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Speech
Pathology
Australia

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

24 January 2013

Dear Senator Moore and Committee Members

Re: National Disability Insurance Scheme Bill 2012

Thank you for the opportunity for Speech Pathology Australia to provide feedback on the above bill.

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing approximately 5000 members. Speech pathologists are university qualified specialists who provide a variety of services to people with communication and swallowing difficulties that may present across the lifespan, including support of people who require augmentative or alternative communication methods.

Speech Pathology Australia extremely supportive of the National Disability Insurance Scheme, as a means to provide much needed assistance for people with disabilities and their carers across Australia. Our submission is attached for consideration.

For further clarification on any comments or points contained within, please feel free to contact the following:
Dr Jemma Skeat, National Advisor, Research and Policy

Yours sincerely

Gail Mulcair
Chief Executive Officer

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Speech
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Submission to:
Senate Community Affairs committee

Re: NATIONAL DISABILITY INSURANCE SCHEME BILL 2012

Prepared by:

Speech Pathology Australia
January 2013

Speech Pathology Australia (SPA) welcomes the opportunity to provide feedback on the National Disability Insurance Scheme Legislation, introduced to Parliament in November, 2012.

General Comments

SPA is extremely supportive of the National Disability Insurance Scheme, as a means to provide much needed assistance for people with disabilities and their carers across Australia. We support all of the objects and principles of the Act as set out in Chapter 1 of the legislation. In particular, we are pleased to see that the legislation is guided by the objects of supporting both the social and economic participation of people with a disability, and enabling people with a disability to exercise control and choice over their supports.

We are also pleased to see a number of changes from the 'Eligibility and Reasonable and Necessary Supports' draft statements. In Section 24, the extension of the wording around functional limitations to include communication, social interaction, learning, mobility, self care and self management is extremely positive. The specification of Early Intervention eligibility criteria is also a welcome addition, and we are pleased to see that the benefits required of Early Intervention include support to the individual in the form of mitigation, alleviation or prevention of deterioration of functional capacity and strengthening the sustainability of informal supports, including through building the capacity of others.

Specific Comments

Eligibility: Defining developmental delay

SPA would like to see further clarification around the definition of 'Developmental delay' (Section 9, p. 9). The definition used for 'developmental delay' in the draft legislation appears to be a definition of 'developmental disability' as commonly used in the Australian context, based on the US Developmental Disabilities Services and Facilities Construction Act (PL 95–602), which defines developmental disability as "*A severe, chronic disability of a person which is attributable to a mental or physical impairment or combination of mental and physical impairments…[that] results in substantial functional limitations…[and] reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and individually planned and coordinated"*

As this definition stands, it appears that there would be a large amount of overlap between the group of children with 'developmental disabilities', and those who are eligible under the Disability criteria outlined in Section 24; in relation to the eligibility for Early Intervention services (p. 20), they would meet Section 25, (i) and (ii).

Developmental delay and *developmental disability* are not synonymous, and SPA would like to see further clarification around this definition so that it more accurately identifies a subgroup of children who are significantly delayed in their development and who would benefit from Early Intervention, but who would not meet the Disability requirements outlined in Section 24 and 25 (i). Developmental delay is not a diagnosis and cannot necessarily be attributed to an underlying disorder or specific impairment; it is a term that reflects that functional aspects of a child's development are significantly behind aged peers in one or more domains (e.g., communication, motor development).

Children with developmental delay may be considered to be *vulnerable to disability*, and the NDIS provides a valuable opportunity for early investment in order to reduce the costs of later support. For example, children with severe language disorder in early childhood are at an extremely high risk of requiring support throughout their school years and beyond, with clear evidence for the impact of early language disorders on both educational attainment and mental health outcomes. These children are six times more likely than peers to have a reading disability by grade 2[1], and twice as likely to have a psychiatric disorder by age nineteen[2].

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[1] Catts HW, Fey ME, Tomblin JB, Zhang X (2002). A longitudinal investigation of reading outcomes in children with language impairments. Journal of Speech, Language, and Hearing Research, 45(6), 1142-1157.

[2] Beitchman JH, Wilson B, Johnson CJ, Atkinson L, Young A, Adlaf E, et al. (2000). Fourteen-year follow-up of speech/language impaired and control children: Psychiatric outcome. Journal of the American Academy of Child and Adolescent Psychiatry, 40(1), 75-82.

If the NDIS Early Intervention component aims to support Australian children who are at risk of disability, in order to reduce later economic and social costs associated with untreated delays, the definition of developmental delay should reflect this population. We would also like to see a more adequate description of communication problems which may be delayed in children, including receptive, expressive and/or pragmatic language functions, or speech.

Further, we believe there is some ambiguity in the use of the age cut off of 6 years within the current definition. While this defines eligibility for Early Intervention, it is unclear whether a child who is identified with a developmental delay and therefore meets eligibility when they are under 6 years would be able to continue to access Early Intervention services through NDIS beyond their 6th birthday. We also strongly feel that the age for identification of developmental delay should be extended to account for poor detection of children with developmental delay in the early years. Many children start school before their delay is identified and referrals made for assessment; these children would miss out on the services provided through NDIS.

A suggested revision of the definition is:

> *A developmental delay means a delay in the development of a child that:*
> *a) is identified on the basis of a substantial reduction in functional capacity, compared to age peers, in one or more of the following areas of major life activity:*
> > *(i) self care;*
> > *(ii) communication: ie, receptive, expressive and/ or pragmatic language, and/or speech;.*
> > *(iii) cognitive development;*
> > *(iv) motor development; and*
>
> *(b) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated; and*
> *(c) is identified before the age of 8 years.*

This definition would identify a population of children for whom early investment in intervention would reduce limitations which are more ameliorable in young children and which lead to disability.

Building the capacity of carers through Early Intervention.
Section 9, p. 8 outlines a definition of a carer, limiting this definition within the Act to a person who provides ‘personal care, support and assistance’ in an informal capacity. There is no term/definition provided for formal carers in this legislation.

This is a problem when interpreting other sections of the legislation that refer to carers, and thus, under the definition, only relate to informal carers. In particular, Section 25, p. 21 states that Early Intervention supports may “strengthen the sustainability of the informal supports available to the person, including through building the capacity of the person’s carer”.

Informal as well as formal carers may require this capacity building in order to reduce limitations and improve participation, and SPA strongly feel that the legislation should reflect this. For example, support for a child who requires augmentative or alternative communication methods (such as a computerised communication device) should include provision of information and training for people who interact with them, so that these carers (both informal and formal) are able to understand and facilitate the use of the communication method by the child. If only informal carers are included, people who interact daily with the child (for example, providing paid personal care) may be unable to communicate effectively with them and vice versa.

We suggest that the definition of carer is split to refer to informal versus formal carers, and that these two groups are referred to within the legislation as needed. We suggest the wording should be:

> *An informal carer means an individual who:*
> *a) provides personal care, support and assistance to another individual who needs it because that other individual is a person with disability; and*

(b) does not provide the care, support and assistance:
  (i) under a contract of service or a contract for the provision of services; or
  (ii) in the course of doing voluntary work for a charitable, welfare or community organisation; or
  (iii) as part of the requirements of a course of education or training.

A formal carer means an individual who
a) provides personal care, support and assistance to another individual who needs it because that other individual is a person with disability:
  (i) under a contract of service or a contract for the provision of services; or
  (ii) in the course of doing voluntary work for a charitable, welfare or community organisation; or
  (iii) as part of the requirements of a course of education or training.

With regard to the definition of Early Intervention Supports (Section 25, (c) ii, p. 21), capacity building for both formal and informal carers should be specified.

Age requirements
SPA recommend the removal of the age requirement outlined in section 22, p. 18-19. The NDIS should support people with a disability throughout their lifetime, and not end this support once a person reaches older age. We believe that the aged care system is not set up to support people with disabilities, and that the support provided under this system will be inadequate.

Planning
This is the first opportunity for public comment on the NDIS planning process. SPA are pleased that the Act supports the participant as being central to the planning process.

Nevertheless, we are concerned at the seemingly static nature of plans. It appears that a single plan is generated which (Section 37, p. 28) “cannot be varied after it comes into effect, but can be replaced under Division 4”. Division 4 outlines two mechanisms for ‘replacement’ of the plan. Under section 47, participants are able to change the statement of goals and aspirations (Section 47); however, this does not impact on the supports as these appear to remain as per the initial plan (Section 47, 2b), even though the plan is now considered to have been replaced. The other mechanism for changing a plan is to request a review (Section 48); this request is considered by the CEO who also conducts the review. We feel that this process is inadequate and potentially unwieldy, and does not reflect the General Principals of the Act outlined on page 4, particularly,

(4) People with disability should be supported to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and

(8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise informed choice and engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.

It is reasonable that participants would be unable to determine up front all of their support needs from NDIS funds when initially developing a plan. It is also likely that plans, goals and aspirations, as well as personal circumstances (including health and social circumstances) will change over time, and that this will necessitate a change to the supports accessed through the NDIS.

SPA would like to see the Act allow for revision of existing plans and/or development of new plans in a way that is more participant-driven.

To enable this, we strongly recommend revision of Division 4 of the Act (p. 34). Section 37 should allow that the plan developed under Section 33 (2) be reviewed upon change of anything in Section 33 (1), including that ‘the goals, objectives and aspirations of the participant’ are met, become untenable for any reason, or are changed. The review of the plan should be by the participant themselves, it should not require a request to the CEO. The process for approval of the updated plan should be identical to that outlined in 33 (2). An alternative process would be for plans to be time-limited, with a requirement for review after the specified time period. However, we feel that participantled review best reflects the aspirations of the NDIS, and will better safeguard the rights of the participant to exercise choice and control, and determine their best interests with respect to NDIS funds.

Reasonable and Necessary Supports

We note that the delineation of what constitutes a ‘reasonable and necessary’ support will be within the NDIS Rules, and we look forward to the opportunity to comment on this. The definition provided in the Act outlines the principles of what these supports entail, and while we agree with these in the main, we are disappointed to see that point 34 (f) on p. 27 specifically excludes supports that are “more appropriately funded or provided through other general systems of service delivery or support services”.

At present many people do not have their support needs met by the ‘appropriate system’, or there are long delays before another system provides support. For example, many children with severe communication disabilities do not receive the level of support they require to participate in education, even though the education system should meet their needs. Several states in Australia do not include communication disability under their model of targeted funding for school students with disabilities. Therefore, these children do not necessarily have access to an aide, extra equipment or therapy support through the school. It is unclear how support provided to children through an NDIS (for example aids, equipment, therapy input) will extend into the classroom, if the support provided by the Education system is inadequate or not available at all.

SPA strongly feels that the statement at 34 (f) should not be that the supports are “not more appropriately funded or provided through other general systems of service delivery or support services” but that the supports are

> *not adequately funded or provided through other general systems of service delivery or support services*

We are also concerned that this clause will lead to the provision of piecemeal services for individuals, with some aspects of their needs supported through NDIS because it meets the criteria and other aspects either not covered or covered through external systems, leading to a complex arrangement of care. For example, a child with a complex disability may be funded for mealtime support for school lunchtimes through NDIS, while their access to the curriculum and ability to participate during class time is supported through the provision of an aide by the school. It is not in the participant’s best interests for bits and pieces of support to be provided by different people because their support needs fall into or outside of the scope of various services. At the least, the NDIS plan needs to take these other supports into account, and this is currently not detailed as part of the planning process, discussed above. In order to address this, we would like to see Section 33 (2) on p. 25 revised so that the relationship of NDIS-provided supports to other supports provided by other systems is outlined:

> *2) A participant’s plan must include a statement (the statement of participant supports), prepared with the participant and approved by the CEO, that specifies:*
> *(a) the supports provided to the participant by other general systems of service delivery or support services under Section 34 (f); and*
> *(b) the reasonable and necessary supports (if any) that will be funded under the National Disability Insurance Scheme; and*
> *(c) the general supports (if any) that will be provided to, or in relation to, the participant, including those that address the relationship between (a) and (b); and*
> *(d) the date by which, or the circumstances in which, the Agency must review the plan under Division 4; and*
> *(e) the management of the funding for supports under the plan (see also Division 3); and*
> *(f) the management of other aspects of the plan.*

This will better enable the NDIS general supports, which include coordination and referrals, to be carried out.

We would also like to see point 34 (d) (p. 26) "… having regard to current good practice" expanded. We suggest that this statement should refer to "available evidence, current guidelines and relevant standards", rather than 'current good practice'.

National Disability Insurance Scheme Rules

While the legislation outlines the key components of the NDIS, the true substance of the scheme will clearly be described within the NDIS Rules, including how and when payments are made, persons who can conduct assessments for the purposes of determining eligibility for Early Intervention, and description of the supports that will and will not be funded or provided under the National Disability Insurance Scheme.

We would like to iterate how important it is that there is a strong consultation process with stakeholders for the development of these rules, which will determine how the scheme works in practice across Australia.

If Speech Pathology Australia can provide further assistance or additional information please contact Dr Jemma Skeat, National Advisor, Research and Policy

Dr Jemma Skeat
National Advisor, Research and Policy
24 January 2013