Disability Directory

Information, Resources, & Opinion online

26 January 2013

NDIS Consultation
Australian Senate
Community.affairs.sen@aph.gov.au

Dear Sir/Madam

NDIS Draft Bill

Attached please find my submission with respect to this Bill.

In summary:

- The Bill is, on the whole, a significant step forward in overcoming the disparity between the ways that social policy responds to abled and disabled peoples in Australia;
- There are some minor issues that I believe need further consideration, including age limits, advocacy and support, the processes surrounding children and nominees, review processes, and overarching responsibilities of the Agency.
- Aspects of the submission that follow are questions for consideration; whether the
 appropriate document for resolution is the Bill, the Rules, or other subsidiary legislation is
 not commented upon.

Thank you for the opportunity to comment on this very important legislation.

Yours sincerely

Naomi Anderson Founder Disability Directory www.disabilitydirectory.net.au

Submission to Parliament

National Disability Insurance Scheme Bill 2012 No., 2012

Introductory Sections

Section 3 Objects of Act

Does this Act also have the object of assisting in the development of a vigorous and competitive market for disability products and services in Australia? While this may not be the primary aim of this legislation, without development of such a market, there will continue to be ongoing difficult for many people attempting to access supports.

Section 4 General principles guiding actions under this Act

People with disability are currently well behind the rest of the population on most scales of inclusion, security, participation and visibility. Their ability to use the various Discrimination Acts to ensure their access to education and employment has been limited.

Is there scope for adding to these principles to the effects that:

- Insofar as people with disability continue to be educated and employed at lower rates than
 the remainder of the community, an implied principle is the improvement of participation
 rates in these areas
- Insofar as education and employment are critical to inclusion in many other areas of society, where a choice of interpretations is available, it is to be understood that enhancement of opportunity is intended

In principle 12, an acknowledgement is needed that not all people with disability have families, carers or other significant persons in their lives.

5 General principles guiding actions of people who may do acts or things on behalf of others

This section is not echoed in the sections related to the workings of the Agency. It is submitted that the best and most effective way of enhancing the involvement of people with disability in decision making processes, in supporting others with disability, and with sharing knowledge and support is to avoid over dependence on informal networks.

The employment of university graduates without direct experience of disability, at the expense of providing opportunities to people with disability, is an unfortunate practice which prevents involvement, opportunity, and advancement. If these principles are to be given form, the employment of people with disability at all levels of this scheme must be guaranteed.

6 Agency may provide support and assistance

Does this include providing support to collectives or peer support groups? Going forward, it is critical that the community can begin to develop, and work together to support individuals making

applications under the scheme. While this section may imply a right to seek the support of an advocacy, stronger language would be preferred.

The exclusion of people with disability from many decisions that affect their everyday lives, and their inability to consider options or to engage fully with the community, places a significant premium on the activity of assisting people with the activities required under the Act.

This will also require far greater provision of information in alternative formats and media, as discussed below.

Will the NDIS include a right to access advocacy services within the individual plan? Will people with disability be able to choose their own advocate? Will they be able to select a peak body to which they would like to become a member?

The current arrangements privilege certain peak bodies on the basis of their current arrangements, and membership numbers are based on a sign-on activated at some point in time, but quite often never renewed. There is no ongoing process for determining whether these bodies represent the views of these "members" and there is no space for new organisations to receive support, even if they represent a broader cross section of the community. A system whereby individuals can nominate their membership of advocacy bodies, and have this amount allocated as a component of their plan would lead to greater accountability for disability organisations generally.

While this does not apply to individuals not included in the NDIS, whether they are applicants or excluded by definition, this would provide a basis for nominating the potential supports available for such individuals.

7 Provision of notice, approved form or information under this Act etc.

The documents provided for the consultation around this Bill illustrate the need for stronger protections in this section. While there was a simple English version of the explanatory documents, the simplification was of such a degree that there really was nothing to comment on.

A reliance on written documents will be insufficient to reach the community in question, especially a reliance on legislation.

Members of Parliament have a role to play here, in reaching out to the electorates, both federal and state, and understanding how information is shared in that community.

Using a range of techniques will be critical to ensuring that people are able to access information, and in the short term, this may need to include the appointment of NDIS advisors across the country, to both develop appropriate materials for different communities, but also to speak personally to the various groups and audiences.

This could be achieved with the addition of the words "Where appropriate information will be disseminated through existing community channels and mechanisms. All members of Parliament, Federal and State, have a role in supporting these mechanisms in their electorate."

9 Definitions

There are some unreferenced definitions that need tidying. For example, *registered plan management provider* is defined in reference to paragraph 70(1)(a), which does not use the term, but first appears in s 42, which does.

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.

Whether here, or elsewhere in the Bill, it is important to note that carers have rights and needs of their own, and that the relationship of carer is one which at best can be negotiated by the parties concerned over time.

While it is important to recognise the role of carers, it is also important to recognise that carers are often assumed to be available to provide care on a full time basis, simply because they currently must. This does not necessarily imply this is the optimal state of affairs for either the person with disability, or the carer.

community care has the same meaning as in the Aged Care Act 1997.

This term is only used to refer to people who are over 65, and thus in the context of the Aged Care Act. It would thus be clearer to leave the definition out and to refer to this in the relevant section. "Community care" as defined in the Aged Care Act, could refer to other circumstances never intended by the Aged Care Act, with the definition being imported into this Act:

45-3(1) **Community care** is care consisting of a package of personal care services and other personal assistance provided to a person who is not being provided with residential care.

15 Agency may provide information

See comments regarding section 7 above.

18 Person may make a request to become a participant

A person may make a request (an **access request**) to the Agency to become a participant in the National Disability Insurance Scheme launch.

Are there likely to be obligations on health services and other institutions in relation to the timeliness of requesting NDIS participation? Currently, in Victoria, at the Royal Talbot Rehabilitation Centre, a patient is referred to disability supports immediately before discharge. This means that if an individual experiences a significant loss of function, and is in rehabilitation for 6 months, and the waiting period for equipment is 4 months, that individual will in effect wait 10 months, because staff do not commence such referrals until days prior to discharge. In settings where individuals are likely to have become eligible for NDIS participation, there needs to be requirements on the service providers to ensure such applications are made, and supported as soon as possible. The effect of this would be to expedite discharge from healthcare settings, freeing up beds in rehabilitation, and reducing the pressure on hospital beds that are currently occupied by patients awaiting a rehabilitation bed.

19 Matters relating to access requests

See comments regarding s 6 above.

22 Age requirements

- (1) A person meets the age requirements if:
 - (a) the person was aged under 65 when the access request in relation to the person was made; and
 - (b) if the National Disability Insurance Scheme rules for the purposes of this paragraph prescribe that on a prescribed date or a date in a prescribed period the person must be a prescribed age—the person is that age on that date.

With an ageing population, the prescription of an age cut-off seems arbitrary. An otherwise youthful 65 year old could sustain an injury the day after their birthday and be ineligible, forced to rely instead on aged care services, while a 64 year old whose disabilities are age related would be eligible for the NDIS.

Would it not make more sense to seek advice as to whether the impairment is dominantly disability related, or dominantly age related? A failure to make this distinction could reduce the working life of otherwise capable adults who sustain a disability in later life, as aged care services are focussed on a gradual decline in participation.

Will individuals above the age of 65 be eligible for the NDIS under section 25 if early intervention would prevent a predominantly disability related impairment from becoming a disability/age related impairment by atrophy?

31 Principles relating to plans

(k) provide the context for the provision of disability services to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.

Is it necessary, or even workable, that the plan co-ordinates the delivery of disability services? Would it not be more effective to state that the plan will provide for the co-ordination of disability services?

33 Matters that must be included in a participant's plan

- (1) A participant's plan must include a statement (the **participant's statement of goals and aspirations**) prepared by the participant that specifies:
 - (a) the goals, objectives and aspirations of the participant; and
 - (b) the environmental and personal context of the participant's living, including the participant's:
 - (i) living arrangements; and
 - (ii) informal community supports and other community supports; and
 - (iii) social and economic participation.

What is the purpose of including the living arrangements, supports, and social and economic participation? If it is to explain the context of the plan, this makes sense. If it is to lock an individual into a certain arrangement, over which they may have little control, this is counterproductive. It may be helpful to use some qualifying language here.

- (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 general supports (if any) that will be provided to, or in relation to, the participant; and
 - (b) the reasonable and necessary supports (if any) that will be funded under the National Disability Insurance Scheme; and
 - (c) the date by which, or the circumstances in which, the Agency must review the plan under Division 4; and
 - (d) the management of the funding for supports under the plan (see also Division 3); and
 - (e) the management of other aspects of the plan.

Does this include the arrangements for nominees and etc? Is there provision for nominee arrangements to be stipulated as an evolving process, for e.g. beginning with high levels of support, but tapering off to self management?

(6) To the extent that the funding for supports under a participant's plan is managed by the Agency, the plan must provide that the supports are to be provided only by a registered provider of supports.

Will it be possible to have a plan that has mixed funding management? It is possible that certain components would be better managed by the Agency, but others may require access to mainstream services and/or products, which under this restriction, cannot be utilised by individuals with Agency managed funding. A simple example would be where an item of supportive clothing is available by order through a disability provider, but just as easily, and perhaps less expensively, through a sporting goods store, or specialist apparel retailer.

34 Reasonable and necessary supports

For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(h) the funding of the support complies with the methods or criteria (if any) prescribed by the National Disability Insurance Scheme rules for deciding the reasonable and necessary supports that will be funded under the National Disability Insurance Scheme.

Does this section anticipate a prescription on sourcing of equipment? Currently the equipment available in Australia is very limited, and there is a virtual monopoly in some areas. Competition in the market, including the ability to purchase equipment from overseas, can be expected to stimulate the growth of an innovative and efficient market in Australia. To date this has been impeded by lack of reliable funding sources. A requirement to purchase equipment from existing suppliers will have the impact of forcing many people with a disability to use sub-standard, and ill fitting equipment, when superior products are available on the international market.

35 National Disability Insurance Scheme rules for statement of participant supports

(2) The methods or criteria prescribed by the National Disability Insurance Scheme rules for assessing or deciding the reasonable and necessary supports that will be funded may include methods or criteria relating to the manner in which the supports are to be funded and by whom the supports so funded are to be provided.

On what basis could the rules prescribe by whom the supports are to be provided, and comply with section 4(4)?

36 Information and reports for the purposes of preparing and approving a participant's plan

- (2) The requests the CEO may make are as follows:
 - (b) that the participant do either or both of the following:
 - (i) undergo an assessment and provide to the CEO the report, in the approved form, of the person who conducts the assessment;
 - (ii) undergo a medical, psychiatric or psychological examination (whether or not at a particular place), and provide to the CEO the report, in the approved form, of the person who conducts the examination.

In the likely event that people with disability are expected to undertake medical or other examinations for the NDIS, who will pay for such examinations? Given the number of such assessments required for the various programs in place, and the small number of specialist doctors in certain fields, this has the potential to either delay applications significantly, or impose a high admission fee for certain groups.

40 Effect of temporary absence on plans

- (2) The **grace period** for a temporary absence of a participant is:
 - (a) 6 weeks beginning when the participant leaves Australia; or
 - (b) if the CEO is satisfied that it is appropriate for the grace period to be longer than 6 weeks—such longer period as the CEO decides, having regard to the criteria (if any) prescribed by the National Disability Insurance Scheme rules for the purposes of this paragraph.

This period seems unnecessarily short. If the NDIS is to be a scheme for lifetime care and support, an absence of six weeks is hardly significant. There needs to be a requirement for any application process related to this measure to be simple to access and not unduly burdensome. As an example, for a person with mobility difficulties to travel overseas for, say, a family wedding, the costs are considerable. The travel itself can be exhausting, and the time required to recover from a lengthy international flight may cause the outbound journey to consist of a period up to a week. The access to transport is often limited, and difficult, and this creates additional delays. Travel insurance is unlikely to cover anything disability related, and care must be taken to manage the condition in a strange climate, and without the usual supports. Coupled with this is the high likelihood that this trip is the only time in the foreseeable future that this individual will travel overseas. To have administrative barriers that overly complicate such a journey is unduly harsh. A more reasonable period would be three months.

In the case of an individual transferred overseas by their employer for a period of 12 months or less, whereby they remain tax resident, and continue to pay Australian taxes, on what basis is it reasonable that they are unable to access NDIS supports during this period? Does this not create an inequity in the workplace?

41 Suspension of plans

- (2) The effect of suspension of a statement of participant supports in a participant's plan is that the plan remains in effect but, during the period of suspension:
 - (a) the person is not entitled to be paid NDIS amounts, so far as the amounts relate to reasonable and necessary supports that would otherwise have been funded in respect of that period; and
 - (b) the Agency is not required to provide or fund other supports under the plan, but is not prevented from doing so if the CEO considers it appropriate; and
 - (c) the participant is not entitled to request a review of the plan under subsection 48(1).

How does the plan reactivate once suspended? An absence of this step, or an overly complicated step, will lead to avoidance of declaration in order to avoid suspension. A simple step to reactivate is more likely to encourage transparency and declaration of all changes in circumstances.

Will the NDIS plan continue if the individual is an inpatient in a hospital or rehabilitation facility for an extended period? If not, what will the cut off be? If so, how does this interact with the supports provided at the medical facility? In particular, will support workers be provided to a patient in hospital, so that the patient can attempt to continue their "normal" routines as much as possible, and reduce the overall period of hospitalisation?

45 Payment of NDIS amounts

- (2) Without limiting paragraph (1)(b), the National Disability Insurance Scheme rules may provide that:
 - (a) an NDIS amount is to be paid to the credit of a bank account nominated and maintained by the person to whom it is to be paid; and
 - (b) an NDIS amount is not payable to the person until the person nominates an account.

Is there to be an associated change to banking and taxation regulations to facilitate the simple and efficient establishment of appropriate bank accounts for this purpose? Who pays the transaction costs of such accounts? What happens to interest payments?

46 Acquittal of NDIS amounts

- (1) A participant who receives an NDIS amount, or a person who receives an NDIS amount on behalf of a participant, must spend the money in accordance with the participant's plan.
- (2) The National Disability Insurance Scheme rules may make provision for and in relation to the retention of records of NDIS amounts paid to participants and other persons, including requiring that prescribed records be retained for a prescribed period.

Will there be training and tools provided for individuals who wish to self manage their funding? In the absence of such tools and/or training, what is the expectation that people can learn to navigate this system in accordance with section 4, without fear of penalty for incorrect record keeping?

Is there provision for government negotiation with various private sector industries for which payment continues to be problematic? An example would be the Cabcharge system, which does not currently provide an arrangement whereby an individual could self manage any funding related to taxi fares without factoring in various transaction costs?

51 Requirement to notify change of circumstances

- (1) A participant or a prospective participant must notify the CEO if:
 - (a) an event or change of circumstances happens that affects, or might affect, his or her access request, status as a participant or plan; or
 - (b) the participant or prospective participant becomes aware that such an event or change of circumstances is likely to happen.

Please see comments above about ease of accessing the reporting system, ease of understanding the requirements, and ability to report changes when it is reasonably possible to do so.

53 Power to obtain information from participants and prospective participants to ensure the integrity of the National Disability Insurance Scheme

(1) If the CEO has reasonable grounds to believe that a participant or a prospective participant has information, or has custody or control of a document, that may be relevant to one or more of the matters mentioned in subsection (2), the CEO may require the participant or prospective participant to give the information, or produce the document, to the Agency.

What privacy protections are afforded to such information? Currently Centrelink can fax a document, identifying an individual and the nature of the claim, and addressed to "payroll" to the main fax number of a major corporation. This is a very low level of protection of sensitive information. The nature of information the NDIS might reasonably be expected to obtain is likely to be equally sensitive, and appropriate protections need to be created to ensure people with disability and confident sharing such information freely.

74 Children

Will there be modified review periods for children?

Where a parent, or other person, is a nominee for a child, will there be a process of review as to the appropriateness of this arrangement? The current Centrelink arrangements related to age are not graduated, but require a complete change of plans at age 16. This change of status is not well explained, and can cause significant hardship to families who are suddenly unable to call on behalf of their child, whether or not that child is capable of managing the situation themselves.

103 Applications to the Administrative Appeals Tribunal

Applications may be made to the Administrative Appeals Tribunal for review of a decision made by a reviewer under subsection 100(6).

Is there to be a specialist section of the AAT to handle NDIS appeals? How will developing policy be reflected, and decisions be communicated to the disability community? How will advocates and other interested parties understand the evolving case law in this area?

Ideally a special sitting of the AAT would be less adversarial and more inquisitorial, and accessible to people with disabilities and their supporters. In order to gain proficiency in dealing with the NDIS, and the nature of disability and the difficulties encountered, it would be worthwhile contemplating an alternative dispute resolution approach to such hearings. This would allow all parties to better understand the full context and the reasons for any decisions made.

Will advocacy groups be allowed to access records of such hearings? This would be extremely useful for specialist groups that represent specific types of disability, to understand the approach taken, and to better prepare their membership to make such an application. Many people with disability are daunted at the very concept of a tribunal of any kind, their experiences of being heard and understood having been extremely limited. Any efforts to ameliorate this will build confidence in the process and its accessibility to all.

Will the Commonwealth Ombudsman be able to hear complaints about the NDIS process?

104 CEO may require person to take action to obtain compensation

The compensation requirement, while financially sensible, would appear to impose an additional barrier to individuals for whom the ability to commence compensation proceedings is limited, and the chances of success insignificant.

In the same way as motor vehicle insurance ensures that the claimant is paid, and the insurance company pursues the claim against the third party, is there scope for the NDIA to pursue such claims against third parties on behalf of NDIS participants?

118 Functions of the Agency

(1) The Agency has the following functions:

The Agency should also have a function related to the employment of people with disability. While it is not expected that the Agency can, by itself, turn around the appalling unemployment levels of people with disability, it can lead by example. In supporting the principles enunciated in section 4, it must be recognised that the people most likely to be able to provide a responsive and effective service to people with disability are people with disability. In creating an Agency which is intended to significantly impact the disadvantage and exclusion of people with disability, by providing services and support, it must be recognised that the most effective means to economic and social participation is employment.

While it may be considered sufficient to place a statement in the position description of every role at the Agency to the effect that applicants "must understand the needs of people with disability etc etc", this has historically lead to university graduates with academic qualifications in disability, social work, sociology, etc being paid to advise people with disability on how best to manage their situation.

The only redress to the current arrangements is a policy that positively selects people with disability (and this means diverse disability, not one group or another), and as the next alternative, families of people with disability. Only then will a real understanding of the issues surrounding disability infiltrate the Agency at all levels. Only then will issues of access and inclusion become a part of the day to day life of those working in this organisation. Failing to employ people with disability creates a risk of an organisation with excellent intentions, but no real life understanding of the issues.

The first time a colleague can't attend a meeting because the room only has access by a staircase, the first time a colleague can't understand a direction because the communication method is inaccessible to them, the first time a comment is made that is offensive to the person with disability at the next cubicle: these are all critical learning experiences in an organisation that is defining its culture.

127 Appointment of Board members

- (2) A person is eligible for appointment as a Board member only if the Minister is satisfied that the person has skills, experience or knowledge in at least one of the following fields:
 - (a) the provision or use of disability services;
 - (b) the operation of insurance schemes, compensation schemes or schemes with long-term liabilities;

- (c) financial management;
- (d) corporate governance.

This eligibility describes service providers, insurance companies, accountants and managers. It does not provide for the lived experience of disability. While it is critical that Board Members have these skills, it is also critical that there is sufficient lived experience of disability to ensure the organisation does not become simply another organisation that has good intentions, but is completely inaccessible, or patronising, towards the reality of day to day life for people with disability in this country.

Why are there no conflict provisions for the Board, similar to those of the Advisory Council? Would it be appropriate for a director of a large service provider to serve as a Board member? Would this not create a conflict of interest? Given the small number of qualified individuals in Australia, and the concentration of supply in certain sections of the disability services industry, should there not be very strict conflict provisions for Board membership?

144 Function of the Advisory Council

Does the Advisory Council have any independent capacity to report directly to Parliament on the functioning of the Agency?

170 Services of other persons to be made available to the Agency

While it makes sense logistically for the Agency to be able to access staff from other Commonwealth and State departments, the transfer from other organisations that operate under old models of service and support provisions risks the integrity of the new system. There needs to be safeguards against transfer of old cultural ideas about disability, dependence, scarcity, and exclusion, in order to ensure that the Agency is able to fulfil its obligations under section 4.

172 Annual report

The annual report should also include data and commentary about:

- Applications received, and applications rejected
- Plans created, and plans revised, suspended or cancelled
- Evolving policy matters, and refinement of position in areas where the legislation is still being interpreted
- Case studies (de-identified) to allow advocates and individuals to understand the workings
 of the Agency, and the processes by which decisions are made
- Decisions taken to the AAT for review, and outcomes from these decisions
- General feedback about the accessibility, responsiveness, and efficiency of the Agency
- Number and nature of complaints

208 Review of operation of Act

(1) The Minister must cause an independent review of the operation of this Act to be undertaken commencing on the second anniversary of the commencement of Chapter 3.

As a general comment, it can only be productive of members of parliament, both state and federal, are invited to assist in the implementation of the NDIS in their electorate. As a bipartisan initiative,

there is no reason why MPs can no host information sessions in their offices, offer to hear the concerns of their constituents, and form their own impressions about what is working, and where the problem areas are. Not all people with disability will be able to comment on the legislation, nor to provide feedback as to the operation of the Act. Their elected representatives should be encouraged to do this, to use the implementation of the Act as an opportunity to learn more about the experience of disability in Australia, and to provide feedback to the Minister as to what is working well, and what is problematic. Regardless of the party in power at the time of review, this is an essential function of inclusion in a democratic nation, and a formal process to encourage such feedback would be welcomed. For many people with disability it is far less daunting to visit the office of their local MP, whose photos they have seen all over the neighbourhood at election time, and have a chat, than it is to understand what exactly they would see in relation to the operation of the NDIS Act.