Senate Standing Committee of Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

24 January 2013

Dear Standing Committee

Cerebral Palsy Alliance welcomes the opportunity to provide comment to the Senate Standing Committee into the National Disability Insurance Scheme Bill 2012.

We recognise and value the effort taken by the Government in undertaking such a significant consultation and the Committee's commitment to conduct public hearings. Although, it is disappointing that draft NDIS Rules are not yet available for comment.

It is noted that it is proposed that people with cerebral palsy will be eligible to be included within the National Disability Insurance Scheme, and it is within that context that we now provide comment in respect of several features of the draft legislation to the Committee.

Our comments have been summarised on the following pages and the views contained within this submission reflect our desire to represent the interests of our organisation and those that it serves, children and adults with cerebral palsy and their families.

We would be happy to give further information to the Committee upon request and to attend any Committee hearing.

Yours sincerely

Rob White
Chief Executive Officer

BACKGROUND

About Cerebral Palsy Alliance

Cerebral Palsy Alliance, formerly The Spastic Centre of New South Wales, was established in 1945 and provides direct services from 55 service sites in NSW and ACT to more than 4,000 children and adults each year.

Cerebral Palsy Alliance has over 1,000 staff, and an annual operating budget in excess of $75 million.

Cerebral Palsy Alliance was the first organisation of its type in the world, and currently is the largest provider of services in NSW and ACT to children and adults with cerebral palsy, and others with significant physical and multiple disabilities.

Cerebral Palsy Alliance is a public company limited by guarantee, and accredited by the Australian Taxation Office as a public benevolent institution with deductible gift status.

About Cerebral Palsy

Cerebral palsy refers to a group of disorders that affect movement. It is a permanent, but not unchanging, physical disability caused by an injury to the developing brain, usually before birth.

Cerebral palsy is a condition that is often misunderstood, as individuals' acquire both permanent and lifelong neurological and physical impairments and a range of secondary health impairments. Whilst the physical effects of this condition can vary, an individual may experience substantial secondary impairments with cognition, intellect, communication, pain, epilepsy, continence/constipation, vision, hearing, self care or self management.

In Australia, there are approximately 33,000 people with cerebral palsy. Worldwide, the incidence of cerebral palsy is 1 in 500 births. For most people with cerebral palsy, the cause is unknown. There is no known cure.

COMMENTS ON THE DRAFT BILL

Our comments are summarized under 5 key topic areas:

1. Eligibility: its definition and inclusions
2. Funding administration
3. Inclusion of children
4. The intersection with compensation payments
5. The Transition Agency's role in conducting research

1. Chapter 3 (Clause 20) Eligibility: its definition and inclusions

A prospective participant's access is based on a number of criteria being: age, residence, disability and benefit and impact of early intervention. Although clearly outlined within the Bill in separate clauses, our concern rests with the areas of intersection between these clauses. We identified four (4) issues of concern.

Chapter 3 (clause 23)

- *Issue 1 How will young people with disability already residing in nursing home care become eligible for assessment and access to Individual Support Packages?*

Although much has been done within many jurisdictions to transition young people out of nursing home care, this will not be completed by July 2014 or the eventual NDIS roll out. It is well recognised that the Aged Care system does not serve these young people well and access to opportunities for social participation are limited.

It is our position that young people with disabilities living in nursing homes should not be excluded as a result of their residence status.

Chapter 3 (clause 24)

- *Issue 2 Are all children with developmental disabilities automatically eligible, even if early intervention services may not have an impact on mitigating or preventing deterioration of the functional capacity?*

For all children under 6yrs the goal of intervention is to build and support functional capacity, so there may not necessarily be a demonstration of impact on mitigating or preventing the deterioration of functional capacity in all circumstances.

This clause fails to reflect the situation of young children who may not yet have developed functional capacity in those areas and need therapy to develop that capacity. The clause should be amended to include the phrase: "or build the functional capacity of the person".

We would strongly recommend that all children 6yrs and under with development delay are automatically considered eligible.

- *Issue 3 The use of the words 'substantial' and 'social participation' are not clearly defined and there is concern about who and how these will be assessed?*

Greater clarity within the NDIS rules would be welcome.

Chapter 4 (clause 74)

- *Issue 4 Early Childhood Intervention as distinct from Early Intervention*

As per the ECIA (Early Childhood Intervention Association), definitions, early childhood intervention is provided to children 0-6 years of age. This is a critical developmental window, where lifetime care and support needs are often developmentally dynamic and prognosis is unclear. As children enter the schooling system, greater certainty of lifetime care and support needs become clearer to parents, nominated guardians and specialist service providers. At this time, people are often in a much better place to determine and plan for the care and support needs of the child.

We would strongly recommend that provision is made for early childhood intervention as opposed to reference to just early intervention, and that these guidelines and supports are made clearer within the Bill.

2. Funding administration

We identified four (4) issues of concern.

Chapter 3 Clause 40

- *Issue 1 Effect of temporary absence on plans*

The reference made about the effect on the temporary absence from Australia is very general and it is unclear whether this covers absences for leisure and recreation. It is an aspiration of many people with disabilities to travel overseas and enjoy the benefits that travels bring. It is a harsh reality that this is not achieved by many, particularly those with high physical support needs, as the cost of arranging personal care support is often prohibitive.

It is unclear whether a participant is able to use the funds allocated to them under their ISP for such absences and whether or not funds could also be used to purchase supports from international providers during this absence from Australia. Greater clarity is required to whether this would be allowed and under what circumstances.

We would strongly support the use of participant's funds during temporary absences from Australia.

Chapter 3 clause 45

- *Issue 2 Payment of NDIS amounts to participants*

Currently, it is a requirement that service providers must set up separate bank accounts for the management and acquittal of government grant payments. Will this be an expectation for participants who are approved to self-manage? If so, this may cause undue bank fees and charges for the individual.

In addition, given the low return rate on investments, payments made under the NDIS could in fact be more effective for the individual if they were added to existing balances within personal accounts. Will there be any restrictions on what type of account can be used by the individual and or the plan nominee?

Chapter 4 clause 75

- *Issue 3 Definition of parental responsibility*

Will it be possible for foster parents to assume the role of plan nominees and therefore manage NDIS payments for children with disabilities in their parental care? Additionally, grandparents are increasingly taking on this role for many young children we support, will they be able to be plan nominees?

Our position is that the definition of parental responsibility be inclusive of foster parents and grandparents.

- *Issue 4 Plan nominees*

It is unclear whether it is possible for a participant to elect more than one plan nominee. There may be times when a participant would like to involve the skills of the Agency for managing part of their plan and therefore their funds, while at the same time, self manage part or engage a second nominee. Is this possible or is it an either or option?

We would strongly support that the NDIS rules give flexibility for this combination to be possible.

3. Children

There are times at which some children have the ability to make decisions for themselves and this should be acknowledged and supported. However, the power for the CEO to over-ride the decisions or wishes of a parent is of concern.

We would support the position of NDS "that if the CEO can over ride parental responsibility, it is inappropriate for the CEO to be also in a position to determine how much support it is reasonable to expect a family to provide. This must be carefully considered".

4. The intersection with compensation payments

Chapter 5

This section seems at odds with key objects and guiding principles of the Act. Cerebral Palsy Alliance endorses the opinion of the former AMA president Dr Andrew Pesce, that the measure is "disconcerting" and against the fundamental no-fault principle of NDIS. "This is a very unexpected development", said Dr Pesce, "and if it goes through it will be a fundamental change to what people are talking about".

Currently, no Australian citizen can be compelled to take action to obtain compensation and the possibility that the CEO of the Agency could invoke this for some prospective participants seems at odds with the Convention of the Rights of Person with Disabilities. It hardly seem in line with involving people with disabilities in the decision making process and the fundamental principle of choice and control to compel them to take action for compensation.

Specifically, it is noted that the consequences of refusal by a person to take legal action will result in their care and support under the Scheme being "suspended" (clause 105)

It is our specific concern that the financial and personal costs involved in obtaining an assessment of the merits involved in a probable legal claim, and any resultant litigation, will, in all probability, be a considerable burden for a person with cerebral palsy. In addition in the event of unsuccessful litigation, the person with cerebral palsy would almost certainly be required to pay the defendant's, and their own, legal costs.

We would respectfully request that the provisions which require people with disabilities, in particular people with cerebral palsy, to take legal action to seek compensation be appropriately deleted from the draft legislation in order to obviate the stress and financial hardship that consideration of a legal case would necessarily entail.

However, we do support the Bill providing the Agency with the ability to recover compensation fixed after NDIS amounts have been paid and to have these amounts considered in the future NDIS payments.

5. The Transition Agency's role in conducting research

Chapter 6

The importance of undertaking research is acknowledged and has merit. However, the function and role that the Agency will play in this should be clearer. There is a difference between program evaluation and research.

Evaluation is a process which aims to seek how a specific program can be improved and how best it can accomplish its goals and objectives. It looks at the processes & procedures of the program with a view to reviewing, revising and refining with a view to deciding should the program continue, stop or be modified.

Research, is the process used to prove an hypothesis that is designed to provide answers and results that go beyond the individual program. The study results hopefully can be generalised to other populations, conditions or circumstances.

Regardless of whether the Agency plays a role in program evaluation or research, the ethical conduct of the Agency should ensure the rights of participants are respected and protected and that informed consent is given at all times.

We strongly recommend that adherence to the National Statement of the NHMRC would be recommended at the very least although a process by which all research was reviewed by a Human Research & Ethics Committee would be ideal.