National Disability Insurance Scheme Legislation
Submission to Senate Community Affairs Committee
Samantha Jenkinson, January 2013

The National Disability Insurance Scheme is a massive change and reform to how people with disability are supported and funded so that we can participate in our community and live ordinary lives in Australia. For this reform to work in the long term, I believe it must have the following elements

- a direct connection to the UNCRPD
- flexibility
    - to cater for the diversity of people with disability,
    - to give people with disability choice and control,
    - to allow the system to change and adapt with learning and input from people with disability
- people with disability as active participants and decision makers at all levels
    - governance
    - policy and rules development
    - planning and assessment
    - review
- locally situated and relevant
    - for plans, support and funding to match local circumstances
    - decision making and mediation/negotiation at a local level
- supporting and building the capacity of people with disability.

These elements must be reflected in the legislation and the rules to ensure that the NDIS will work for people with disability and all Australians in the long term, not just stated in principles. I have made suggestions throughout my feedback which captures these elements including identifying gaps. I would be very willing to discuss any aspects further with you at a hearing.

Personal Background

I am a person with an acquired disability from a motor vehicle accident in 1989. I am a C6/7 quadriplegic and I use a manual wheelchair at all times. I also recently realised that I am a person with a severe and profound disability, although I have very rarely thought of myself as such. I am also a wife and mother of two young children.

I received a lump sum compensation payout to pay for my care and support. I have always worked on a budget of what my monthly income needs to be for support and ensured that I could stick to it. This is something I had to learn to do, and would have been made easier by have a sum each year rather than the lump sum.

I currently employ my own support workers. Over the years I have sometimes used service providers (both not-for-profits and commercial entities), and some times employed my own support workers, and sometimes done a combination. This has been dependent upon my situation, and time. I require and pay for approximately 45 to 50 hours a week of support. When I lived on my own this support was provided solely by support workers, and now my husband provides approximately 10 hours a week of support.

Due to having my own funding that I have been able to manage and control, I have had the flexibility to employ a nanny when I needed it and take support workers with me on holiday. I have got the wheelchair and cushion I need and been able to get other supplies as and when I need them. Without this flexibility, I would not have met my husband, nor had the support to have children.

After my accident I returned to university, and completed a degree in social work. Since 1993 I have worked in the disability sector in Western Australia and Victoria as an advocate, case manager and policy officer.

Legislation

Chapter 1, Part 2 - Objects and Principles

Giving effect to the Convention on the rights of Persons with disabilities is a core objective of the NDIS and therefore needs to be the top objective of the legislation. Clause 3h, which states this objective, says that it gives effect to certain obligations rather than the whole convention. There needs to be greater clarity around which parts of the convention the NDIS is giving effect to such as article 8,19, 26 and how the NDIS supports all of the other elements of the convention.

The National disability strategy is a government policy which aims to give effect to all other areas of the convention, but currently does not have legislation which gives it effect. There are a number of sections in the NDIS legislation which talk about people with disability getting support from other areas which would not be covered by the NDIS. There is a general understanding that the reason behind this is so other systems like education, health and employment will still provide the necessary support required for people with disability to access those systems. Building the capacity of mainstream community and general support systems such as health and education require the National disability strategy to be taken seriously and to be working in conjunction with the NDIS. It is difficult to reference a policy in legislation and so it is even more important to reference the convention upfront, as this is the basis for all of the reform. This also shows that the NDIS is about more than giving effect to specific articles of the convention, but rather is an important component to giving effect to the whole convention.

People with disability are looking for this legislation to address the rights that they have to be supported to participate in community. Section 11 of the Exposure Draft of the Human Rights and Anti-discrimination Act is an example of acknowledging the human rights instruments that we must follow. A similar section referencing the Convention could be used in this legislation.

The principles are there to engender a culture of choice and control for people with disability, and an expectation that people with disability will participate in the broader community. However the aspect of duty of care often stops this from happening. Including reference to the dignity of risk in the principles would assist that cultural shift.

Section 5 of the NDIS Bill sets out principles to guide people acting on behalf of others. What is concerning with this section is that there is not a first point assumption of mental capacity. The reality is that this area is much more complex than this section conveys. Any form of substitute decision-making which occurs should be only occurring as a result of guardianship order. Where there is support needed for a person with a disability to make decisions, then principles similar to those suggested by the public advocate in Victoria would be better principles to have in place. These are listed below. (2009 Office of the Public Advocate Victoria)

- People have the right to make all personal decisions that they are capable of making.

- Support and assistance with decision-making should be available to any person with a disability who seeks such support.
- The person makes the decisions. The supporters assist the person but do not take over the decision-making.
- Any supported decision-making arrangement must have the free agreement of the person and their supporters. The person with a disability may terminate the arrangement at any time and a supporter may withdraw from the arrangement at any time.
- Decisions made under supported decision-making arrangements cannot override the will of the person with a disability.
- The interests of the person with a disability are paramount in supported decision-making arrangements.
- Responsibility for decisions made may lie with the person with a disability or with the group, depending on the areas of decision and the arrangements agreed to.

Principles D and E of section 5 would enhance the principles stated above.

The inclusion of this section also begs the question of why there is no reference to independent advocacy. The principles and objectives of the legislation should include a principal of any person with a disability being able to access the support of independent advocacy. A definition of independent advocacy should then be included in the section with definitions. Including the right to access advocacy should not be confused with the need to fund advocacy, which should be done through current systems as recommended by the productivity commission to keep it independent. The importance of advocacy being independent means that an advocate can represent and advocate with the person with a disability with no other conflict of interest. There is such a large diversity of people with disability with many who are vulnerable because of their disability and others who are vulnerable because of their personal circumstances, that access to independent advocacy must be a given. (note: in the disability sector advocates are not legal council, but rather a person who can speak on your behalf).

Section 6, which allows for the agency to provide support and assistance to participants to meet obligations under the act is ambiguous. There are a number of potential obligations in the act, such as the obligation to provide information seek medical assessments and possibly seek compensation from other sources. It is unclear whether these types of obligations could also be paid for by the agency. It is also concerning that this section does not allow financial assistance for a person to gain legal advice in relation to review of the decision, particularly as the act currently has the Administrative Appeals Tribunal as the external body to review decisions. It is my understanding that to use the Administrative Appeals Tribunal requires having legal assistance. This disadvantages any person with a disability wanting to appeal the decision externally to the agency.

Chapter 2

This chapter of the legislation is extremely important as it essentially provides the agency to fund other entities to provide support for people with disabilities for capacity building activities. For people with disability to utilise the options for self-management and self directing their funding and supports there needs to be development of training, education, and other support mechanism. Currently this chapter is missing a clause which allows the agency to fund other entities to provide capacity building support for people with disabilities to self-direct their plans and services, and self manage their funding. It is also unclear what role the agency might play in developing sector capacity, particularly in areas where specialist services are required, for example support for people with high medical support needs.

Chapter 3
The productivity commission in its detailed report recommended that there be multiple tiers for the National disability insurance scheme. My understanding of the design of the scheme is that people with disability, who may not need funded support would still be able to access information and referral supports as detailed in chapter 2. Ideally a person who moves from needing information and referral support to funded support should be able to go through a seamless transition with the people they have already developed a relationship with as they move through to assessment and planning. This may need to be detailed in the rules.

There may be people who are eligible to be a participant in the scheme as detailed in the eligibility criteria, yet who are currently receiving the support they need from family and friends, and although they do not wish to access the scheme at a particular point in time they wish to be clear that they are eligible and assessed as eligible, for when those informal supports are no longer able to be provided. For example, parents providing support to a teenager or young adult may wish to continue providing the support, but want the certainty of knowing their son or daughter would be eligible to access funded supports when they are no longer able to provide that support. Currently, the legislation would require a person who is eligible to start the process of going through assessment and planning within a specified timeframe. For many people with disability, they will want to be moving on to the assessment and planning stage as soon as possible to get the support they require. However, if a person is eligible, but does not want to start planning and support at that time, they should not be penalised in any way.

Age requirements
Although the productivity commission also recommended that there should be an age cut-off of 65 in the NDIS, there are a number of issues that this raises. Currently, the amount of funding and support that is able to be accessed in the aged care system is simply not adequate, where somebody acquires a significant disability that is not age-related such as quadriplegia. There are also a number of disabilities, particularly sensory disabilities which increase with age. Ideally, a person with a disability of this nature should be able to purchase supports from service providers regardless of whether their funding comes from aged care systems or the NDIS. However, this needs to be monitored, particularly if funding is allocated in different ways is in the different systems. Services which are block funded such as conversion of printed material into Braille and audio will need support to transition to this different way of providing services.

It is understood that to make the NDIS sustainable the age requirement may be a necessary feature of the access criteria. A suggestion is that the age criteria matches the age criteria for the aged pension and changes with that age criteria.

Disability requirements
In discussion on the design of the scheme, many people have talked about obvious eligibility being part of accessing the NDIS. There is a tension here in that we do not want to have a list of conditions which are eligible for the NDIS that could potentially exclude many people with rare conditions or with undiagnosed functional support needs. However, there is a case for putting in the legislation a clause around manifest eligibility which would enable a fast tracking of disabilities which were known to meet the disability criteria of the access criteria.

Early intervention.
There is concern that the requirement using the term developmental delay may not include children who are designated 'at risk' before a formal diagnosis of autism is delivered. Children who are 'at risk' benefit greatly from early intervention, particularly in the areas of communication.

Part 2 – Participants Plans
This area is potentially one of the most difficult in this legislation. For the purpose of providing funding the agency needs to have something which a person can be accountable to that shows what the funding is for. However, for people with disability the purpose of planning could be for a number of things, depending on their personal circumstances and the support they have to direct, plan, and control the services and supports they require. For some people it is extremely important that the planning process includes the context of persons living arrangements and social and economic participation. For other people, for example, a person with a physical disability who requires personal support for showering, dressing etc, they may not wish to share or plan for their social and economic participation if it is not something that requires funding.

Good person centred planning is not something that can be prescribed through legislation or other form filling. The principles relating to planning are good principles for any type of planning. However, section 33 then goes on to state what must be included in a participant's plan and essentially gives ownership of that plan to the CEO. For the purpose of the agency, the plan needs to provide justification for the funding and goals and objectives that can be accounted for. The role of the agency in planning should be to fund other independent people who can facilitate and provide support to do planning, and to approve or authorise the funding for the plan. The plan itself with its goals, aspirations and details of the persons life belong to the person. If agency staff are facilitating and approving the plan they are in a conflict of interest as they are not able to be totally focusing on the participants needs but also have the agency's needs to contend with.

This section also references the need for a person whose plan is managed by the agency to only use registered provider of supports. In legislation, this could be extremely limiting for some people, and this would be better detailed in the rules where further detail could be given on the sorts of things which may not need to be provided by a registered provider of support; for example, equipment, which may be necessary to support a person's disability, but not provided by a disability specialist provider.

Section 38 again makes the assumption that the plan is owned by the agency rather than the person. This section should simply be that the person is provided with a copy of the approved funding details.

Another essential element of person centred planning is that it is flexible to change as a person circumstances change. If a person chooses to change the service provider they use, but there is no change in the reason why they require that service or the goal pertaining to that type of support, then a person should not have to do undergo a review of the plan. Division four details when a persons plan can be changed or reviewed, however, it does not take into account where a plan must be changed retrospectively because a crisis situation has led to a person changing in reality what they had to do before being able to get approval for changes.

Reasonable and necessary supports.

There are grave concerns about how value for money will be subjectively judged and who will be judging what is considered value for money. There is concern that the current wording does not take into account the long term benefits and outcomes when looking at value for money.

Although it is understood that there is a need for other parts of the community to undertake their universal obligations for service and access, there is concern that in many areas this will mean people missing out or experiencing disadvantage when trying to access other services. A suggestion could be that the agency or the coordinator who is referenced in chapter 2, play a role in checking and lobbying for universal service obligations to be met. Another suggestion is that where there is an overlap of service, a person could choose whether the funding comes through the NDIS system or the alternative system. By the agency, playing a role in lobbying and checking the universal service obligations are being met by other departments, they are also able to collect data on unmet need and gaps in service.

I am pleased to see in the legislation that there is an emphasis on the rules prescribing what might not be funded rather than a list of what can be funded.

There is a number of times in this section where reference is made to people being requested to undertake assessments or other examinations. It is concerning that this power could be abused and it is unclear why this power is necessary if there are clear criteria in the rules as to what information needs to be provided in the access criteria and in documentation to support a plan. It is also unclear as to who will pay for these assessments and examinations. The earlier clause that talks about the agency providing support and financial assistance seems to be subjective in nature by stating that the agency 'may' provide support.

Plan and funds management

Section 43 part 4 seems to contradict the default position that the participant manages their own plan and funding, in that is says if a person does not specifically make a plan management request then the funding must go through the agency or a registered plan management provider specified by the agency. The default position should be that the participant is in control. This is unclear and seems to take choice away from the participant.

Who and what can be a plan management provider is very unclear. There is concern that if this is arduous then potentially flexible, innovative and creative ways of supporting plan management may be missed. People using an accountant or financial planner for example, or co-ops or micro-boards.

Local decision-making and engagement.

A big concern for many people with disability is that decision-making and engagement will be with a large bureaucracy rather than a local person or team who they know and have worked with. Although there is understanding that reference to the CEO in the legislation does not necessarily mean that the CEO themselves will make those decisions, there is concern that the legislation is supporting a hierarchical decision-making structure. One suggestion is that rather than have approvals done by the CEO within a certain time frame, that approval or authority to fund a plan could happen at the level of the agency closest to the person and as quickly as possible. A clause of this nature could include that any aspects of the plan that can and should be approved on the spot are approved. In this instance criteria for when aspects of plan needs to be approved at a higher level should be detailed in the rules.

Engagement at the local level is also the key to building capacity within mainstream organisations to fulfil the universal service obligations. This is why many people with disability want to do planning with people that they know who also know the local area that they live in. Local people are more likely to build relationships and have connections with mainstream services that they can liaise and work with to ensure people with disability have access to those services. Potentially this could be further detailed in clauses in chapter 2.

Chapter 4 - Administration

This chapter holds a lot of information which gives power to the CEO over many aspects of gathering information. It is hard to see the principle here that information about the person belongs to that person. More emphasis needs to be given to the notion that the person with a disability owns the information about themselves and has the right to give permission for its use.

There are also concerns when it comes to the section on privacy. Again, an external agency should not be compelled to provide information without permission from the person. In particular, there is a section which allows for sharing of information on the basis of public interest. It is unclear whether this is to allow for generalised data collection or whether this is relating to criminal matters. Either way, they should be specific clarification in the legislation on this matter.

Complaints and review

All decision points in this process should be re-viewable. Currently this section does not allow the right to independent advocacy. The external review process currently states that applications can be made to the AAT, however no funding is provided to take that step and people with disability are already disadvantaged because of the cost of retaining a solicitor that is required. It seems rather extreme to go from an internal review mechanism straight to the Administrative Appeals Tribunal. A better system would see an equivalent to the SSAT. There should also be something between the internal and external SSAT type review at local level, such as a mediator or ombudsman. At any point a person should be able to have an independent advocate present to speak on their behalf.

Currently, there is no national mechanism about complaints against service providers. This is a gap which requires filling so that service providers are accountable both to the agency and to people with disability.

It would be good to see the legislation contain principles of independent complaints process.

Registered services providers

This concept is raising many concerns and questions for people with disabilities. There is a need for organisations who are providing specific disability expertise and support to meet standards and be accountable, yet there is also a need for people with disability to have a much broader range of choices and flexibility in who they can purchase supports from. A person should not be limited by this section, especially if they are forced to only use registered providers of support because their plan and funding are managed by the agency. (see example in section on planning).

There is an opportunity here to ensure that services provided do not use restrictive practices and that service is embedded with evidence based practice.

Nominees

It is very unclear in the legislation how the role of the nominee may differ from a legally appointed guardian. There is also a concern that the CEO cannot legally appoint a nominee, as that is the role of Guardianship and Administration Board in each state. In relation to nominees Article 12 of the UN Convention on the rights of people with disability should be referenced and as reflected in the objects and principles, the process followed should be one of supporting decision-making by the person with the disability rather than substitute decision-making.

Chapter 5 - Compensation

The biggest concern in this section is that people will be forced to try and get compensation if the agency believes that they should be eligible for compensation. There is a cost, both emotional and financial which comes with undertaking legal cases for compensation. Unless the agency is prepared to support and assist the person to try and get compensation (where it is not evident that compensation can be easily obtained), then no-one should be forced to try and get compensation.

Chapter 6 – Part 2 Board and Advisory Council,

Both the Board and the Advisory Council of the agency must have people with disability. It is not ok to assume that you will get board members with disability. There are people with those skills but if the legislation does not specify that there are people with lived experience of disability on the Board then it may not happen.

Chapter 7 – Part 5 Development of rules and regulations

A lot of this legislation requires details in rules which are tabled in Parliament to take effect. The same points I made in my introduction apply to rules as to legislation. They must be flexible and aimed at giving choice and control to people with disability. I believe that the legislation must specify that rules (dis-allowable instruments) must require affirmation by parliament before coming into effect so that there is awareness of what is being regulated and as a check on the follow through of the principles in the legislation.

Gaps

Status of funding held by participant

It is unclear in this legislation that funds going directly to a participant or a nominee for the purpose of funding the participants plan are not considered income for tax purposes or in relation to income support.

Involvement of people with disability in ongoing feedback, review and policy development

There is an opportunity here to embed the participation and engagement of people with disability in ongoing feedback, evaluation, review and development of policy, rules and regulations, in legislation. The catch cry for many years from disability advocates has been 'nothing about us, without us' and so we should take the opportunity to make this a reality within how the scheme, agency, and Councils in the legislation operate.

Reference
Supported decision-making, Background and discussion paper
November 2009
The Office of the Public Advocate Victoria