

**Input for:**

# **Senate Standing Committees on Community Affairs:**

## ***National Disability Insurance Scheme Bill 2012 - exposure draft***

Authorised by:

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The Cerebral Palsy League (CPL) welcomes the opportunity to provide input to the Senate Standing Committee on Community Affairs Inquiry on the draft exposure of the *National Disability Insurance Scheme Bill 2012*.

CPL strongly supports the introduction of the National Disability Insurance Scheme (NDIS) Bill and commends the positive difference it will make to the lives of Australians with a disability and their families and carers.

CPL's vision is: ***An inclusive world for all people.***

The following comments have been developed in consultation with members of our Regional and Statewide Client Consultative Committee (SCCC) who have a lived experience under the Disability Services Act and the associated State and Commonwealth government funding processes existing in Queensland.

CPL is comfortable with any comments made in this submission relating to the National Disability Insurance Scheme (NDIS) being made public after committee's consideration.

## 1. Introduction

CPL is the largest non-government service provider for Queenslanders who have a physical disability and provide a broad range of services throughout Queensland. We anticipate that all individuals and families who are currently supported by CPL support will be ineligible to participate in a National Disability Insurance Scheme.

A brief guide to CPL is attached to this submission. CPL's 2011-12 Annual Report is available on the web at <http://www.cpl.org.au/docs/miscellaneous-documents/cpl-annual-report-2011-12.pdf?sfvrsn=0>.

Please note that the following comments have been developed in the absence of an analysis of the 'National Disability Insurance Scheme Rules' that would operate within the proposed legislation.

## 2. What is missing from the draft Bill? - A tiered approach to providing supports under the National Disability Insurance Scheme

CPL acknowledges the intentions of the legislation under a three tiered system are to minimise the impacts of disability for all Australians by providing multiple service responses that include:

- providing insurance against the cost of support in the event that they acquire a significant disability
- promoting opportunities for people with a disability; and
- creating general awareness within the general community of the issues that affect people with a disability; and
- drawing on data and research capabilities to engage with other agencies to improve public health and safety; and
- the provision of assessed and targeted individualised supports to meet people's ongoing support needs.

However the legislation does not specifically acknowledge or reference the information services and relationship and referral streams that will need to exist within the multi-tiered system to ensure that best possible outcomes for participants to become informed and sophisticated purchasers.

Much the same as sector calls to include funding for independent advocacy under the NDIS, an investment is required to maintain and expand expert information services. These will be critical to participants in all three tiers of the NDIS to ensure that passive recipients of support can make the leap to become sophisticated and informed purchasers of services.

Research and innovative service development require sector-wide investment or they will likely become non viable activities for providers operating in a highly competitive market.

## Recommendations

1. While recognising that the Bill is designed primarily to enable the operation of Tier III of the NDIS, the legislation make specific reference to the existence of the three Tiers of the NDIS and how they will interact to achieve the aims of the Scheme, in full.
2. The legislation makes specific reference to government investment in information services and for research and development in the disability sector.
3. Additional information be developed within the legislation and/or the associated 'National Disability Insurance Scheme Rules' to provide clarity on the relationship and roles and responsibilities of a referral stream between the various tiers of the scheme to ensure individuals and service providers within the scheme are able to ensure maximised participation.

### 3. Proposed Rules that should be included in the Bill

CPL understands the need to keep the legislation as free from specific rules as possible to avoid the inherent difficulties of (a) modifying legislation through Parliament when changes in rules are required; and (b) increasing the complexity of the legislation.

However, CPL considers the legislation would benefit from the inclusion of a number of proposed Rules in the legislation itself:

- A participant's life goals must be at the centre of the system and drive assessment, resource allocation and supports planning.
- Consideration of the appropriateness of supports should be based on achievement of life goals - this takes into account that all support should be for a purpose that is included in the participant's life goals.
- A participant has capacity to make their own decisions unless otherwise proven.

This is validated in the COAG Regulatory Impact Statement (p36), which states "*Participants would be presumed to have the capacity to exercise choice and control including, depending on their circumstances, with the right kinds of decision support. Any restrictions on choice and control would be minimal and information provided to the participant, their carers/family, to ensure transparency and understanding.*"

- A clear process for the appropriation of funds to resource the NDIS should be enshrined in legislation to reduce the likelihood of the government of the day or government departments changing fiscal priorities which leave the NDIS under-funded for its purpose.

### 4. Objectives & Principles (Sections 3-8)

CPL has been a long term supporter of fundamental change in the way disability services in Queensland and indeed Australia are funded and delivered. We believe that:

- specialist disability support must empower people with disability and their families to maximise their independence and contribution to society, not simply provide care and support, which promotes a (real or perceived) dependency on government or community hand-outs
- we must fundamentally change the way it approaches disability in this country, not simply change the funding regime for disability support
- we must support individuals and families to actively take opportunities when they exist, rather than just passively seeing the opportunities that might exist.

Self-directed funding is a key foundation in empowering people with a disability and their families to live the life they want to live. It will provide them with purchasing power and enable them to establish relevant and tailored packages of support. This in turn will provide them with greater opportunity to participate and contribute to community life.

We recognise that the National Disability Insurance Scheme legislation embodies these same principles.

#### Recommendations

4. **Include as a Principle, *Participants are presumed to have the capacity to exercise choice unless proven otherwise.***
5. **Include a Principle that a participant's life goals must be at the centre of the system and drive assessment, resource allocation and supports planning – this would influence all provisions in the Bill related to a participant's "goals".**

#### 5. Requests a CEO can make - Section 26

CPL recognises that the CEO must be allowed to compel participants of the scheme to produce relevant information to ensure sound decision-making. However, there are situations where relevant information is held by third parties and cannot be accessed by the participants. An attempt to compel the participant to provide the information in this circumstance is fraught.

#### Recommendations

6. **Section 26 of the Bill be amended to include a caveat however that an individual is not placed at a disadvantage if their inability to produce information has been the result of a third party failing to fulfil an obligation.**
7. **Further, that consideration is given to the CEO having the power to compel a third party to provide relevant information, if not forthcoming.**

#### 6. Assessment

It is important that NDIS legislation heeds the lessons learned from the past two decades, most recently in Queensland, about trying to implement an approach to assessment that involves the use of a single assessment tool.

Simply put, there is unlikely ever to be a single assessment tool that will be fine-grained enough to deliver assessment results to consistently and validly underpin eligibility testing, resource allocation and support planning in all circumstances. In fact, the many attempts to do so have resulted in uneven, fragmented and ineffective outcomes for individual, families, providers and government.

CPL suggests from experience over many years that the key is to develop a **single assessment process** that clearly articulates the results required from the assessment to enable consistent decision-making, regardless of the purpose for the assessment. This notion of a single assessment process should be included in the NDIS rules.

Once the assessment process and clear result expectations are articulated, a skilled assessor should be empowered to use any assessment tool that is proven to produce valid results for that assessment process.

## Recommendation

- 8. That a Rule be implemented requiring a single assessment process that clearly articulates the results required from the assessment to enable consistent decision-making, regardless of the purpose for the assessment.**

**Once the assessment process and clear result expectations are articulated, a skilled assessor should be empowered to use any assessment tool that is proven to produce valid results against the requirements set for that assessment process.**

## 7. Principles relating to Plans (Section 31 – 35)

When determining who should be considered an acceptable person to assist planning for a participant of the scheme CPL suggests that the legislation and associated Rules should not limit this activity to any one stream of health professional.

The legislation needs to recognise that the individual person is the primary expert in relation to their lives. Unless otherwise assessed as not having the capacity to make their own decisions, participants should take a lead in the development of their plan to ensure their life goals and aspirations are not inadvertently diminished by other people's judgements of their ability.

The allowance for dignity of risk in decision making is paramount in ensuring participants become sophisticated purchasers of supports and not simply purchasing the safe (but likely less successful in terms of achieving life goals) option.

## Recommendations

- 9. The legislation and the associate rules need to encourage and establish processes to ensure participants have access to relevant information, resources, training and the opportunity to lead and participate in the decision making and planning process under the Scheme.**
- 10. Only after all efforts to allow the individual to exercise their own decision making capabilities have been made should other arrangements be made to appoint a "planner".**
- 11. If such a planner is appointed then individual choice should be a key tenant of this appointment.**
- 12. The concept of dignity of risk should be enshrined in the legislation to ensure that participant's are not penalised for misguide choices while they are acquiring and developing skills as sophisticated purchasers.**

## 8. Decision making by underage participants (Section 74)

There is debate within the disability sector about how children with a disability and their families are dealt with under the legislation. Of concern is the "one size fits all" fashion in the way decision making and signing off of a plan is dealt with.

Some CPL constituents have identified that as the legislation currently stands there is a possibility that a family of a minor could be left to assist administering a plan which they have not signed off on, given the CEO has the power to override parental responsibility.

At the same time, CPL recognises and strongly advocates that at all times the best interests of the family member with a disability (whether a child or an adult) is the paramount focus of the NDIS.

Accordingly, a number of factors must be taken into account when determining if an underage participant in the scheme should be afforded decision making capability, including:

- the best interests of the child (based on evidenced based practices of which interventions are proposed)
- the age of the child (there is a big difference between a child of 3 and a child of 10 similarly a child of 17)
- the cognitive ability of the child and other family members.

These are issues that are dealt with on a regular basis by bodies such as the Family Court of Australia.

## Recommendations

**13. The Bill or its associated Rules should reflect best evidence-based practice in decision making by minors in family settings, which already exist across jurisdictions, for example, the Family Court of Australia may be a good starting point for dealing with these issues.**

## 9. Cost benefit of particular interventions (Reasonable and necessary support) (Section 34)

With regard to what will constitute reasonable and necessary support, the statement at 34(a) *the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;*

CPL believes this statement needs strengthening to ensure the **cost benefit** equation of a support or intervention is taken into account prior to the **value for money** statement.

The Cost Benefit and appropriateness of a particular support needs to be determined in the context of a participant's life goals and in terms of more than the immediate cost-benefit. Downstream benefits and costs need to be considered in the context of investment in the most effective support regime in the long term for the participant.

CPL encourage that all support under the Scheme needs to work under a principle of “**Support - To What Purpose?**” The Scheme needs to focus on encouraging and resourcing the support alternative that brings about the greatest opportunity.

The Scheme needs to transform the accepted premise of disability support:

- from providing Care and Safety
- to **enabling Opportunity and Contribution.**

This will move disability support into a consistent social policy space with Education and Labour Market support – where the aim is, again, to enable every individual Australian to maximise their opportunities and to contribute to the social and economic fabric of their communities and the nation.

This approach will see outcomes of the investment being easier to measure. Outcomes that are linked to people's life goals and to how we assist them to realise the greatest opportunity from every support provided - opportunity for the individual first, then their informal carers and the community at large.

For example, why provide a support worker to “hold someone's hand” and do everything for them in “visits” to their local community, when we can assist those same people to participate in community life independently and in their own right. This may be as simple as providing public transport education, a piece of equipment, money management skills, connections with local community business and groups, and then limited personal care when and as required – rather than the current “care” dominated regime of support.

## Recommendations

**14. Both Cost Benefit and Value for Money need to included and defined in the Definitions section of the Bill and include the concepts of downstream benefits and costs and investment in the most effective**

**support regime in the long term for the participant - to ensure that those charged with the legislation's implementation interpret these key concepts consistently.**

I hope that the information provided in this submission assists in the Committee's consideration of the draft exposure the *National Disability Insurance Scheme Bill 2012* and in the decisions that result.

CPL would be only too pleased to expand on any of the information provided in this submission.

**Angela Tillmanns**  
**Chief Executive Officer**

1 February 2013

## About the Cerebral Palsy League

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.

CPL's vision is:

### ***An inclusive world for all people***

CPL is a company limited by guarantee, with turnover and assets of \$85 million in 2011-13. CPL has a Board of Directors, who volunteer their services and expertise.

The organisation has grown, from humble beginnings in 1948 led by a group of parents of children and concerned citizens to one - sixty four years on - that provides direct support services to assist more than 5,000 Queenslanders with cerebral palsy and related disabilities and their families/carers to achieve their life goals, each year.

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

CPL groups its services to some 5,000 individuals and families annually under five areas:

- **My Life** – where we discuss people's goals and work with them about options for support and providing a host provider/broker model for individuals or families who wish to self-manage their support and available resources;
- **Support at Home** – providing a range of support services to adults with a disability and families of children with a disability in their homes
- **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
- **Allied Health Services** – providing or organising a broad range of professional services, including access to assistive technology support
- **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:

- **North Queensland/Far North Queensland** – stretching from Mackay to Mt Isa across the state and all areas north
- **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
- **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
- **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
- **Metro South** – covering all Brisbane City region suburbs below Brisbane CBD and Kangaroo Point
- **South Coast** – covering Redlands, Logan and Gold Coast cities and far-northern NSW; and
- **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.



CPL also provides:

- a state-wide information and referral service to more than 5,000 individuals with a disability and their families, workers in the disability sector, medical and allied health professionals and the general community; and
- an internationally recognised research program.

CPL hosts the **Queensland Cerebral Palsy Register**, funded by the Queensland State Government, which produced its first biennial report on the incidence and prevalence of cerebral palsy in Queensland in 2010. The second report is due in late 2012.

In addition to these services, CPL is also **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 in the printing and packaging industries.

CPL employs approximately more than 1500 staff to provide and support its range of support services.

In 2012, CPL achieved re-certification under the following quality management systems:

- National Disability Employment Standards
- Queensland Disability Service Standards and
- AS/NZS ISO 9001:2008.

CPL has an evolving range of vehicles for engagement with our constituency, 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
- a feedback system (including complaints management)
- 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 CPL's advocacy on public policy and community issues impacting on the lives of people with a disability and their families/carers.

## Who does the Cerebral Palsy League support?

CPL is a recognised expert in supporting people with cerebral palsy and related disabilities. In a service delivery context, this extends to CPL using that expertise to provide support primarily to people with a physical disability across perhaps the broadest range of service approaches of any provider in Queensland. Of course, many people CPL supports have a range of other disabilities and a small number do not present with a primary physical disability.