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Senate Inquiry

into:

National Disability Insurance Scheme Legislation Bill

community.affairs.sen@aph.gov.au

Dear Senate Committee

Please find attached a submission from Physical Disability Australia Ltd (PDA) as the national disability peak organisation representing the interests and views of people with physical disability across Australia.

PDA is funded by the Commonwealth through Department of Families and Housing, Community Services and Indigenous Affairs (FaHCSIA) to be the national secretariat for PDA.

PDA supports an NDIS that meets the individual needs and support of people with a range of disability and is pleased to see that the NDIS focusses on the informed choices and decisions of people with disability and recommends also that the legal rights to justice, using an advocate or advocacy service, the right to independently vote, to all levels of education and to employment or the right not to work are also observed as a matter of priority.

PDA would also like to see the mention of the United Nations Convention on the Rights of Disabled Persons (UNCRPD) to which Australia is a signatory, as well as the National Disability Strategy which all States and Territories are signed on to, as a framework that underpins the work of the NDIS agency and staff.

PDA anticipates the much heralded rolling out of the NDIS in Australia and will continue to work and ensure that those with disability are always paramount in the decision making and focus of the NDIS.

If you require further information, please contact the writer on the above address or email.

Thank you for the opportunity to provide comment on the legislation.

Yours sincerely

Physical Disability Australia Ltd (PDA)
Submission
to
National Disability Insurance Scheme
Draft Legislation.
January 2013.

(c) PDA.

Comments on the Draft Legislation.

Part 2—Objects and principles

3 Objects of Act

(1) The objects of this Act are to:

(a) and (b)

PDA believes that not all people with disabilities will want to be employed and that the NDIS must accept that for some this will not be one of their goals.

(c)

PDA is concerned about the term 'reasonable and necessary', and wonder who interprets these terms, or is this determined by staff of the agency in collaboration with the participant?

The supports needed by people with disability should be determined by the participant in terms of their daily life and desired goals and abilities and not determined by someone without experience of disability. Supports differ from person and therefore should be determined on a case by case basis.

(d)

Many people with disability have never had choice or control over their lives before so this may be a whole new concept to many in that they will need time, choices and examples of how to make the decisions that will be necessary to manage their own supports and/or funds.

PDA believes that in the initial stages of the NDIS, training opportunities should be offered so that people will be able to make decisions fully informed and able to manage their future lifestyle.

(e) and (f)

PDA is concerned as to how a service is high quality or not? Are they to be measured against quality assurance, best practice, standards etc?

(g)

Is this to be another arm of the agency, in educating and creating awareness of disability? Is there to be a training and awareness area in each NDIS agency? If so, all training must be planned and delivered by people with disability.

2.

(a)

PDA is concerned that the NDIS is already jeopardised because some states are not signed on to the NDIS, so how is it intended to bring these on board.

(b)

What exactly is an insurance based approach, as these seem to be only words with no substance.

In addition, how is it proposed to fund the NDIS fully over time?

PDA has concerns that the NDIS could fall apart at the whim of a government change or placed on hold because some other issue is raised as a priority.

Initiating a 'Medicare style levy' would be more acceptable to Australians. In much the same way as the Medicare levy is part of life, so too can an NDIS levy that ensures in the case of accident or illness that a person is taken care of. If this then is available to every Australian in a similar way to the NZ Accident Compensation system that incurs an annual levy by all citizens we believe it would be embraced by Australians. This provides certainty for the ongoing financial support of the NDIS and is the recommendation of the Productivity Commission.

(3)

(a)

No mention has been given of the next stages, so how are we to comment on this?

(b)

See above for considerations.

4 General principles guiding actions under this Act

(1)

There is no mention of a rights based approach yet Australia has signed up to the UNCRPD. PDA believes that this is a crucial framework for international compliance that should also be applied to all of Australia.

(2)

And of their own choice - choice must be an integral part of all aspects the NDIS.

(3)

The statement "Over their lifetime, is at crossed purposes with section **(22 Age requirements)** which state that NDIS is only for those under 65. People with disability do not die at 65, nor does their disability disappear - in addition we believe that there is no disability friendly path to aged care in the Ageing sector, is not rights based in the same way as disability is. Much more work is needed in the aged care sector to match the intention of the NDIS so that there is a smooth transition to the Aged Care services, and that these services provide supports in the same way as the intention in the NDIS.

Nothing less.

(4)

Including being able to access the NDIS after the age of 65 years.

(5)

PDA inquires if there to be a direct referral system from hospitals, CRS, and other services to the NDIS to enable early intervention in the case of a newly acquired disability?

(7)

PDA states that as yet people with disabilities have had little success in pursuing grievances under the current DDA legislation and we fail to see how this clause (7) will make much difference. Other members of Australian society are not discriminated against in the same way as people with disability..

(9)

PDA has concerns about how this is to be achieved in the case where parents or guardians are in direct conflict with the person with the disability in terms of choice. For instance if a participant wishes to move out of the family home, and the family are against this, how is it decided that the participants wishes will be observed?

(10)

Many people with disability have never had privacy, respect or dignity, which reinforces the huge need to provide training in confidence building, knowing your rights, what choice and supports are available and how to set their own goals.

(11)

Again, who determines what is reasonable and necessary?

(b)

If that is their choice, and only after they understand the significance of choice!

(12)

PDA believes that in the instance where a person is over the age of 18, parents and others are secondary in decision making. The individual with the disability must come first in all decisions.

(13)

Is this to be a referral system to other services outside of the NDIS?

(14)

Promoted maybe but how are they measured as being the correct supports? Is this to be defined before the agency commences taking participants? If so, how?

(16)

(a)

(b)

See previous comments on the financial sustainability.

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

(a)

This should read 'all decision making''

(b)

Community of choice not just because it is seen by others as a good idea but needs to be a community where the participant will be accepted and respected for their dignity and worth, and not a community that someone else chooses for them.

(c)

How is this to be determined, how would you intend to assess this?

(d)

Or the impaired communication ability and alternate methods sought.

(e)

Only with the permission of the person with the disability in the first instance.

6 Agency may provide support and assistance

(1)

Does this include paying for external support to prepare and cost a personal plan?

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

(2)

PDA assumes that if a person is unable to communicate by traditional methods, then alternate ways will be found to communicate with participants, such as National Relay, or an independent person to mediate to ensure that the participant is fully aware and cognisant of decisions and choices made on their plan and for their future..

Part 5—Ministerial Council

12 Ministerial Council functions etc.

(3)

PDA believes that the Ministerial Council should comprise a number of people with disability on the council as the Ministers or their Advisor often have little experience of disability.

In addition, an education and awareness aspect must be introduced to expand the learning about disability at all levels.

Chapter 2—Assistance for people with disability and others

13 Agency may provide coordination, strategic and referral services etc. to people with disability

(1)

Individuals must at all times be in agreement with introducing a third party into the relationship with the NDIS agency

14 Agency may provide funding to persons or entities

PDA assumes that the funding issues will be documented clearly in the rules of the NDIS and Operations of the agency, otherwise it could be misconstrued that there is 'carte Blanche' in the way of supports and services. In other words will a budget be established early in the relationship with agency and person with a disability?

17 National Disability Insurance Scheme rules

Any information provided should be accurate and up to date and shared or available in all varieties of accessible information including using the internet to transmit information for convenience.

PDA wonders whether item (1) (a) restricts the agency providing information

Chapter 3—Participants and their plans

Part 1—Becoming a participant

18 Person may make a request to become a participant

Can there be direct referrals from agencies, ngo's, CRS, social workers, hospitals and other services or organisations?

Can a service organisation refer individuals? Is this in the Rules section?

PDA believes that in the instance of early intervention, a variety of avenues must be open to the NDIS for referrals.

(2)

(b)

Does this mean that if a person was actually receiving a service at the time of an application that they would be refused the opportunity to move across to the NDIS?

22 Age requirements

(1)

PDA has enormous concerns about the age limit of 65 years of age for the NDIS. The Ageing and Health Department has not been geared to be a rights based social model approach but rather comes from a health perspective, and for many people with a disability who have been active since 1981 the International year of Disabled Persons, they are not ready to lay down their activist and advocate hats, but would rather continue to live a life in the community of choice, and supported in order to live this way.

In the same way PDA believes that it is inappropriate to place people with high support needs disability into a nursing home simply because the Health and Ageing Department have not developed programmes for addressing these big issues in the same rights based way that disability has.

It seems to PDA that there needs to be a decision made on whether a person who has a disability and has support needs to live independently should be entitled to the NDIS regardless of age, and assisted to continue to live in that community of choice if it is already in place;

and

A decision needs to be made that at a certain level of disability, increased support is needed for a person to remain living in the community, regardless of age, regardless of the type of support needs and does not include being placed in a nursing home. If this person is not able to be funded under the NDIS then a nursing home should not **ever** be the last solution and alternatives need to be found.

That would solve the huge issue of more and more young people going into nursing homes, because there is no alternative and the issue is in the 'too hard basket.' NDIS should also be about about addressing some of these issues.

23 Residence requirements

(1)

PDA believes the NDIS should be available to only those who meet the legal residency status and requirement of every other Australian citizen and be restricted to these rules and requirements.

Must be recognised by all Australian laws and requirements.

24 Disability requirements

(1)

PDA believes that all decisions must be decided individually and be flexible in the approach to disability and not consider disability categories or diagnosis to mean each person is the same and therefore requires the same supports. Individual and flexible approaches to all assessment processes is essential and part of the assessment is to listen to the participant and his/her views and experience, as well as desired lifestyle and goals.

25 Early intervention requirements

PDA is pleased to see that the NDIS is applicable to children with disability as well as adults, and is especially pleased to see that the legislation includes a focus on early intervention, not only for children but for all participants.

PDA encourages early intervention for participants to also be flexible and innovative in focus which may assist in preventing further developmental, social or physical delays.

26 Requests that the CEO may make

(3)

PDA is pleased to see that the requests the CEO may make are restricted to being reasonably necessary although this language is obscure. We assume therefore that needs will be assessed in the same way as reasonable and necessary supports.

28 When a person becomes a participant

(1)

PDA supports the process of keeping participants up to date on decisions and when to commence programmes, and we urge caution in relying only on written (letter) communication. We believe all methods of communication should be used including electronic communication.

29 When a person ceases to be a participant

PDA is concerned about the number of young people with disability who are already in nursing homes and is disturbed that this section could be read as 'if a person who is under 65 and already living in a nursing home by any other name, they are ineligible? Is this correct?

If this is the intention then PDA would stress that young people in nursing homes are there because there is no option in the community, and therefore believes that the NDIS should focus on assisting those who wish to live in the community to do so. This may need to be addressed separately, but if the NDIS does not address it then nothing will.

We therefore recommend taking out the word “or” in section (b) “or is being being provided with community care; on a permanent basis.

30 Revocation of participant status

PDA supports this.

Part 2—Participants’ plans

Division 1—Principles relating to plans

31 Principles relating to plans

PDA Believes that all participant plans must be based on realistic abilities and achievements, individually focused and flexible in both recording and in delivery of the Plan.

PDA believes that participants plans must take into account the lack of opportunity that individuals have been faced with in the past, and focus should be to try and build on this.

PDA believes that plans should be innovative enough to include training for confidence building, social expectations,

Division 2—Preparing participants' plans

38 Copy of plan to be provided

PDA states that this plan must be presented in the most appropriate format for the participant, which should include electronic means.

PDA asks if there is to be a written contract of any kind between NDIS, the participant and any external support services?

Division 3—Managing the funding for supports under participants' plans

42 Meaning of managing the funding for supports under a participant's plan

(1)

PDA believes that all participants should be made fully aware of who is managing the funds for their plan, if/who makes decisions on their behalf, what this in effect means and how this will work for their support needs. This is a crucial part of choice so that the participant is clear how the plan will work.

45 Payment of NDIS amounts

(1)

PDA is not aware of any information relating to what an 'NDIS amount' is likely to be and wonders if this will be a further consultation.

Division 4—Reviewing and changing participants' plans

47 Participant may change participant's statement of goals and aspirations at any

time

(1)

PDA is pleased to see that participants can change their plan at any time, to reflect changing life situations.

Chapter 4—Administration

Part 1—General matters

Division 1—Participants and prospective participants

PDA cannot stress enough the importance that every party to a participants plan must be fully aware of their responsibilities and legal duties to comply with the NDIS. This includes: funds for supports, understanding their responsibilities in receiving, spending, and accounting for funds and the full legal responsibility to act in the best interests of the participant.

We emphasise the urgent need for training in managing a participant plan and a complete 'how to' guide by the agency itself.

54 Written notice of requirement

PDA asks if there is a penalty for not complying?

Part 3 Registered providers of supports

70 Registered providers of supports

What safeguards are there for the CEO in relation to approving service providers? Are service providers to have some kind of accreditation or recognition that the service is reputable and has experience in service delivery of the kind needed by the individual. (See rules?)

What safeguards are there in place for the participant to observe or approve any changes to their plan by the service provider that are not authorised by the NDIS agency?

PART 4—CHILDREN

75 Definition of *parental responsibility*

PDA inquires as to what happens in the instance that both parents have 50/50 parental

share, and there is an application for support from both parents?

Would this be addressed by allocating the support to the child and the child takes the support where ever it happens to be?

For instance if there is physical support by way of equipment, then this goes of course with the child. What if the equipment or support is not movable? Does this mean there needs to be for instance 2 sets of ramps, or other items?

PART 5—NOMINEES

Division 1—Functions and responsibilities of nominees

78 Actions of plan nominee on behalf of participant

(1)

PDA believes that every effort must be taken to determine the wishes of a participant in the first instance.

Nominees or any other party must never speak for or on behalf of the participant without their prior permission.

PDA believes that the participants plan and actions by any parties including nominees must be agreed upon by both the participant, the nominee and the CEO in the case where a “participant is not capable of doing the act.”

80 Duty of nominee to participant

(1)

PDA believes that an effort and duty to ascertain the wishes of the participant must be determined as having taken place by the CEO.

81 Giving of notices to correspondence nominee

PDA recommends that the CEO ensure Participants receive correspondence at the same time as the correspondence nominee and not after the nominee.

82 Compliance by correspondence nominee

(1)

PDA is concerned that there is no safeguard to ensure that participants are not left out entirely if correspondence is deemed to have been “so given on the day” (1) (i) to a participant.

We believe the CEO or agency has a responsibility to ensure at all times that the participant is notified of every procedure and decision concerning their own lives. This

must be done mindful of the participants communication requirements.

83 Nominee to inform Agency of matters affecting ability to act as nominee

PDA believes that in all instances the participant is of primary importance in all actions and decisions and not the nominee as in the case of a child.

PDA believes that the clause containing 'reasonable excuse' **(7) Subsection(6)** ' contains a term that has been used very loosely in the disability sector. The sector has been the reasonable part whilst excuse is mainly seen from those who have abused or broken trust, discriminated or not complied. We therefore feel that this section in the case of nominees who break this trust should be much stronger.

We also believe that in the instance of an offence being committed by a nominee the agency has a responsibility to investigate this immediately.

85 Right of nominee to attend with participant

(2)

PDA believes that any assessment must take place away from the agency or the individual's home, at a place that is independent of all parties. This must be suitable to the participant.

Division 2—Appointment and cancellation or suspension of appointment

PDA believes that In the instance of severe physical, mental or financial harm, legal authorities must be notified.

Division 3—Other matters relating to nominees

Part 6—Review of decisions

PDA believes this section fits more within the scope of rules and procedures of the CEO and agency.

Chapter 5—Compensation payments

Part 1—Requirement to take action to obtain compensation

104 CEO may require person to take action to obtain compensation

PDA believes that the participant must be given support to pursue action of compensation by the CEO in the event that no compensation actions have been initiated.

Chapter 6—National Disability Insurance Scheme Launch Transition Agency

Part 1—National Disability Insurance Scheme Launch Transition Agency

118 Functions of the Agency

Part 2—Board of the Agency

Division 2—Members of the Board

126 Membership

The Board consists of the Chair and 8 other members.

PDA believes that at least 50% of the membership of the board should be people with disability who are experts on their own lives and possess the lived experience of disability.

Part 3—Independent Advisory Council

Division 1—Establishment and function

146 Membership

The Advisory Council is to consist of the following members:

- (a) the Principal Member of the Council;
- (b) not more than 12 other members.

PDA believes at least 50% of the membership of the Advisory Council should be people with disabilities in order to obtain and maintain expert advice. People with disability have the lived experience of disability and are therefore experts on their own experiences and the experience of others is also part of their experience and knowledge.

Chapter 7—Other matters

Part 1—Debt recovery

Division 1—Debts

182 Debts due to the Agency

PDA assumes that the NDIS amount referred to here is an established rate or system/method of payment that is consistent across all participants. However we can find no information on how these figures are or will be determined?

Part 4—Review of the Act

208 Review of operation of Act

PDA is pleased to see that the Act will be reviewed 2 years after commencement and stresses that people with disability from external sources to the agency or government should be involved extensively through the Review of the Act also.

Thank you for this opportunity to comment on the Legislation.

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