care for children with a disability and their siblings, assistance with transport, peer support, access to information and community linking.
4. **My Allied Health Services** – providing or organising a broad range of professional services, including access to assistive technology support.
5. **My Employment Support** – providing open and supported employment options to people with a disability – in real jobs on award wages.

The first four of the above services can be accessed through CPL’s regional network. CPL has seven regions:

1. **North Queensland/Far North Queensland** – stretching from Mackay to Mt Isa across the state and all areas north
2. **Wide Bay/Central Queensland** – stretching from just above Gympie in the south to the communities below Mackay in the north and across to Longreach in the west
3. **Moreton/Sunshine Coast** – stretching from Strathpine in the northern suburbs of greater Brisbane in the south to Gympie in the north and covering most of the Somerset Regional Council area
4. **Metro North** – covering Brisbane suburbs and surrounds from Brisbane CBD in the south to immediately below Strathpine in the north and across to Samford Village in the west
5. **Metro South** – covering all Brisbane City region suburbs below Brisbane CBD and Kangaroo Point
6. **South Coast** – covering Redlands, Logan and Gold Coast cities and far-northern NSW; and
7. **South West Queensland** – stretching from Ipswich and Scenic Rim in the east to the NSW, SA and NT borders in the south-west and up to Boulia and Winton shires in the west.

From its Head Office, CPL also provides:

- a state-wide information service

- a research program
- service practice support and development; and
- CPL hosts the Queensland Cerebral Palsy Register, funded by the Queensland State Government, which in August 2010 has produced its first report on the incidence and prevalence of cerebral palsy in Queensland (for the 1996 birth year).

In addition to these services, CPL is a Registered Training Organisation providing a range of accredited and non-accredited training for people with a disability as well as workers in the disability community and health sectors.

CPL also operates four Social Enterprise businesses that employ both people with and without a disability on award-based wages.

CPL makes a large contribution to the Queensland economy employing approximately 1600 staff, and through its services, provides many people with a physical disability and their carers with opportunities, they otherwise may not have had, to access paid employment.

CPL is a company, with a Board of Directors, who volunteer their services and expertise.

In 2010, CPL achieved recertification under the following quality management systems:

- National Disability Employment Standards
- Queensland Disability Sector Quality System; and
- ISO 9001:2008.

CPL is committed to engaging with and representing the people with disability it supports and its large constituency who are unable to access scarce government-funded programs or self-fund the services they require.

CPL has an evolving range of vehicles for client engagement including:

- formally constituted bodies separate to the organisation, such as the state-wide Client Consultative Committee and the Parents and Guardians Association
- regionally based client committees
- regular surveys seeking feedback and input on client satisfaction, suggestions for improvement and unmet needs
- complaints management system
- issue-specific forums; and
- a range of less formal gatherings of clients and families with CPL staff.

The views put forward through these engagement mechanisms are fed directly into CPL's strategic and business planning, CPL policies, service development and CPLs advocacy on public policy and community issues impacting on the lives of people with a disability and their families/carers.

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Signature

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METHODOLOGY

The evidence for this submission has been gathered by:

- Consultation with CPL's Client Consultative Committee which is made up of client representation across Queensland;
- Public Policy Forum within the organisation;
- Attendance at consultation and information sessions carried out throughout the sector;
- CPL consultation, focus groups and discussions with managers, supervisors, staff and clients of Children's and Adult Services at the Cerebral Palsy League of Queensland;
- Research on Adult and Children's services at the CPL;
- Conversation feedback carried out at our services within the last two months; and
- Research identifying international benchmarks.

APPROACH OF THE SUBMISSION

This Submission follows the Productivity Commission's Questionnaire Template.

EXECUTIVE SUMMARY

Disability Reform must take place if we are to sustainably cater to our ageing population and perform as a civil society. A new disability system will provide universal access similar to that of health and will acknowledge people's citizenship and right to participate in society. It will be built around a person directed and strengths based framework and use the support a person's natural networks especially their families and enduring friends.

A recent report by the OECD (2010) states:

Disability policy has become a key economic policy area in most OECD countries. Disabling medical conditions are on the rise among people of working-age, causing problems not only for individuals but also for the labour market and social policies. More and more people are relying on disability and sickness benefits as their main source of income, and employment rates of persons with disabilities are low. Those reporting a mental health condition or disability have the lowest labour market participation of all and are the fastest growing group of new disability benefit claimants. There are a number of reasons behind this, including workplace developments as well as education, health and benefit system failures. The relationship between these factors needs to be better understood to push forward with necessary structural reform in this area (OECD 2010)¹.

A new framework will need to work in concert with services such as health, housing, education and transport to enable people with disability to reach their full potential and maximise their contribution to society. A new framework will need to be portable, flexible and responsive to changed circumstances.

A new system will ensure there is an effective transition process to support clients, their families, carers and service providers who are prepared to operate in a new system.

¹ http://www.oecd.org/document/20/0,3343,en_2649_34747_38887124_1_1_1_1,00.html

Key features

Key features of the national system of lifelong support and care would be the universality of its eligibility criteria and the range of benefits to the individual with a disability through the appropriate funding to purchase essential services. A national system of lifelong support and care would finance:

- personal care, support, therapy, and community access;
- options planning to facilitate independence, maximise potential and plan for changing support needs and transitions over peoples life stages;
- aids, technology and equipment and home modification needs met on a timely basis; and
- Training, development and access to work to build self-esteem and reduce long term costs.

It would provide a fair and effective national system that includes:

- access to specialist support;
- social inclusion strategies;
- training and support for people with disability and their loved ones;
- a transition phase to prepare people with disability to use the new system and for service providers to make necessary adjustments;
- capacity for research and evaluation; and
- safeguarding strategies such as independent advocacy, administrative appeals, simple transparent accountability measures.

Models already exist in Australia. There is the fully-funded no-fault insurance scheme to meet the needs of people injured in the workplace in NSW, VIC, SA and NT. There is Medicare and the Superannuation scheme.

Financing

A national system of lifelong support and care would be funded through a levy on all taxpayers similar to the Medicare Levy. It is suggested that this levy would raise a sufficient resource and investment base if set at a maximum of one percent. Challenges will exist in convincing taxpayers, carers, service providers and the peak bodies, of this investment, which is best met through education campaigns run by the disability sector and people with disability.

Power

To create a life just like everyone else, purchasing power must sit with the individual person with a disability (or their representative) – a range of mechanisms could enable this and we outline the finer elements of this process throughout the submission.

Scope

Once again to create a life like everyone else people with disability must be able to source their support in whatever form, from the most appropriate source for them. This could be from a range of different suppliers across the community in both the profit and not for profit sectors.

Benefits of aspiring to a systems transformation can be:

- Embodies the UN Convention on the Rights of the person with disability;

- The planning is undertaken by or with the person with a disability or their close ones thereby encouraging more autonomy and independence;
- Formal supports complement and help build informal supports instead of alienating them;
- Support is centred on individual needs and choices at the time, knowing that future changes will be accommodated;
- Supports early intervention rather than a crisis model;
- Aids, equipment and home modifications needs met on a timely basis;
- Increased capability, capacity and self-esteem of people with a disability and their families and carers will reduce long term outlays;
- Lessen the demands on other government services such as the justice system, health, child safety and institutional types of arrangements which can be more costly and harmful than support in the community; and
- Increased social inclusion and citizenship with the contribution, opportunities and responsibilities and opportunities that come with it.

Cerebral Palsy League Position

Cerebral Palsy League supports a national system of lifelong support and care that allows people with disability to design and direct their services so that they receive the right amount of services, aids and equipment to maximise their independence. Maintaining the momentum is vital in order to solve the dysfunctional crisis driven system where demand has way outstripped resources and kept people with disability out of mainstream society.

Daniel's Story (for more detail please refer to the Productivity Hearing Notes in **Appendix A**)

Daniel is a young man with a physical disability who lives in Redcliffe, on the Northern shores of Moreton Bay and receives support services at home and in the community from the Cerebral Palsy League (CPL).

The issues Daniel faces on a day-to-day basis can be distilled as:

- lack of flexibility and choice (in how he organises and lives his life, from day to day);
- lack of certainty (of support to enable him to do any life planning); and
- lack of opportunity (to contribute to society and community life, to work, to be who he can be).

Daniel makes the point that he experiences this impact on his life even though he is one of the lucky minorities who receive funded support and wonders how his life experiences are magnified for the majority of people with a disability, who receive no funded support at all.

CPL's View

In 2008, Australia was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disability, and last year the Optional Protocol, but for many people with disability in Queensland these rights remain out of reach.

Theoretically, people with disability have a right to a life similar to everyone else, to have a home of their own, family and friends, meaningful work, education, a connection to the community and freedom of choice about their lives. Yet people with disability continue to struggle to obtain the supports that help make these things a reality.

The general community presume all is well and are in denial that people with disability are second class citizens in Australia. It is not until you have direct contact with a person with a disability that you begin to understand just how broken the current system is.

Daniel's issues (lack of flexibility and choice, lack of certainty and lack of opportunity) are all outcomes of Australians with a disability not having automatic access to the support they need to

take their place and live their lives in their own communities.

The current system is based on continual rationing of government financial resources and presents a view that Australians with a disability are simply a drain on the public purse.

Access to life-long disability support is not just the right thing to do, it is the only sensible thing to do to enable people with disability and their carers to contribute to community life and to enable higher labour market participation, leading to increased productivity. Providing access to life-long support and care is anything but a drain on the public purse, it is in active investment in Australia's social and economic future.

The Problem of Unmet and Under-met Need

There is general acceptance in government circles and the disability sector that there is a significant problem of unmet need for formal support and assistance for people with disabilities. The 2003 [ABS Survey of Disability, Ageing and Carers](#) identified that 1.9% of people with a profound or severe core activity restriction (resulting from their disability) receive no assistance at all and 45.2% only had their needs partially met (*ABS Survey Table 14*). Across all domains of life the supply of formal support falls well short of the assistance that is required. Table One taken from an ABS survey outlines just how severe the unmet need is. This unmet need is a major barrier to people with disability taking their rightful place in Australian society.

Table One: People with a Profound or Severe Core Activity Restriction Requiring Assistance who Receive Formal Supports²

	<u>Number requiring assistance</u>	<u>Number receiving formal support</u>	<u>Ratio</u>	<u>Percentage</u>
<i>Requiring assistance with:</i>				
<i>self care</i>	529,600	88,300	1 in 6	16.7%
<i>mobility</i>	810,500	188,700	1 in 4	23.3%
<i>communication</i>	206,600	113,300	1 in 2	54.8%
<i>cognition or emotion</i>	426,800	197,800	1 in 2	46.3%
<i>health care</i>	595,300	298,500	1 in 2	50.1%
<i>paperwork</i>	256,500	25,100	1 in 10	9.8%
<i>transport</i>	569,400	79,100	1 in 7	13.9%
<i>housework</i>	544,300	161,700	2 in 7	29.7%
<i>property maintenance</i>	573,400	181,600	1 in 3	31.7%
<i>meal preparation</i>	264,200	43,400	1 in 6	16.4%

Carers providing informal support shoulder most of the responsibility and, in turn, receive little or no support, themselves, to fulfil their caring role.

Because the current system operates in an environment where demand exceeds formal supply many times over, the imperative of government funding programs is to ration resources, which brings a crisis mentality to the sector. The bigger the crisis, the higher the priority and, perversely, the more it costs to provide formal support – resulting in bigger funding packages. This, in turn, reduces the coverage of available government funds and leads to even greater levels of rationing – a vicious cycle indeed.

² 2003 ABS Survey of Disability, Ageing and Carers- Table 15

A crisis driven approach also leads to individual outcomes of higher dependence on formal supports, and learned helplessness, which may be permanent, rather than building social capital, the capacity and resilience of individuals and, their informal support networks.

In 2002 the Australian Institute of Health and Welfare completed a major study into the unmet need issue ([Unmet Need for Disability Services](#)) and found that, despite additional funding being injected into the system by State and Commonwealth governments, growth in demand continues to outpace growth in supply. It is also known that Australia is well under the OECD average when it comes to employing people with disability (see Footnote One).

A system in urgent need of reform

In Australia today, people with a disability, their families and carers are still left to struggle, alone, twenty four hours a day, seven days a week. There is a general community assumption that if people are born with a disability or acquire one later in life, that some system, somewhere, will take care of them.

Nothing could be further from the truth. People with a disability, their families and carers know only too well the daily struggle for services and support and how often the system fails to deliver essential services. They know how often desperate families are left to fill the gaps. There is also considerable inequity, with people receiving different levels of support depending on how, when and where their disability was acquired. The 2009 *Shut Out* report released by the Federal Government eloquently describes the impact for Australians with a disability and their families and carers.

Barriers to active workforce participation and an income support system that does not address the additional cost of disability leaves the majority of households, in which a person with a disability lives, with disposable income levels well below their peers in the broader community. This means that the capability and capacity to purchase mainstream or generic support solutions is greatly reduced for these households. This in turn leads to greater need for or reliance on specialist formal supports, which ironically for the majority of households, do not exist. **Appendix B** outlines the current services available to a person who manages to get support in a stressed system.

The situation will only get worse in the future. As the population ages, the number of people with a disability will increase. At the same time, the number of unpaid family carers able to provide support is likely to decrease and, without positive action, the available paid workforce will be even less able to cater to the demand (See **Appendix C**, which outlines the findings from the Intergenerational Report information).

A reliance on traditional government funding programs to deliver the support people require, despite the best intentions and actions of governments of all persuasions, has proven unsuccessful over the past 25 years. Such programs are subject to appropriations through government budgetary cycles and represent one voice, in many, competing for available (and sometimes diminishing) government revenues. The procession of government bureaucrats attempting to secure additional funding, going cap in hand to central agencies each year, in the face of an escalating divide between demand and supply has proven a fruitless and almost pointless challenge. A situation of service providers attempting to spread their services more thinly then creates tension at the coalface. Service providers see first-hand on a daily basis the dysfunction that ensues and the resulting compromised outcomes when the system is crisis driven.

CPL's VISION FOR A NEW SYSTEM

It is therefore time for Australia to take stock and plan for the future. A national universal system of life-long support and care represents a fundamental reform to the way services are funded and delivered. It is a social reform on the scale of Medicare and compulsory superannuation - two safety nets that we now take for granted in the Australian community.

A national system of lifelong support and care could be delivered through a National Disability Insurance Scheme (NDIS see [Appendix D](#)), resourced along similar lines to the Medicare health insurance system, through a levy on all taxpayers and held in a fund that is nationally managed and grown, rather than a through a share of taxation revenues.

The national system should not be means tested. The system will recognise that individuals and families living with disability regardless of income experience additional costs, compared with peers in the broader community. This reduces their opportunities to participate and contribute in the same fashion.

Such a national system of lifelong support and care would provide the opportunity to promote universal access to a person-centred, strengths-based system that would be embedded as part of the National Disability Strategy.

People with a disability would access resources to purchase support from their choice of services operating in an open, regulated and sustainable market. The relevance and quality of support delivered by a service provider should drive consumer choice.

This national system would represent a major transformation of the disability sector and will require a clearly planned transitional period. The implementation strategy will need to focus on developing the capability and capacity of Australians with disability, their families and carers, service providers and the broader community to understand and utilise the system. Australians with disability, their families and carers will need to become informed purchasers of services that best address their support needs. Disability service providers will require time to prepare to operate in an open market environment and restructure their organisations accordingly. Work also needs to be undertaken in the broader community to break down the physical, attitudinal, and structural barriers experienced by people with disability every day so they are welcomed into the community and workplaces.

ANSWERING PRODUCTIVITY COMMISSION QUESTIONS

WHAT SHOULD A NEW SYSTEM ASPIRE TO ACHIEVE?

“Life Building,” Is Much More Than Just Moments of Planning”

At the core of a new national system of lifelong support and care must be the person with disability and their family and carers – moving from passive recipient or unheard voice to informed purchaser and client.

A person-centred or person-directed approach relies much less on the formal service system by enabling truly individualised, natural and creative supports to achieve meaningful goals based on the individual's strengths and preferences. Successful disability systems reform in Australia will no longer see planning that is based on "the services available at the present time," a thinly veiled excuse for rationing resources that has restricted our thinking, planning, and actions. The person-centred or person-directed approach enables the individual and the natural team of people who know and care about the individual to come together to develop and share a dream for the person's future and to work together to organise and provide the supports necessary to make that dream a reality.

Guiding Principles of a reformed system

Any changes in the way the disability system works in Australia must have a set of principles that guide policy development. The CPL believes these should be:

1. **Universal access** - all Australians with a disability eligible to access the system will have access to appropriate supports and services to meet their level of support need and “no wrong door”. A National Disability Insurance Scheme will be enshrined in the National Disability Strategy, signed by all levels of government in Australia.
2. **Equity** - across disability groups, geographic boundaries, socio-economic groups and cultural and language divides.
3. **Sustainable** - people will have confidence that they will receive the support they need without resorting to “creating” a crisis to be eligible. This approach also implies **flexibility** throughout a person's life. At times requiring less support and able to “relinquish” hours knowing that in future times when more may be required it will be there.
4. **Invest in a transition phase** – building the capability and capacity of Australians with a disability and their families to operate as informed, assertive purchasers. Ensuring sufficient numbers of service providers are prepared and organised to compete in an open market so that clients continue to have choice and a guarantee of quality safe services where needed.
5. **Invest in a transparent service system** - across all jurisdictions, where quality can be assured and tested and where a robust independent complaints mechanism exists.
6. **Investment in people with a disability** - support needs to be person-centred and strengths-based, measured through improvements in an individual's or family's key socio-economic indicators such as education levels, life expectancy, income levels, home ownership etc.

7. **Invest in early intervention** - invest both at early points in a person's life-stages; and as soon as practicable once a disability or situation has occurred to improve outcomes for the individuals and to reduce total government outlays in areas such as health, social justice, housing etc.
8. **Human rights** - are protected as a fundamental cornerstone of government policy and practice.
9. **Invest in inclusive communities** – where Australian with a disability do not encounter physical, attitudinal or systems barriers to contributing to their communities of choice as citizens.
10. **Consistent nationally** – with supports being portable across all Commonwealth, State and Territory jurisdictions.

The key features of a reformed disability system at all levels will commence with the person with disability. CPL has been an active participant in the development of the *Blue Skies Vision* in Queensland and believes that the following excerpt from their vision is relevant to this discussion and is included in **Appendix E**.

Planning with a person who has disability

The new system will be driven by people rather than services. This represents a fundamental shift in the existing paradigm. An example of this type of paradigm shift is demonstrated in Person Centred Planning.

1. the person is kept at the centre of the process;
2. Person-Centred Planning focuses on the individual's strengths, wishes and preferences;
3. Person centred planning puts the power and control with the person and their allies, whereas, in the past, the power has resided with professionals;
4. The person-centred plan looks beyond what is available at present to what might be possible, whereas a traditional individual plan is restricted by what is currently available from a disability service provider;
5. the plan uses, whenever possible, natural and community supports;
6. the resulting plan reflects what is important to the person, their capacities and the supports that the person requires;

These differences can present challenges for the service and government sectors because traditional models require that staff behave in a synchronised and standardised way. Person centred approaches a flexible, responsive and timely approach guided by the principles of good planning rather than standard procedure.

There are significant barriers to the successful development of a person directed approach that need to be addressed in any reform and these include:

- changing organisational structures, systems processes and resource allocation to support person-centred or person-directed approaches;
- skilling sector staff to operate and communicate with the person supported in a totally different way;
- strong leadership to support the development and implementation of person-centred or person-directed approaches;
- educating people with disabilities and their families to use the system effectively and manage expectations; and
- monitoring achievement of client's goals / outcomes through the person centred approach.

Benefits of aspiring to a systems transformation can be:

A new system needs to be structured so it delivers the following benefits:

- Embodies the UN Convention on the Rights of the person with disability;

- Planning undertaken by or with the person with a disability or their close ones and provides more autonomy;
- Formal supports complement and help build informal supports instead of alienating them;
- Support is centred on individual needs and choices;
- Supports early intervention rather than a crisis model;
- Provide aids, equipment and home modifications needs on a timely basis;
- Builds capability, capacity and self-esteem of people with a disability and their families and carers to reduce long term outlays;
- Lessens the demands on other services such as the justice system, health services, child safety services and institutional care; and
- Increase social inclusion and citizenship with the contribution, opportunities and responsibilities and opportunities that come with it.

WHO SHOULD BE ELIGIBLE?

The guiding principles that assist in the eligibility process include:

Fairness The national system of lifelong support and care would be available to all eligible people who have a disability. Eligibility would be assessed by an agreed upon generic assessment process consistent across all jurisdictions. It should be available to all people who require support with core daily activities (not age related).

Timely Support is provided in a timely manner across all life stages and especially should be responsive to life transitions to mitigate crisis and/or emergency situations.

Equitable The scheme should offer equitable access and level of support across all jurisdictions.

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

- All **infants** who have “developmental delay” and who are at such a young age where the medical profession does not wish to provide a diagnosis of a disability specific condition. The national system must address disability from birth in order to implement effective early childhood intervention strategies. It is through these strategies that families are kept together and independence is maximised thereby reducing government outlays in other areas and later in life. CPL regards eligibility from birth essential in promoting better outcomes and productivity.
- For all **children** with a **mild, moderate, severe or profound** core activity restriction – an early investment in support for any child with a disability is vital to enable the child to reach their potential and to take up opportunities for mainstream education, community participation and social interactions. This is an active strategy to ensure that many children need not have severe and profound core activity restrictions as adults. To date children with mild and moderate core disabilities have not been recipients of funding interventions. Children should be considered as a special cohort in the eligibility criteria to reduce downstream public outlays and by doing so increase Australia’s productivity and future social and economic health.
- For **adults** – all people with permanent profound or severe core activity restrictions acquired before the age of 65, without reference to cause or fault and treated equally based on assessed need. CPL is of the belief that if sufficient investment is made during childhood years that most people with mild to moderate disabilities are highly self-sufficient and need very little government support beyond what is offered to the general population.

- Disability per se should not have to rely on a medical diagnosis alone to be legitimate. **Assessment by formally accredited staff with expertise in particular disabilities (employed by government or licensed organisations)** could also be used to identify eligible applicants to the system. Four main categories for assessment that come to hand are physical, sensory, intellectual and mental health. A system of regulated assessment teams could be considered.
- **No fault** - the provision of support and care for people with disabilities would be separated from legal action for negligence/culpable behaviour. The principle of universal access to support will need to be based on “**the benefit of doubt**” where an approximate balance of the evidence is to be resolved in the client’s favour.
- **As people with disabilities age beyond 65 years**, their requirements for assistance to be dovetailed with the aged care system to allow them to age in place.

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

Defining Criteria

Although it is difficult to easily define what is meant by a 'disability', Cerebral Palsy League considers it as a condition that in some way hampers or hinders a person in terms of their ability to carry out day to day activities. The extent to which a condition hinders a person will vary from individual to individual and the general range of disabilities varies from conditions that are mild (for example, the need to wear reading glasses) to severe (for example, lack of speech and mobility). In recent times various definitions or classifications of disability have been agreed to.

Disability is conceptualised as being a multidimensional experience for the person involved. There may be effects on organs or body parts and there may be effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognised in ICF: body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions). The classification also recognises the role of physical and social environmental factors in affecting disability outcomes.

Cerebral Palsy League supports the definitions of disability that are present in the Disability Service Acts and the ABS definitions. These could be reviewed based on personal goals and outcome measures and should have service provider input.

Definitions are not always consistent and change according to who is defining it (for example refer to **Appendix W** for three examples), what is being measured, the type of legislation being developed, the type of assistance program being developed, the clients interpretation of their disability and the service delivery 's definition. The Commission needs to also take into consideration the *Convention on the Rights of the Person with Disability* and the current time in history and develop a definition that suits the paradigm shift to person centred and strengths based which we propose in the reform.

That the standardised instruments for eligibility include the International Classification of Functioning (ICF); the International Classification of Diseases (ICD); the DSM – IV and where applicable the Gross Motor Functioning Classification System (GMFCS). This would enable; a consistent, measurable, validated, internationally recognised system across the sector which would allow benchmarking; these are explained in **Appendix F**.

The CPL does not believe a single assessment tool exists now or ever will and so there will need to be extensive consultation around assessment if a nationally agreed assessment outcome/deliverable is required against which to make decisions. There should be a timeframe around assessment and reassessment.

Assessment

There will need to be an agreed process to determine those people eligible to enter the national system of lifelong support and care in a formal sense.

CPL supports a national assessment process/mechanisms, with State-based application. Where individuals/ families have existing validated assessments, these need to be given credence in the process (reduce duplication wherever possible);

It is important to use tried and tested assessment instruments such as those mentioned in 4.3 (ICD, ICF, DSM – IV, GMFCS) in order to attain consistency, validity, and confidence in assessing support needs. This way benchmarking could occur within organisations, across jurisdictions and internationally as the first tier of assessment. This data is also collected as a matter of normal procedure by most of the larger Disability focused NGO's.

Other Service Needs Assessment instruments that focus on Individualised Planning carried out by professionals who will be providing the brokered services. We are conscious that some jurisdictions are using instruments such as the Inventory for Client and Agency Planning (ICAP) and we urge caution with the use of such instruments as they are funder oriented instead of being person centred. Moreover they are outdated and in need of a more contemporary approach that incorporates the Social Model of Disability. Research is needed to ascertain the commonalities and differences of instruments currently in use with the intent of establishing a consistent and agreed upon tool for Individualised Planning. Individualised Planning should have as its focus personal outcome measures in order that organisations can assess the outcome and impact of their services on the individual³.

Assessment Interpretation at Government Administrative Levels

It is also important that government departments at all levels are not given the power to create their own eligibility criteria in order to meet their budget requirements. There are a number of areas of government where this is happening and these are outlined in **Appendix G**.

Benefit of doubt

Where problems will occur and where assessment will create difficulty for those people who decide the level of disability for people who sit on the margins between mild, moderate and severe. The philosophy of entitlement will need to be based on "the benefit of doubt" where an approximate balance of the evidence is to be resolved in the client's favour. A pro-client position may be in conflict with the philosophy of a social insurance mission and there will need to be strategies in place to ensure the system remains pro-client focused.

CPL's Position around Service Options Assessment

CPL is of the opinion that providers will decide how they meet client need and wants. An example of Individualised Planning can be found in **Appendix H**.

My Service Provider Checklist

It is anticipated that people eligible for support and seeking a service provider will require education to do so. At the same time quality needs to be ensured. The CPL recommends the following:

³ For example the Centre for Quality and Leadership has developed an instrument *Personal Outcome Measures* (POMS). This approach requires an organisational culture shift to a person centred, strengths based focus in order to ensure the organisation is providing positive outcomes and impact for the person who has a disability.

- A My Service Provider website rating system (A copy of some of the criteria that could go on this website is available in **Appendix I**.)
- Licensed personal care providers that are subject to audits and standards;

How Long is Support Provided?

People have universal access under the national system of lifelong support and care funding for as long there is an assessed need for assistance with core activities of daily living. Some people such as those with cerebral palsy do not experience an improvement in their disability and should not be subjected to annual reviews for the sake of it. CPL would favour a system where people whose disability does not substantially change from year to year maintaining consistent access to indexed financial support with review of that support based on changes in assessed need.

What services, aids, what can people choose?

- Personal Support to live in their own home or a place a person calls home
- Aids and Equipment (including home modifications)
- Early Intervention approaches
- Support in school to maximise social participation and educational outcomes
- Support to access, participate and contribute to the community at all ages
- Employment support to get and stay in a job
- Allied Health Services to maximise physical and emotional well being at all ages
- Respite
- Transport and mobility allowance

How much funding?

- Requires a person or agent to be an informed purchaser;
- Some form of indexed price regulation, based on evidenced based benchmark. This needs to recognise true costs of service provision for providers. Price/financial support benchmarks could be set for different services and situations as a guide; and
- Based on assessed need the reform should meet 100 per cent of costs of care and support needs.

WHO GETS THE POWER?

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

Purchasing power should be vested with the person with a disability or their agent. Many services including CPL have worked towards self-determination for people with a disability and their families regarding the service they receive. CPL has found that the key elements of a successful service include that people with a disability:

- Decide how and when and what support should be provided;
- Know how much money there is for support and how it is being spent;
- Decide who supports them and can have them dismissed if they no longer provide the support required;

- Have requested on a number of occasions that they would like the funds allocated to them and would like those funds portable.

If the person was able to manage funds it would allow them to have more control over the direction of service, over accountability, coordination and financial management. It would also allow them to delegate the management and direction to a third party which could be a service provider such as CPL. Increasingly CPL finds that the more control we can give individuals the more satisfied they are with CPL's services, the more efficiently and appropriately CPL can direct services and build informal supports around the person.

Good outcomes are more likely if the person is strategic in thinking about what it is to envision, plan and build a good life. It then follows that a new scheme which is client centred and strengths based should also provide the training to develop such necessary skills in becoming an active participant in their life, their choices, and support options. Moreover, if the client does not have the capacity at a particular time in their lives then there needs to be some sort of interim arrangements.

The system should identify the management cost within a total cost of support and people can then negotiate this level of support with their provider. It then stands to reason that services will need to develop unit costing based on the types of services they will offer.

Some Ethical Concerns

There are some ethics issues to consider as we move down the path of reform. Firstly, it takes time for people to take full responsibility for managing funds. People will require training and safeguards. The shift from a Charity model to a social insurance model needs to be defined in terms of shifting paradigms. These concerns are outlined in **Appendix J** where the paradigm shift is further explored. Many positions of power also need to be considered in the reform. **Appendix K** provides further analysis of models of disability that are operating at any one time.

The Matrix in this Appendix outlines the models:

- Underlying assumptions;
- The positioning of people with disability;
- Where the power lies; and
- The tensions within and between each model.

CPL believes that all of these models of disability operate at any one time of the person's life. As the new system is developed it is important to consider these models and their interplay to ensure the underpinnings of a particular service can be understood by all involved.

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

The CPL believes this question should ask, "How can purchasing power be enacted (any by whom)? Canada has had an entitlement program for some forty years and to date there is little wastage or rorting of the funding. Were an entitlement, individual funding framework used for people who wish to use this system then training would need to occur in the areas of monitoring, accountability and openness to change.

The CPL supports many people who would like to make all the decisions about their support services and as a part of the vision and mission of CPL we encourage this kind of involvement. Other people prefer to hand over the administration to CPL and so long as there is continual dialogue on the quality and type of the service this model meets their needs. If there were to be self-determination

in terms of individualised packages based on the “In-Control” Vision ⁴ then there would need to be a framework for those entitlements.

CPL believes that purchasing power could work on a continuum from a rebate for support already purchased (at one extreme) to funding provided from a national system to States and Territories to fund support chosen by the individual (the other extreme). Anywhere along that continuum gives the individual the choice of service, provider and type of support. This does not need to be mutually exclusive and tied to one method. It could be a mix of methods.

A new system needs to avoid the pitfalls of the past and ensure that all stakeholders, including the person with disability and their family are included every step of the way and are not coerced into system that does not work for them or maintains unnecessary dependence on specialised disability service providers.

All people should receive a suitable level of coverage based on their assessed needs and those of the policy and program goals. There should be no waiting lists other than temporary issues due to unavailability of relevant expertise.

WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?

- Personal Support to live in their own home or a place a person calls home
- Aids and Equipment (including home modifications)
- Early Intervention approaches
- Support in school to maximise social participation and educational outcomes
- Support to access, participate and contribute to the community at all ages
- Employment support to get and stay in a job
- Allied Health Services to maximise physical and emotional well being at all ages
- Respite
- Transport and mobility allowance

CPL believes that the non-government sector has proven effective and efficient capability in delivering human services and support for many decades. This extends to not-for-profit and for-profit organisations. If government providers are to play any role, it should be strictly on the basis of a ‘safety net.’

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

Table One on Page Eight of this submission shows the level of unmet demand for supports. It is at unacceptable levels across the board. A new national system will provide individuals and families with the purchasing power to obtain the type and level of support they need. This in turn will

⁴ A number of individuals and organisations in Australia have been impressed by the work done in the United Kingdom by a group called **In Control**, and have been citing this model of support as an example of how practice and policy in disability support could look. Systemic policy change involves many groups from different areas working together. In Control Australia believes that developing partnerships and collaboration allows for greater understanding and sharing of knowledge between diverse groups. A transition towards people with disability self-managing has a greater momentum if families, service providers, and funding bodies are included in that transition. http://www.in-control.org.au/about_us.asp

provide the resources and incentive for providers to develop the capability and capacity to meet those needs.

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

In a new system, the traditional notion of service types and programs become less relevant than being able to respond and meet an individual's needs for support.

Disability Reform Debate Drivers

A number of issues are driving the disability reform debate. These include:

- An Ageing Society;
- Increasing demand for disability services;
- Ageing Workforce;
- Workforce Shortages;
- Economic Rationalism;
- Convention on the Rights of the Person with Disability;
- The OECD's push for disability sector reform;
- A clear message from disability sector at all levels that the system is in crisis; and
- An overdue and welcome debate on reform and the need for social insurance schemes to cater.

The Hallmarks of a good service

The hallmarks of a responsive and cost effective service include:

- The service must be appropriate;
- It must match the need;
- It must be flexible to changing need; and
- The direction, management and decision making must occur as close to the individual as possible
- To the above.

Where improvements can be made

Some areas where improvement can be made to meet new service demands and the new way of conducting business include:

- Strengthening research capacity and infrastructure in the NGO sector;
- Identifying and rewarding exemplary service providers who demonstrate leadership;
- Infrastructure aid;
- Financial support for Training and education;
- Full Indexation;
- Service providers to provide outcomes and impact data; and
- Data linkage and sharing.

Performance Management

CPL views a new system as having no programs but rather consumers with needs. Ultimately following transition the government will not be responsible for programs as such and the individual will have purchasing power.

When the new scheme is decided upon there will need to be a re evaluation of measurements (currently collected by the CSTDA NMDS) and how to go about agreeing across jurisdictions on a newly focused national minimum data set and how to collect the data. This will provide one means of shifting the focus from the level of resources to the use of those resources. Performance measurement can:

- help clarify government objectives and responsibilities;
- make performance more transparent; and

- inform the wider community about socio-economic indicators for people with disability (items such as education, employment, income, home ownership etc).

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

A weakness of the current system is that it is crisis driven and will be most likely to respond to an immediate and urgent demand. Investment in high quality early intervention services will reduce the level of long-term support services and will increase the ability of people with disability to take up opportunities to contribute to their communities and to access paid work.

Early intervention in this context relates both to intervening at an early point in a child's life and to intervening at the earliest possible point in a situation or as circumstances change. Both result in better outcomes for the individual and reduced support outlays into the future.

Early childhood intervention programs are crucial in setting the foundation for learning, behaviour and health outcomes. Early intervention should be available to people with physiological conditions who, without intervention, would require more expensive and long term support.

Improving early childhood intervention services warrants the up-front investment in order to reduce overburdening of the system in later years. Not only this will the intensive intervention ensure social inclusion and better personal outcomes than if no intervention were to happen but also will increase productivity and decrease dependence on government funding, especially among the mild to moderate support needs. Importantly it also increases the likelihood that households retain a viable connection with the labour market to maintain household incomes and the ability to find and purchase support solutions for everyday life.

Access to assistive technology is crucial to overcoming support barriers for people with disabilities but access across Australia is very patchy. This will become more important as technology advances and becomes more accessible (e.g. robotics etc).

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

Statements by our clients indicate they want to play a larger role in how their needs are supported and met. They say:

Given these views it could be safe to say that the community engagement approach would be appropriate.

1. Build on Community Assets

Resources are what the community has going for itself. The simple act of recognizing its resources gives a community a sense of confidence, a sense of energy and willingness to take action. When the community believes that assets exist, it finds them, and uses them; it affects the entire way the community is viewed.

2. Increase Skills of Individuals

Individuals and families assume a more skilled condition, not just one of services, learned helplessness and following community development intervention. A particular activity, such as creating an information centre, stimulates learning around fundraising, media relations, public speaking, marketing and writing. This scheme will work best when there is real investment in the envisioning, planning and decision making of people with disability and their family.

3. Connect People with Each Other to Build Relationships and Share Talents, Energy and Information

Everything happens through relationships. Connecting people together in a purposeful manner produces some clear, intended benefits. Unintended, almost serendipitous benefits are just as intriguing, as relationships drive other relationships.

4. Connect Existing Resources - Create or Increase Community Resources

The scheme will work best when individuals and families are able to invite, include and welcome the contributions of people with a disability. Most communities benefit from intentional assistance to do this.

5. Community Assumes Ownership of Direction, Action, and Resources

Individuals and families decide what to do, and how to do it, not the agency. The agency doesn't seek to extend itself, own more things, or run more things. What the person with disability produces is theirs.

6. Community Members do All Work Possible

An analogy – If a community needs a well dug. Dig us a well, they say. Nope, we say. We'll help you dig your well, first by looking at all the things the community can do to dig the well. Only someone outside of the community will do those things on the list that can't be done by the community. The community has its well, more skilled members, and sense of its ability, not disability.

7. Create Beneficial External Relationships

Individuals and families connect with each other and with other external supports, such as, bringing in needed assistance to expand skills, offer support and share resources.

8. Increase Community Self-Reliance and Confidence

All these actions help individuals and families to believe in themselves and their abilities. The scheme will work best when individuals and families are able to invite, include and welcome the contributions of others in their support network.

9. Build Self-Sustaining Organizations

Organized action brings new energy, new leadership, and new vitality. A new Scheme will see optimal use of the funds if people with a disability are assisted to find work, leisure and creative opportunities in the community available to everyone.

10. Enhance Quality of Life

People with disability and their families move past problems, to believe that better is possible, it is even likely. It is certainly deserved and can be expected.

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

- There will need to be a transition phase of approximately 3-5 years;
- The transition implementation phase will need to be clearly outlined;
- There will need to be extensive training to facilitate smooth transition;

The national system will benefit from incremental implementation, so that those people and organizations that are not ready can be supported adequately to develop skills and move on to a transitional phase.

Over the transitional period people could elect to:

- Continue to be supported by the established service structure;
- Be provided with transitional assistance to become more self determining; and
- Be offered options to transfer to the new system or remain in existing or a combination of both.

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

Cerebral Palsy League commits many resources to enable people to be supported “in place.” We have firsthand experience on how creative a service has to be to provide support to people in rural and remote areas. There are travel expenses and workforce shortages which are exacerbated in rural and remote areas of Queensland.

This will require that mainstream services in rural areas have resources to contract specialist disability support.

The CPL has initiated many research projects, pilot programs on how best to meet people’s needs in the bush including outreach, skills development for the mainstream and virtual service delivery. We see a huge role for a National Broadband Network that can facilitate electronic rehabilitation assessment and follow up. This will require additional:

- Resourcing of tele-rehabilitation research and service delivery;
- Resourcing to convert paper client records to electronic records;
- Resourcing to improve data linkage within and between health systems and the disability systems;
- Examine the feasibility of a generalist allied health professional for the rural and remote regions similar to what is being developed in the health system; and
- Make the Medicare Category of Case Conferencing available to the disability sector and the experts working in disability specific areas.

The more people with disability have the authority to manage and direct their own service, the more likely they are to find local practical solutions. The flexibility of self-directed funding will mean that people will seek to find practical solutions in their own community. That said it will be important to enhance tele-rehab services, access grid networks to cater to people living in regional, rural and remote areas of Queensland. This will require that mainstream services in rural areas have resources to contact specialist disability support and expertise to ensure the relevance of this service delivery or “buy in” expertise on a transactional basis.

FUNDING

How should a new scheme be financed?

A sustainable disability service system is essential to support people with significant disability to have choice in their lives and to decide what they will do, when, how and with whom they will do it. This requires adequate funding levels – that reflect the actual costs of service delivery. A fully funded social insurance scheme is the best mechanism to deliver this.

A no-fault National Disability Insurance Scheme (NDIS) paid as a tax levy by taxpayers, would ensure funds are available for those who currently have a disability, and those who may acquire one in future, due to illness, age, accident etc. This way, equity is possible among Australians regardless of disability.

Embedded in the National Disability Strategy the NDIS would enable the development of a National Aids and Equipment Program that is situated outside of the health system.

Much has been stated in previous sections of this Submission but at the heart of the funding should be:

- Person Centred and strengths based support

- Direction and management of service choice ranging from service funding to self directed funding.⁵ A system should be portable, flexible and timely

There are six areas where the funding policy framework needs to change.

1. A new and 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, including reform of state/territory based insurance schemes to include all traumatically injured people, people born with disability and returned services personal who acquire disability by way of their work.
2. Early Childhood Intervention Services
3. System changes to divert young people with disability (<65 yoa) away from residential aged care facilities
4. A strong income support system that facilitates people with disability who cannot support themselves through work, to live in dignity.
5. A range of measures to enable increased private contributions.
6. A strong Aids and Equipment Program that entitles eligible people to the timely and appropriate support they require without co-payments.
7. Investing in a Centre for Excellence for Disability Research.

The Scheme should not compensate for generic services such as medical care, hospitals, housing, education and transport should meet the needs of people with a disability in the same way that these services meet the needs of other Australians.

ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY

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

The national system for lifelong support and care should be enshrined into the National Disability Strategy committed to by all jurisdictions. The NDS with the NDIS embedded will not be self-implementing, and will require concerted, coordinated action by jurisdictional stakeholders and gatekeepers other than those who adopted the policy.

Implementation may stall, it may be diverted or subverted by implementers with conflicting interests, it may attenuate due to insufficient resources, it may encounter any number of pitfalls as has happened in the UK where rapid implementation without training for service providers and people with disability has hampered successful implementation.

A flawed implementation process makes the accomplishment of policy objectives all the more difficult.

The Cerebral Palsy League recommends the following guidelines:

- ***Maintaining the Momentum of change***
- ***Bipartisan commitment***
- ***COAG reform commitment***
- ***Commitment to the recommendations from the Productivity Commission's Inquiry into the Contribution of the Not For Profit Sector***

⁵ Cerebral Palsy League does not endorse forcing people to receive self-directed funding, however, it does endorse a range of funding models, including service funding, self-directed funding that is flexible and portable.

- *Commitment of funding to facilitate the transition process*
- *Stakeholder Analysis*
- *Transition Workshops*
- *Negotiation*
- *Coordination*
- *Avoid “nobody in charge” attribute of reform settings*
- *National Quality System*
- *National Aids and Equipment Program embedded in the National Disability Strategy*
- *Courts / tribunals / appeals / conciliation / adjudication*
- *Work towards an Open Market*
- *Provide assistance for smaller non-viable NGOs to amalgamate*
- *No Wrong Door Approach*
- *Optimising of electronic processes*
- *Portability and flexibility*
- *Complaints Processes*
- *Outcomes and Impacts measures*
- *Private / NFP mix*
- *Invest in service providers around information and training*
- *Invest in people with disability around information and training*
- *Build workforce capacity, retention, recruitment, awareness of the reform and its intention will assist with transition*
- *Strategy for peak bodies and disability advocates*
- *Build a national network of Expert Local Assessment Teams*

Talking Notes
For Angela Tillmanns, CEO
Cerebral Palsy League of Queensland

Productivity Commission's Research into Disability Care and Support

16 July 2010

Productivity Commission Hearing

Daniel, private citizen receiving services from the Cerebral Palsy League

Ms Angela Tillmanns, CEO Cerebral Palsy League

16 July 2010

Daniel is a young man with a physical disability who lives in Redcliffe, on the Northern shores of Moreton Bay and receives support services at home and in the community from the Cerebral Palsy League (CPL).

The issues Daniel faces on a day-to-day basis can be distilled as:

- lack of Flexibility and Choice (in how he organises and lives his life)
- lack of Certainty (of support to enable him to do any life planning)
- lack of Opportunity (to contribute to society and community life, to work, to be who he can be)

Daniel makes the point that he experiences this impact on his life even though he is one of the lucky minority who receive funded support and wonders how his life experiences are magnified for the majority of people with a disability who receive no funded support at all.

Angela Tillmanns is the CEO CPL

- In 2008, Australia was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities, and last year the Optional Protocol, but for many people with disability in Queensland these rights remain out of reach.
- People with disability have a right to a home of their own, family and friends, meaningful work, education, connection to the community and freedom of choice about their lives. Yet people with disability continue to struggle to obtain the supports that help make these things a reality.
- Daniel's issues (lack of flexibility and choice, lack of certainty and lack of opportunity) are all outcomes of Australians with a disability having no entitlement to the support they need to take their place and live their lives in their own communities.

- There appears to be universal agreement that the current system for funding and accessing adult and children disability support services is broken.
- The system is based on continual rationing of financial resources and presents a view that Australians with a disability are simply a drain on the public purse.
- Entitlement to life-long disability support is not just the right thing to do, it is the only sensible thing to do as an investment in Australia's social and economic future.
- Key features of the NDIS would be the universality of its eligibility criteria and the range of benefits to the individual with a disability through the appropriate funding of essential services. An NDIS would finance:
 - a. accommodation support, therapy, support and community access
 - b. options planning to facilitate independence, maximise potential and plan for changing support needs and transitions over peoples life stages
 - c. early intervention as a top priority in the areas of therapy, education and accommodation support
 - d. aids, technology and equipment and home modification needs met on a timely basis
 - e. training, development and access to work to build self-esteem and reduce long term costs
- Models already exist in Australia. There is the fully-funded no-fault insurance scheme to meet the needs of people injured in the workplace in NSW, VIC, SA and NT. There is Medicare and the Superannuation scheme.
- An NDIS would sit alongside other entitlement models – for health care, for education and for adequate income support.

Disability Support and Care for Australians

1. FINANCING

- The NDIS would be funded through a Levy on all taxpayers similar to the Medicare Levy. It is suggested that this levy would raise a sufficient resource and investment base if set at a maximum of 1%.

2. POWER

- Purchasing power should sit with the individual person with a disability (or family for children and others with capacity issues) – a range of mechanisms could enable this.

3. SUPPLY

- Any mainstream, community or specialist provider who can meet the needs of the individual or family.

4. SCOPE

- a. **Who** gets it (eligibility)?
 - for adults – those assessed as having severe and profound core activity restrictions
 - for children – early investment in children who have mild, moderate, severe or profound disability is vital to enabling the child to reach their potential and as such should be considered as a special cohort in the eligibility criteria. This investment would in turn reduce downstream public outlays and increase Australia's productivity and future social and economic health.

- National assessment process/mechanisms, with State-based application. Where individuals/ families have existing government-based assessments, these need to be given credence in the process (no duplication).
- b. **How** long for?
- People have an entitlement to the NDIS funding for as long there is a assessed need for assistance with core activities of daily living
- c. **What** services, aids, what people choose
- Personal Support to live in own home
 - Aids and Equipment
 - Early Intervention
 - Education Support
 - Support to participate in and contribute to the community
 - Employment support
 - Allied Health Services
- d. How much funding?
- Based on assessed need – 100% for identified core supports (for individual)
 - Perhaps contribution for “elective” support

What CPL clients and their families say

The types of supports our clients noted specifically were:

- “At home, to get ready in the morning/evening and prepare meals”;
- “In moving around the community, like in a taxi, van”;
- “In getting suitable equipment such as wheelchair and/or other kinds of technology”;
- “Accessing appropriate health support”;
- “At pre, primary, secondary school and in further education following school such as TAFE and university”;
- “In finding finance to make modifications to our workplace, car and at home”;
- “In finding and keeping a job,”
- “In getting some rest from caring for my twins who both have cerebral palsy”
- “In being able to retire,”
- “In being able to financially get ahead on two wages instead of one or none because someone has to be home to care for my child who has disability.”

APPENDIX..B

Commonwealth Support

The main forms of support provided by the Commonwealth for people with disabilities include:

- income support (for example, the [Disability Support Pension](#), [Carer Payment](#), Carer Allowance ([adult](#) and [child](#)), [Sickness Allowance](#), [Mobility Allowance](#) and [Wife Pension](#))
- funding to organisations to provide employment services as well as the direct provision of employment and training programs
- the provision of services and support through the [Commonwealth Rehabilitation Service](#)
- the provision of funding to the States and Territories for accommodation support, respite, independent living and recreation services
- joint funding with the States for the [Home and Community Care \(HACC\) Program](#)
- funding to the States for administering aids and appliances schemes
- funding of organisations to provide advocacy, information and print disability services
- funding of organisations under the [Continence Aids Assistance Scheme](#)
- funding to sponsor industry projects
- funding for research and development projects
- providing services for Veterans. A major source of income support for veterans is the [Veteran's Disability Pension](#).
- the provision of pharmaceutical and other medical benefits.

Second Intergenerational Report

The second intergeneration report was published on 2 April 2007. It follows the first report in the series, which was released on 14 May 2002 as Budget Paper No. 5.

The demographic challenge

The main issues that the intergenerational reports address are the financial consequences of the structural ageing of the population. This trend refers to the rising proportion of the population over working age (that is, aged over 65), and the consequent decline in the proportion of the population able to participate in the workforce. This will lead to:

- a decline in the rate of economic growth
- a slowdown in the rate at which government revenue grows, and
- increasing government costs in meeting the needs of the growing number of those outside the workforce.

What is an intergenerational report?

Section 20 of the *Charter of Budget Honesty Act 1998* requires that the Treasurer publicly release an intergenerational report every five years to assess the long-term sustainability of current government policies over the following 40 years.

What are the main conclusions of the second report?

The overall conclusion of the intergenerational reports is expressed in terms of the 'fiscal gap'. This is the difference between expected government revenue and projected expenses at a certain point in time, measured in percentage of gross domestic product (GDP).

By 2046–47 the projected fiscal gap is 3.5 per cent of GDP, in the absence of further government policy measures.

Other significant conclusions are:

- budget surpluses are expected to continue until about 2022–23, then the federal government's net debt is expected to rise quickly to about 30 per cent of GDP in 2046–47
- rising health and aged-care expenses are expected to be the main contributor to the fiscal gap, and
- rising age pension payments are also projected to contribute significantly to the fiscal gap, but will not be nearly as significant as rising health costs.

Comparisons with the first report

The overall conclusion of the first intergenerational report was that the fiscal gap would be about 5 per cent of GDP by 2041–42. The improved projections for the fiscal gap in the second report are

based on:

- a projected lower rate of growth in spending per person, mainly in health areas, and
- a higher projected rate of GDP per person, mainly from improving terms of trade, increased rates of workforce participation and higher levels of skilled migration.

Significantly, the second report notes that most of the rise in health costs can be attributed to such factors as the introduction of new, higher-cost medical technologies. That is, most of the health-cost increase is not simply due to the structural ageing of the population.

What is not covered

The intergenerational reports deal only with the projected fiscal position of the Commonwealth Government. However, the Productivity Commission in a 2005 [study](#) projected the fiscal positions of both the state and Commonwealth governments, and broadly confirmed the conclusions of the first intergenerational report.

Howard Government Treasurer Peter Costello also noted that the second intergenerational report did not include the impact of climate change. Rather, its conclusions are based on tangible historical factors such as demography, participation rates, tax and expenditure, and do not include the intangible variables associated with environmental change.

Documentation

Australian Government, [Intergenerational Report 2007](#), Commonwealth of Australia, Canberra, 2007.
Australian Government, Budget Paper No. 5, [Intergenerational Report 2002-03](#), Commonwealth of Australia, Canberra, 2002.

NATIONAL DISABILITY INSURANCE SCHEME

The concept of a National Disability Insurance Scheme (NDIS) was most recently discussed at the 2008 *The 2020 Summit*. Based on Medicare and Compulsory superannuation schemes, the model would conform to international best models/practice benchmarks exhibited by leading countries in the world such as: France, Germany, Sweden, Norway, UK, NZ, and Canada.

Two recent *Intergenerational Reports* released by the Productivity Commission in 2002 and again in 2007 showed that Australia, like those countries mentioned above, has entered the first phase peak of their ageing population pyramid. It highlighted that Australia has an ageing population, people are living longer and with disability, there is an ageing workforce, and there are workforce shortages. While at the same time there is an increasing demand for disability services and rising disability costs across the nation. Waiting lists are growing and services find they are having to “water down” their support services in order to cover diminishing funding availability, reduced capacity for fundraising, due to the global financial downturn

In 2009 the Productivity Commission also carried out research on *The Contribution of the Not For Profit Sector*. Many of its key recommendations are relevant to this current study. These include:

- Smarter regulation of the NFP Sector;
- Building Knowledge Systems;
- Improving Arrangements for effective sector development;
- Stimulating social innovation;
- Improving the effectiveness of direct government funding;
- Removing impediments to better value government funded services; and
- Implementation of the proposed package of reforms.

The Federal Government (FAHCSIA) then commissioned PriceWaterhouseCooper (PwC) to carry out research into a National Disability Insurance Scheme. This report recommended that further research be conducted to explore further the issues related to sustainable disability support and care and it also recommended the development of a National Disability Strategy (NDS).

Following on from the PwC recommendations, FAHCSIA carried out national consultations around the NDS and the *Shut Out: The experience of People with Disabilities and their Families in Australia (Shut Out)* report is the first publication release that focuses on a broken system that is in crisis. People with disability, their carers, their service providers, and planners at state and Federal levels were united in agreeing that the current unmet and under met need was indeed overwhelming. Thus giving validity to the lived experiences of the disability sector. This Public Policy Submission does not specifically focus on what is wrong with the system but rather how it can be fixed. People with disability are entitled to support in the same way that all Australians are entitled to a health services through Medicare.

“It is time to cement a National Disability Insurance Scheme at the heart of the National Disability Strategy to give essential security to all Australians”

Key features of the NDIS would be the universality of its eligibility criteria and the range of benefits to the individual with a disability through the appropriate funding of essential services. These benefits would include:

- Care, accommodation, therapy, support and community access;
- Case management to facilitate independence, maximise potential and plan transitions over the live course;
- Early intervention as a top priority in the areas of therapy, education and accommodation support;

- Aids, technology and equipment and home modification needs met on a timely basis; and
- Training, development and access to work to build self-esteem and reduce long term costs.

NDIS models already exist in Australia. There is the fully-funded no-fault insurance scheme to meet the needs of people injured in the workplace in NSW, VIC. SA and NT. There is Medicare and the Superannuation scheme. Moreover, there are excellent models of disability insurance operating in France, Germany, Sweden, Norway, and Canada plus there is the Accident Compensation Commission in New Zealand.

Things that will assist in making real change include:

Eligibility

It is envisaged that principal beneficiaries would be those Australians with profound and severe disabilities (approx 700,000) who need assistance with daily living tasks (self care, communication and mobility) while people with more moderate disabilities could also be eligible for some assistance based on their lesser needs.

The defining criteria should be needs, as determined by clear eligibility criteria, which would include measures of physical, intellectual and behavioural disabilities preferably based on the ICD, ICF, DSM-IV, GMFCS which are internationally renowned measurements that are validated, accepted, comparable and can be benchmarked across disability categories.

People, Power, Policy and Practice

- Train policy makers, economists, clients and families, practitioners, doctors, rehabilitation counsellors, social workers, general counsellors in a thorough grounding of each of the models of disability, the underlying assumptions, where the power is placed within each model and the tensions between models of disability. To do so would reduce the yawning gap between what policy makers develop and what support services, clients and families want in an open, transparent manner.
- Encourage flexibility and skill on the part of all people involved and including policy makers, “experts,” tribunals, funding bodies, service providers, clients, families and carers from the client to the Commonwealth.
- Ensure that “economic rationalism” and “person centred” are not mutually exclusive.
- Open up opportunities for interdisciplinary and consistent interagency collaboration and interdependent professional services.
- Decrease power differentials.
- A pro-client position may be in conflict with the philosophy of a social insurance mission and there will need to be strategies in place to ensure the system remains pro-client focused and provides the *Benefit of Doubt* on borderline eligibility cases.
- If a shift from the non-adversarial charity model is to occur then the Due- Process Administrative Model of social insurance needs to be imbued with *special beneficence and be uniquely pro-claimant* and take into account the *Duty of Care* and the *Duty to Assist*.
- Implementation a NDIS should be a staged process with Social-For-Profit Organisations coming on board further down the track when national disability standards are developed and the body of regulation surrounding can be policed.
- Delay the introduction of the For – Profit – Sector (FPO) until the fine tuning of the NDIS and the further development of National Quality Standards and associated infrastructure are established.
- Where possible ensure a person centred strengths based model will prevail in care, support, therapy, and access based on functional impairment.
- Case Management to facilitate independence, maximise potential and plan transitions over the life course, when required.
- Income support and/or housing are excluded from the NDIS.
- Person-centred services and support based on the needs and choices of each person with a disability and their family.
- Early intervention a top priority.
- Aids, equipment and home modification needs met on a timely basis.
- Training, development and access to work to build self-esteem and reduce long term costs.

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

Families / carers and power

- Families expected to fulfil normal age-appropriate caring roles.
- Tailored support for carers, through respite, information, counselling, training and education based on family structure and disability.
- Families able to choose to work or provide informal care, as for families without disabled members.
- Part-time work and labour force engagement facilitated.

Governance and Scheme Management: In whose interests?

- Pooling of individual risks.
- Mix of Commonwealth and state schemes (including catastrophic injury schemes) with Commonwealth coordination to ensure a consistent national framework.
- Coordinated approach to funding, including Commonwealth, states and territories
- National standards of assessment, care, support and case management
- Governance framework to manage scheme assets, liabilities and data collections to optimise scheme performance and monitor usage.
- Active claims management.
- Independent review/appeals process.
- National curriculum for the disability sector with a major proportion of required study hours in “client and family placement experiences.”

Other features

- Better coordination with aged care, health, education, housing and other sectors.
- Research into best practice and prevention strategies to drive effectiveness, efficiency and to reduce long term costs, as happens now, for example, with the Victorian Transport Accident Commission.
- Built in and funded program logic evaluation research and personal outcome measures to systematically collect data related to outcomes and impacts and not only inputs and outputs.

BLUE SKYES VISION

The role of the person with disability

People with disability:

- identify their own vision for a good life, their needs and preferences wherever possible;
- participate actively in the life of community to their full potential (in whatever sense community has meaning for them); and
- inform and support continuous improvement in service delivery at a local level.

The role of a faithful family and/ or enduring friends

Faithful family and enduring friends:

- have a natural authority in the life of the person with disability;
- assist the person with disability to envision, plan and build a decent life;
- preserve their ordinary roles and relationships as family or enduring friends;
- be allowed to envision , plan and build a decent life for themselves, and
- are a consistent, enduring link between the person, the community and support system.

The role of Community

Community:

- acknowledges, embraces, promotes, establishes, maintains, and develops further and rewards the gifts, talents and contributions of all of its citizens;
- works in partnership with 'significant others' in the addressing of barriers that restrict valued community participation for all; and
- values the opportunity to both individually and collectively act, so as to ensure that the *Convention on the Rights of Persons with a Disabilities* is evident within the daily life circumstances of individuals with a disability within community.

The role of services

A disability service system responds, person by person, within a universal set of principles including:

- consistency of application and funding response;
- entitlement and certainty for people using services;
- building capacity, competency and interdependent community relationships *in place*;
- helping build a thriving, supportive network of family, friends and community from the outset;
- respect for the natural authority and roles of family and enduring friendships in any service response;
- design of service response (generic and/or specialised) to meet individual need; and
- a focus on the least restrictive alternative and review of outcomes.

The role of government

Government across all jurisdictions had:

- worked diligently to understand and ensure that the United Nation's *Convention on the Rights for Persons with Disability* was reflected in their policy and practice;
- ensured the service delivery system is driven by social policy predicated on disability as a social construct rather than personal tragedy; policy that assumes universal entitlement to adequate support to live a decent life; and
- put in place a [national disability insurance scheme](#), similar to the Medicare levy.

International Classification of Functioning, Disability and Health (ICF)

This link will take you to the specific instrument <http://apps.who.int/classifications/icfbrowser/>
The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental factors.

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 trial purposes only, the ICF was endorsed for use in Member States as the international standard to describe and measure health and disability.

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed ICF allows to records the impact of the environment on the person's functioning.

ICF Application and Training Tools

To facilitate the application of ICF in various settings the following application and training instruments and materials are available:

ICF Checklist: The 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.

[ICF Checklist \[pdf 200kb\]](#)

WHO DAS II: The ICF based Assessment instrument to generate a disability summary score, which can be used to measure severity, monitor impact of programmes, determine the score of individuals or groups in relation to the general population, compare groups with respect to their disability. The instrument is available as a survey and clinician version in multiple languages

[WHO Disability Assessment Schedule II \(WHO DAS II\)](#)

[ICF training Beginner's Guide \[pdf 226kb\]](#)

GMFCS - Expanded and Revised (2007)

The Gross Motor Function Classification System (GMFCS) is a 5 level classification system that describes the gross motor function of children and youth with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility. Distinctions between levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement.

The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

Children who have motor problems similar to those classified in "Level I" can generally walk without restrictions but tend to be limited in some of the more advanced motor skills. Children whose motor function has been classified at "Level V" are generally very limited in their ability to move themselves around even with the use of assistive technology.

The [GMFCS - E&R](#) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The descriptions for the 6 to 12 year and 12 to 18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

Distribution and Translation of the GMFCS E&R

<http://www.canchild.ca/en/measures/gmfcs.asp>

<http://motorgrowth.canchild.ca/en/AboutTheMeasures/resources/FAQ-GMFCS.pdf>

CanChild grants permission for printing of this document but does not allow the sale of the GMFCS-E&R, which should be made available for free everywhere. In addition, the GMFCS-E&R has been translated by colleagues, and made available to all, in the following languages:

Please refer to the [CanChild Guidelines for Translation of the GMFCS](#) for details about obtaining permission to translate the GMFCS E&R.

The recently developed [GMFCS Family Report Questionnaire](#) presents an option for parent involvement in classifying children's motor abilities and is available for three age groups of children: 2 to 4 years, 4 to 6 years, and 6 to 12 years and is also available in French/aussi disponible en français.

The [Motor Growth Curves](#) and [Percentiles](#) for children with cerebral palsy describe development of children with cerebral palsy grouped by GMFCS level. These "growth curves" help doctors, therapists, and families understand how the gross motor abilities of children in each level change with age and how much independence children are likely to achieve.

<http://www.canchild.ca/en/measures/gmfcs.asp>

<http://motorgrowth.canchild.ca/en/AboutTheMeasures/resources/FAQ-GMFCS.pdf>

There are a multitude of functional assessment instruments already in operation, including:

- Instruments already in use in CSTDA and HACC programs
- The Australian Community Care Needs Assessment (ACCNA) and Carers Eligibility and Needs Assessment (CENA) tools being investigated as part of the National Access Points programs in community care (Department of Health and Ageing)
- The Aged Care Assessment process (through ACAT teams)
- The Functional Independence Measure (FIM), which is especially useful for severe brain injury
- The Inventory for Client and Agency Planning (ICAP) tools, which is used by the TAC in Victoria
- The Care and Needs Scale (CANS), which was developed by the Royal Rehabilitation Centre in Sydney¹¹³
- Specific modules for assisting people with mental health disabilities
- Specific modules for assessing work capacity and therefore the need for income support, for example, the Job Capacity Assessment (JCA) (DEEWR, FAHCSIA, Centrelink)

However, functional assessment tools introduce other complications such as when and how often to undertake assessment. In particular, it is most unlikely that functional status will develop quickly and remain stable during the lifetime of the claimant.

Also, the tools do not provide an ability to predict or explain 100% of the services that will ultimately be needed. Studies in the US have suggested that ICAP may satisfactorily capture data that explains 50% of service requirements.

To a large extent, the design of the NDIS will determine which eligibility assessment tool(s) is appropriate. In this context, the *International Classification of Functioning, Disability and Health* (ICF)¹¹⁴ provides a very useful framework for the further discussion and development of assessment mechanisms.

Assessment

In this context, we would recommend the following requirements for the development of any entry assessment tool:

- It be based on functional requirement rather than impairment or medical diagnosis. However, these may inform and clarify the functional requirements
- To the extent possible, it be objective, have clinical credibility and take account of the individual in question
- It be developed in collaboration with users of existing instruments, and in particular existing CSTDA and HACC programs and clinical researchers in appropriate areas. In particular, the instrument should be developed within the framework of the ICF

The threat to an insurance scheme that does not assess eligibility within the principles described above lies in the financial consequences of potential erosion of:

- The severity of disability that ultimately gains access to services
- The duration that clients remain in receipt of those services

The consequences of these would inevitably be a return to unsustainability of the system within the available resources. This risk underscores the need to develop a robust and objective national assessment process.

Assessment process

It is not just the instrument of assessment which is important, of course, but also the process, which is now considered.

Assessments of health condition or functional limitation serve two purposes in a potential NDIS. One is to determine eligibility for admission into the scheme, and the second is, once applicants are admitted, to determine the appropriate selection and quantity of services to be provided. The two issues are, of course, related. To the extent that disease and function change with time, future assessments may alter the view as to appropriate services, and in fact with a deteriorating condition may suggest that “late” entry into the scheme is appropriate. The services which may be considered “appropriate” for inclusion in a NDIS are mentioned below.

Initial assessment

For scheme entry, the timing of assessments is a balance between delays (to increase the certainty of the decision, particularly evident for gradual onset or progressive conditions), and the implications that this delay may have. Untimely delivery of appropriate services may be detrimental to rehabilitation and ultimately more costly to the scheme. Delay may also result in negative community attitudes over the treatment of people with severe disabilities.

A recording and reporting process should be linked to appropriate health and hospital pathways and databases and community access points – much exploratory work has already been undertaken with

Single Point of Access pilots. For some health conditions and jurisdictions, links should be established with existing registries (for example, cerebral palsy, trauma), the National Perinatal Registry and Injury Surveillance processes.

Periodic updates of major cases should be made at six months and 12 months post initial assessment, with a review of eligibility and need at regular intervals post initial assessment.

With any eligibility decision there will be those on the borderline who miss out on entry. A possible implication of this is that there may be significant legal involvement in these borderline cases arguing the eligibility decision. It is a typical feature of both no-fault and common law accident compensation schemes that pressure is placed on eligibility thresholds, with corresponding financial pressure.

Ongoing review

Review of function or disease after the initial assessment would normally need to take place when significant events in the clients' lives occur, or at least on a periodic basis. The review would determine the appropriateness of existing service provisions and potential changes. Reasons that NDIS services would need to change include change of personal situation (marital status, ageing – both younger people requiring more independence from parents or older people becoming more dependent on others), changes to employment status and changes to the disease status or functional ability (aggravation, complications, 'natural' deterioration).

On the other hand, the Scheme will require a clear statement of when scheme responsibility stops – review also makes "finalisation" of claims a possibility. If function returns to levels that would no longer require NDIS support, no further support should be offered. Such a function of regular review may reduce the pressure on the initial assessment.

The uncertainty surrounding these changes clearly adds to the difficulty in the financial management of the scheme.

Appeals and dispute resolution

Disputes in the scheme may arise in the areas of:

- Eligibility – timing, process, method, and assessment will all be contested
- Services provided – the nature of the service, the number of services, any capped cost, range of services (as new procedures evolve)
- Decisions – the scheme will be responsible for administering the act and each decision will be subject to close scrutiny and appeal

As such, the process for dispute resolution plays a vital role in ensuring that the scheme continues to be viewed by the community as providing fair and reasonable support to people with serious activity limitations.

In order to do this, it is essential that all aspects of the scheme's operations are transparent and defined as objectively as possible. The decision making process for the more qualitative aspects of the scheme will need to be clearly enunciated, as will the entitlement and appeal process, either via an informal internal process, or a more formal external process such a resort to appeals tribunals.

CPL's Position around Service Options Assessment

Services to be provided are determined by the interplay of the wishes of the person and their family as well as relevant others as the case may be. The process begins by ascertaining:

- Why the person has come to the agency
- What services are being requested
- What are their needs, goals, and preferences?
- Is this a situation that involves other professionals as well, and what are their thoughts?
- What is success in the eyes of the child, the family and other interested people?

The process then moves to consideration of the potential relationship between the agency and the person:

- Can the requested services be provided by the agency?
- Can the agency, in partnership with others, provide the service: Or is a referral more appropriate?
- Is the person's age and disability appropriate for the services offered?
- Is the child's health status such that the agency can be useful to him or her
- Are all eligibility requirements met?

Once it is determined that the agency has something to offer the child and family, the request is put in context:

- What is the person's physical health and mental health history?
- Is the family willing to participate in the life of the person?
- What resources do they offer in terms of support and care giving?
- Is there a history of abuse and/or neglect?
- Is there alcohol abuse or other substance abuse present?
- Is there a history of mental health problems?
- Is there a history of violence, or other criminal activity?
- Where does the person reside and with whom?
- How do they currently access the community or get around?
- What are the cultural and ethnic expectations
- What is their spiritual history
- What is the educational level of the person and the family
- What is the level of communication on the part of the person;
- Is the person sexually active
- What does the person enjoy doing in their free time
- What does the person want to be or do?

-This is the first phase of getting to know the person.

-The second phase will involve case management; reunification and post placement services; health care; identity and sexuality; child protection; disclosure and reporting; Community based service delivery; living options; natural support networks; advocacy; personal and continuous quality improvement; agreements rights and responsibilities.

-Administrative review, remedies, grievances and appeals, records and record keeping; confidentiality and management of confidential information. Personal outcome measures commence at the initial assessment. They include:

Aspects around:

- Identity
- Autonomy
- Affiliation
- Attainment
- Safeguards
- Rights
- Health and Wellness.

The plan for support would include aids and equipment assessment, supply, maintenance, and follow up assessments. Using the International Classification of Function, Disability and Health (ICF) and input from the person with a disability to consider personal preferences, the priorities can be defined as:

- The bests combination of equipment, personal care and environmental design to meet their needs in all aspects of life and life changes
- Good quality and long lasting equipment
- A holistic approach where each piece of equipment works well and does not interfere with other equipment or supports;
- Support through the process of getting equipment, including equipment trial, training and maintenance.

My Service Provider Rating Website Criteria

Leadership

- The organisation defines its primary customer
- People served exercise leadership through choice and self determination
- The organisation emphasises the value of listening, responsiveness, respect, and support for desired outcomes.
- The organisation links service users, families and providers to promote individual relationships and increase system capacity
- The organisation appoints service users to the board of directors
- The organisation clearly defines expectations for staff competency and performance
- The organisation regularly evaluates and provides feedback to its staff on their performance
- The organisation has a strategy for developing relationships with other agencies/providers in its service area.

Systems

- The organisation has a clear statement of its mission
- The organisation implements a strategy for listening to and learning about each client
- The organisation promotes coordinated systems of services that are responsive to the needs and desires of service users
- The organisation provides service users and other organisations with relevant information
- The organisation has a strategy for hiring, nurturing, and sustaining staff
- The organisation provides opportunities for staff training and personal development
- The organisation has a personnel development strategy for increasing staff and volunteer competence in facilitation, problem solving and negotiation
- Organisational systems promote personal dignity and respect
- Organisational systems promote continuity and security
- Organisational systems promote natural support relationships

Quality Management and Planning

- The organisation has a process for eliciting and analysing feedback on services and supports from service users, employees and providers
- The organisation periodically analyses and documents the relationship between resource allocation and personal outcome attainment
- The organisation has a process for collecting and analysing information
- Information analysis results in strategies for organisational quality improvement
- The organisation's knowledge management system is based on information about aggregated individual needs and resources within the service area.

The Death of the Charity Model and The Birth Of The Social Insurance Model – Some Ethical Concerns

The stresses already outlined in the *Shut Out* Report signify a major haemorrhage of the existing charity model of support for people with disability. Unless there is change the inability of the existing system to cope, it is set to get worse in the very near future as we move further into the peak of Australia’s ageing population pyramid. Change is not a matter of “if” but “when” and there is an urgent need for change.

Developed countries whose population pyramids have peaked earlier than Australia’s have put in place, a range of social insurance models that signify a responsive change from the charity model to the social insurance model.

There are many ethical issues as we change the disability sector model from that of a Charity model to a model that reflects a changing society – the Social Insurance Model. The key features of the Charity and Social Insurance Model can be summarised in the following table.

Table Two: The two Models of Benefits

Model	Charity	Social Insurance
Obligation	Moral	Quasi-Contractual
Programs	Ad Hoc	Comprehensive
Decisions	Discretionary	Legal Standards
Benefits	Mere Gratuities	Entitlements
Procedures	Non-Adversarial	Due Process
Decision Maker	Agency	Independent

In the Charity Model the givers of benefits stand in a helping relationship to the recipient and not in an adversarial one. The addition of a judicial review may then reinforce this adversarial posture. That noted there is a lot to be said about establishing a judicial review process. Currently there is no such thing and so inequity, inflexible models of service and no avenue for appeal all serve to create a system that does not cater to the very people for whom it was set up.

If a shift from the non-adversarial model is to occur then the Due- Process Administrative Model of social insurance needs to be imbued with **special beneficence and be uniquely pro-claimant** and take into account the **Duty of Care** and the **Duty to Assist**.

In Queensland the Law Reform Commission has recently undertaken a rationalisation of Tribunals. Where would a Non Adversarial Tribunal sit in relation to the legal systems in each state and how would this be streamlined at a national level? Some decisions will probably still be made by people other than the individual — such as whether a person is eligible to be in the scheme or not, or the amount of financial support and services they get.

MODELS OF DISABILITY: Assumptions, power and tensions and how long term disability support and care must be framed.

Much of the way in which rehabilitation practitioners, educators, service support planners and implementers, clients and carers, and researchers undertake their work is guided by the model of disability to which they subscribe (Harper, 1991; Tate & Pledger, 2003). Models of disability define disability, determine casual and responsibility attributions, influence professional practice, drive payment systems, and guide legislation (Dembo, 1982; Hahn, 1993; Nagi, 1969; Zola, 1989). Models of disability permeate every professional relationship in the disability sector; these models also serve as the structure for service support, rehabilitation and disability research development, present a focus of planning support services, provide a position for the individual with disability, and provide the rationale for the funding of large studies and so on. Examining the assumptions underpinning the models, where the power lies and the underlying tensions of each model enables transparency of the power relationship inherent in formulation, implementation monitoring and evaluation of disability policy. Briefly the matrix below outlines a summary of those models.

Further, every type of rehabilitation/disability resource allocation has its basis in a model of disability and agency policies and regulations trace their origins to a model of disability (Albrecht, 1981, 1992; Berkowitz, 1987; Bickenbach, 1993; Fox, 1993; Wolfensberger, 1972). Thus, the daily lives of people with disabilities, if and how they are educated, if and where they work, and their social and familial life, in large part are determined by models of disability. Perhaps, most important, models of disability exert a powerful influence on the public perception of disability and the public's response to people with disabilities. Consequently, models of disability have the capacity to shape the self-identity of those with disabilities (Conrad, 2004; Davis, 1997; Hannah & Midlarsky, 1987; Hulnick & Hulnick, 1989; Longmore, 1995; Nagi, 1969).

Surprisingly, the power of models of disability is rarely acknowledged or addressed; nor, are these models questioned or challenged (Gill, Kewman, & Brannon, 2003; Harper, 1991; Pledger, 2003). Indeed, most practitioners are only marginally aware that there are other models and that patients/clients/consumers may, and often do, subscribe to a different model. A therapeutic alliance, therefore, is difficult to establish if the professional and client define the disability differently and, as a result, envision different treatments and services. Most practitioners function in the way in which they have been educated and trained (Bauman & Drake, 1997; Bluestone, Stokes, & Kuba, 1996; Gill et al., 2003; Hogben & Waterman, 1997; Kemp & Mallinkrodt, 1996; Parsons, Hernandez, & Jorgensen, 1998). For example, if a practitioner has been trained to view disability as solely a clinical concept, he or she will conceptualize the necessary response to be clinical treatment.

Models of disability are the underlying structure for large, complex diagnostic/defining systems, such as the International Classification of Disabilities, Impairments, and Handicaps--2 (ICIDH-2) (WHO, 1993, 2001) and the Diagnostic and Statistical Manual IV--Text Revision (DSM-IV-TR, American Psychiatric Association, 2000) and the International Classification of Functioning, Disability, and Health (ICF, World Health Organization, 2001). In turn, these diagnostic systems are used not only for clinical purposes but also for research development, and administrative and social planning. Diagnoses, therefore, have profound political, social, and financial consequences (Hahn, 1985; Smart, 2005b).

Models provide both casual and responsibility attributions; these attributions determine which academic disciplines study and teach the disability experience. If disability is viewed as only a medical concern, then the cultural, historical, social, and political aspects will not be taught in psychology, sociology, political, science, law, or history curricula. Moreover, most people with disabilities, after

medical stabilization has been achieved, consider the social, cultural, and political aspects of the disability experience to be their most important concern (Bowe, 1980; Dembo, 1974; Smart, 2005a, 2005b). However, it is likely that there are few professionals, who possess the adequate background, training and clinical experience to provide these social, cultural, and family support services. Despite the persuasive power and influence of models of disability and their very tangible results, these models are not reality or fact, but rather human-made representations of reality (Eisenberg, Griggins, & Duval, 1982; Smart, 2001). Each model, then, reflects the needs, values, and purposes of its definers and thus none is morally neutral (Clendinen & Nagourney, 1999; Kirk & Kuchins, 1992; Stone, 1984; Zola, 1993). All models are somewhat time-bound and culture-bound; different concepts of disability have historically led to different methods of dealing with disability and ways of responding to individuals who experience disabilities. Further, at present, there is no single model with the capability to describe and explain every aspect of the disability experience, probably due to the fact that disability is a complex, multivariate experience (Tate & Pledger, 2003). Stated differently, each model is reductionistic or incomplete, emphasizing some aspects of the disability experience and ignoring others (Bickenbach, Chatterji, Badley, & Ustin, 1999; Zola, 1989).

Thus, there are weaknesses and limits to each model of disability. Furthermore, the definitions, casual attributions, and interventions of each model conflict with their counterparts in the other models; however, adherents of one model often do not reject the viewpoints of other models. Nonetheless, each model is capable of change and, indeed, all models are required to make refinements and modifications. The evolutionary path of all models can be easily traced, often through reviewing their results.

In view of the power and influence of models of disability, a general overview of the models will provide insight into the rationale and evolutionary path of each, the weaknesses and strengths of each model and their results in four broad areas: legislation and policy, training and education, professional practice, and research. It is important to discuss all of these models in order to view the evolutionary path and to construct a basis upon which to make comparisons. To present a comparative overview, it is necessary to be somewhat brief, general, and broad. Accordingly, first a brief description of each of three models of disability will be presented. Secondly, the weaknesses and strengths of each model will be discussed. Finally, the diversity of these three models will be considered as broadening the definition and response to disability. All models have strengths and weaknesses and the vestiges of these models are deeply entrenched in the broader culture.

Nonetheless, each model fills important needs.

The six emerging models of disability are now summarised outlining:

- Their assumptions
- The positioning of people with disability
- Where the power lies

Models of Disability	<ul style="list-style-type: none"> ➤ Medical Model ➤ Old and still powerful 	<ul style="list-style-type: none"> ➤ Functional Model: Interactional Approach ➤ 1970s – 1980s 	<i>Economic Rational</i>	<ul style="list-style-type: none"> ➤ Socio-Political Model ➤ Birth of the Rights movement ➤ 1990s DDA 	<ul style="list-style-type: none"> ➤ Social model of disability ➤ Late 1990s early 2000s 	<ul style="list-style-type: none"> ➤ Anti-social model of disability ➤ Late 2000s 	<ul style="list-style-type: none"> ➤ Person Centred/ strengths based ➤ Current
Assumptions	<ul style="list-style-type: none"> ▪ Oldest model ▪ Has prestige and authority ▪ Scientific rigor and objectivity ▪ Ease with which diagnostic/definitional system is understood by general public ▪ Is the dominant model ▪ Disability thought to be pathology, disorder, dysfunction, deformity in an individual ▪ Diagnosis based on deviation from the “normal.” ▪ Can be quantified, measured, and standardized (positivist notions) ▪ All treatment geared towards full rehabilitation and cure of the individual 	<ul style="list-style-type: none"> ▪ The provision of accommodations for and adaptations to the functions of the individual ▪ Deflected away from the rehabilitation of the individual to the adaptation of functions ▪ Challenges the medical model 	<p><i>The rise of economic rationalism</i></p> <p><i>Diagnosis Related Categories (DRG's) and Casemix</i></p>	<ul style="list-style-type: none"> ▪ Minority Group approach ▪ Independent living model ▪ Radical Democratic Approach ▪ Used by governments in policy making ▪ Disability not the problem but instead society ▪ Solution is to change attitudes ▪ Denied their rights ▪ Not all the solutions come from the biomedical model ▪ Birth of the disability Rights movement 	<ul style="list-style-type: none"> ▪ Disability is understood as an unequal relationship within society in which the needs of people with impairment are often given little or no attention. ▪ Considers disability as a result of the barriers that impede disabled and impaired people from accessing traditional services and expectations. ▪ Focuses on the barriers that disabled people are required to circumnavigate in their lives. 	<ul style="list-style-type: none"> ▪ Questioning the idealist notion of the social model of disability ▪ Combined success of medicine, medical technology, and pharmacology have enhanced and saved the lives of people with disability. ▪ There are biological realities to the experience of people with disability ▪ A backlash against the political aspects of the social model being the panacea of the lived experience of people with disability 	<ul style="list-style-type: none"> ▪ Looking beyond the disability and looking at the <u>person</u>. ▪ Takes a little of all of the models ▪ What expectations are how the person lives and how they want to live, what their personal outcomes are. <ul style="list-style-type: none"> ▪ ➤ Goal attainment ➤ Interdisciplinary ➤ Transdisciplinary ➤ Uses all models ➤ Natural environments ➤ Family Centred ➤ Service Access ➤ Service Components ➤ Service Coordination ➤ Assessment ➤ Transition ➤ Exiting the Program ➤ Program Logic Evaluation ➤ Personal Outcome Measures
Positioning of people with impairment/disability	<p>The disability diagnosis is paramount. This then attributes assumptions about the lifestyle and practices of an individual based on the medical evidence</p>	<ul style="list-style-type: none"> ▪ The individual is not able, due to disability to perform his or her functions or roles of society. ▪ Three way interaction between the individual, the disability and the functions. 		<ul style="list-style-type: none"> ▪ Empowering ▪ Self determination ▪ Minority group with rights ▪ Agitate for change ▪ Formalised, collective public actions of governments define who has a disability and who does not thus 	<ul style="list-style-type: none"> ▪ Person with disability holds power ▪ Works on an individual (or micro) level and the societal level (macro) 	<ul style="list-style-type: none"> ▪ Confusion around the positioning of the medical model and the social model of disability ▪ An acknowledgement that many people rely on technology and the medical system for some of their support 	<ul style="list-style-type: none"> ▪ The capability to incorporate the individual's cultural/ethnic/linguistic subjective identity into the disability ▪ Difficult to dehumanise

		<ul style="list-style-type: none"> It does focus on the strengths and assets and their functional needs and desires. 		<p>disabilities are politically manipulated categories</p> <ul style="list-style-type: none"> These cause structural and cultural violence Only in the 1990s were the DDAct inacted 			
	<ul style="list-style-type: none"> It is implied that there is power over the client Client virtually invisible in this model The doctor's diagnosis and treatment is objective and "right" Resulting in discrimination and injustice Power differential between the expert and the individual 	<p>Implies that someone has power to give to the Client if they so wish (so the power still lies with someone outside of the client)</p>		<p>There is an intent that power is a construct that lies with the person who has disability</p>		<ul style="list-style-type: none"> Society has endowed the medical profession with its power Medical and social models informed technology development 	<ul style="list-style-type: none"> People's concerns, the way they live their life, their activities, routines, who they are and what they want from the final design are all important to effective design and personal outcomes
➤ STRUCTURE	➤	➤	➤	➤	➤	➤ AGENCY LIES WITH THE INDIVIDUAL	➤ Shared agency
<i>Power</i>	Power over the individual	Power lies in the hand of someone else such as the allied health professional		Resistance Power being taken back by the individual	Power lies with the individual	<ul style="list-style-type: none"> Crisis of control 	Shared Power with the individual
<i>Tensions</i>	<ul style="list-style-type: none"> Deficits based approach – what the person cannot do Diagnosis driven rather than individual focused Pathologisation of 	<p>It does not have a life span approach Focuses only on enabling the individual to work</p> <p>Focuses only on working</p>		<p>Policy makers, legislators, professional service providers and the general public are considered a part of the problem. In terms of rights there has been progress with</p>	<p>The model creates a climate where each disability group is in competition for scarce resources with the other When designing system of support all models are</p>	<p>Tension between the medical and social models of health</p> <p>Viewing people from a disability perspective</p>	<ul style="list-style-type: none"> Strengths based approach of what the person can do Draws on all models of disability Economic rationalism and person centred

	<p>disability</p> <ul style="list-style-type: none"> ▪ Power differential between the practitioner and the individual ▪ Privatisation of both the cause and the source and the response and intervention ▪ Viewed by some as the “metahandicap” asserting that discrimination and prejudice are a direct result of the biomedical model ▪ General public see disability the concern of medical practitioners thus no need to provide services, civil rights, access. ▪ “blaming the victim” ▪ Caught between two worlds – death or cure ▪ Work disincentive based on the sick role 	<p>class citizens thus excluding children and young people Viewed as the economic modes in that work and economics are closely related. Reduces individuals with disabilities to their economic value or their ability to contribute to the economy May result in prejudice and discrimination against those who do not work. Taken to extreme this model could result in a public perception of people with disabilities as “burdens” or “drains” or luxuries” that society can ill afford. Can lead to victim blaming It is still viewed as pathology, abnormality, deviance.</p>		<p>Aust signing CRPD in 2008.</p>	<p>required Polemicalises and polarises groups of disabilities Very difficult to operationalise (e.g. how to take down and wash the curtains etc).</p>		<p>tensions between the two</p>
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All models of disability have the intent to assist people with disabilities. Rather than attempting to synthesise the models of disability into a single model, it makes more sense to train policy makers, clients and families, practitioners, doctors, rehabilitation counsellors, social workers, general counsellors in a thorough grounding of each of the models. In this way the strengths of each model can be fully exploited and the limitations of each model can be clearly acknowledged and addressed.

Obviously this method will require both flexibility and skill on the part of all people concerned and including policy makers and funding bodies.

Such a cross-model service provision will open up opportunities for interdisciplinary and consistent interagency collaboration and interdependent professional services. For example medical schools might teach a class and provide clinical experience on the lived experience of disability. Such experience and training, coupled with a wellness/preventive approach for people with disabilities will lead to new treatment goals after medical stabilization. Furthermore, if physicians facilitate the empowerment of their patients with disabilities and encourage these patients to take control of decision making in treatment, support, some of the power differentials will be decreased. There is great potential for providing services that are not medically based but nonetheless provided as a valued part of flexible individualised programs. In addition to a medical wellness orientation and the prevention of secondary conditions and complications, psychosocial interventions such as individual and family counselling, provision of assistive technology, and a wide array of services designed to encourage independence and function can be provided in a package of services provided by an interdisciplinary team.

A cross model orientation may lead to research studies that produce more meaningful results because social forces, although more difficult to operationalise will serve as independent variables. Quality of life issues will become more embedded in research studies rather than only the clinical/medical aspects of disability. In short, such a cross-model orientation encourages a more systematic analysis of rehabilitation interventions. It also brings structure and order to research.

COMMUNITY SECTOR MANIFESTO ARISING FROM THE PRODUCTIVITY COMMISSION'S INQUIRY INTO THE CONTRIBUTION OF THE NOT FOR PROFIT SECTOR

Recognising that Government strategies for promoting community wellbeing, social inclusion, and social innovation depend on a vibrant, efficient and effective Not for Profit community sector, the Not for Profit Community Sector calls upon the Australian Labor Party, Australian Liberal Party, The Nationals, and the Australian Greens to commit to:

REGULATION AND THE INSTITUTIONAL FRAMEWORK OF GOVERNMENT

- 1. Fix government –sector arrangements...**
Establish a new government agency to resource and coordinate the Government's work with the sector as a whole. Tasks for this new agency: implementing regulatory reforms; improving the quality of information about the sector; improving the effectiveness of services; streamlining funding arrangements; promoting social innovation; and, facilitating stronger community and business collaboration.
- 2. Set up a one-stop-regulatory-shop ...**
Establish a national Registrar for charities, community organisations and not-for-profit organisations, in collaboration with the sector.
- 3. Build knowledge...**
Facilitate the establishment of a national online resource that presents data and information about community and not-for-profit organisations and the not-for-profit sector as a whole, in partnership with the sector.
- 4. Apply common sense to tax concessions...**
Simplify eligibility for tax concessions, by streamlining the existing 40 statutes and 19 government agencies responsible for this function.
- 5. Sort out vetting systems**
Introduce a streamlined national vetting system for working with children and vulnerable people.

POLICY

- 6. Encourage giving....**
Provide funding for a national campaign to promote and support planned giving, such as regular donations and bequests, and especially payroll giving – and government to work with the sector on this campaign.
- 7. Enable sensible use of borrowed money...**
Facilitate ways for Not-for-Profit community organisations to access debt finance to increase service provision, especially in capital intensive service contexts, where appropriate

8. **Move towards wage justice...**

Fund wages at market rates in all government funded programs as an immediate priority within existing funds and/or through new funding.

9. **Volunteer to help volunteering...**

Facilitate and promote volunteering, especially through support of sector-led initiatives

10. **Support innovation...**

Provide growth funding for social innovation and testing of new approaches to service delivery – and that this should be new funding.

11. **Prioritise community wellbeing...**

Adopt a common, nationwide, 'index of community wellbeing', that maps wellbeing at local, regional, state and national level.

APPENDIX..W

Example One -Education: These include the National Schools Organisation (NSO) funding where eligibility requirements are interpreted differently across all jurisdictions. Government departments are left to balance scarce financial resources that are spread thinly across children with disability. This leaves children with disability vulnerable with not enough interventions to ensure a child can live and learn to the level of their potential. With the implementation of the MySchool website, schools, in an attempt to meet benchmarks are tending to place children in the segregated Special School system because the children are seen as a liability in the ratings contest. For many of the 1500 children to whom CPL provides support service to this is a counter-productive move. What should be happening is that support should be provided to the teachers in order to integrate children into mainstream education systems. This would product a better outcome for children, their families and value add to the future of the nation.

Example Two – Health: There is much documented on the inequities and disparities around eligibility and access to aids and equipment across the jurisdictions. Not one jurisdiction has got it right.

Example Three – Transport: Jurisdictions are currently implementing their automatic ticketing systems. Because there was limited consultation with the disability sector in the development of the ticketing systems many people who have a range of disabilities now cannot use the mainstream ticketing system. Government Departments are now developing a variety of Access Passes some of which are provided free of charge and other with astronomical costs associated. The various definitions of disability prevail and where some clients are eligible others are not despite the same type and level of disability.

Example Four – FAHCSIA: Relates to the inequities in assessment for the two tiered system for mobility allowance. Where there are many inconsistencies in the system. The one of note is for people who are working for Disability Enterprises under the supported wage system. These people are generally the more severely disabled cohort and should be eligible for the higher level of mobility allowance yet this is not the case.