

Submission

Community Affairs (Legislation)

National Disability Insurance Scheme Bill 2012

The Department of Families, Housing, Community Services and Indigenous Affairs (the Department) would like to offer the following submission to the Senate Standing Committee on Community Affairs – Legislation Committee’s inquiry into the National Disability Insurance Scheme Bill 2012 (‘the Bill’).

Introduction

This submission is intended to aid the Committee’s consideration of the Bill by providing additional information to support that set out in the Bill itself, the explanatory memorandum and the Prime Minister’s second reading speech. The Department would be happy to provide any further information that the Committee may require as a result of questions or concerns raised in the course of its inquiry.

The first part of the submission sets out the broad policy development context for the Bill, providing information on the way in which the Council of Australian Governments (COAG) has guided the development of a National Disability Insurance Scheme (NDIS).

The second part of the submission discusses the processes of consultation and engagement undertaken on the draft Bill. As the principles and objectives of the Bill make clear, the Bill is designed to support the aspirations of people with disability in Australia, and give people with disability maximum control and choice over the support that they receive. Both of these objectives require that the development of the Bill be informed by consultation with people with disability.

Policy Development Context for the NDIS Bill

The Productivity Commission

As the Committee will be aware, in August 2011 the Productivity Commission released its Inquiry Report on Disability Care and Support. The inquiry drew from 23 days of testimony in formal hearings held around Australia and extensive evidence from nearly 1100 submissions from people with disabilities, their families, carers, service providers, governments and business.

The report found that the current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. It recommended that there should be a new National Disability Insurance Scheme (NDIS) that provides insurance coverage for all Australians in the event of significant disability, including funding long-term high quality care and support for people with significant disabilities. The Inquiry report, submissions, and transcripts of the public hearings are available at <http://www.pc.gov.au/projects/inquiry/disability-support>.

COAG and Select Council on Disability Reform

COAG has given extensive consideration to the report from the Productivity Commission, and to the design features of a National Disability Insurance Scheme (NDIS). Following the release of the Productivity Commission Report, COAG agreed on the need for major reform of disability services through an NDIS recognising that addressing the challenges in disability services will require shared and coordinated effort.

COAG established the Select Council on Disability Reform, consisting of Treasurers and Disability Ministers from each jurisdiction, to progress the foundation reforms required to improve the system of care and support for Australians with disability, their families and carers. In April 2012, COAG agreed on high-level principles to guide development of the scheme. These principles are set out at [Attachment A](#).

The Select Council's progress report of April 2012 shows governments have given extensive consideration to the key design features of the scheme, including how people would access the scheme, what sorts of supports the scheme would provide, who would be eligible and how this would be determined, how people would be able to exercise more choice and control, and how the NDIS should be funded and governed. The Select Council has also considered how to build the infrastructure for an NDIS and develop the workforce and disability sector. The Select Council's progress report to COAG is set out at [Attachment B](#).

From late August to early October 2012, COAG undertook consultations to inform the final approach to eligibility and reasonable and necessary support, as well as further work on how these definitions would work in practice, and how they would be reflected in legislation, regulations or guidelines.

As it stated in the communiqué from its meeting on 25 July 2012, COAG wanted people with disability, their families and carers, the workforce and disability sector and peak bodies to have a chance to comment on the proposed approach to eligibility and reasonable and necessary support under an NDIS.

Following COAG's consideration of the descriptions of eligibility and reasonable and necessary supports, officials from the Commonwealth, states and territories jointly developed a paper to engage stakeholders on the proposed definitions. This document ([Attachment C](#)) outlines what the Productivity Commission said about eligibility and reasonable and necessary support, the proposed draft definitions, and poses questions to help readers focus their feedback.

Consultation commenced on 31 August 2012 and concluded on 28 September 2012. Feedback was able to be provided via:

- state/territory based NDIS Advisory/Reference Groups;
- the National Disability and Carer Alliance Engagement project; or
- the NDIS 'Your Say' online forum (www.ndis.gov.au).

Feedback was collated into a formal report that has resulted in the revised statements on 'eligibility' and 'reasonable and necessary supports' being incorporated into the Bill.

Consultation and Engagement

National Disability Insurance Scheme (NDIS) Advisory Group and Expert Groups

The National Disability Insurance Scheme (NDIS) Advisory Group was established by the Prime Minister on 10 August 2011 to help steer the development of the NDIS by providing advice to the Select Council on Disability Reform. In addition, NDIS expert groups were established in May 2012 to help the Australian Government design a scheme that meets the lifetime care and support needs of people with significant and permanent disability. Details of the Advisory Group and Expert Groups are at [Attachment D](#).

The Advisory Group has met with state-based NDIS and Disability Advisory Groups to listen to their views and discuss key challenges in the design of an NDIS. Advisory Group members have also participated in events by invitation including events with Alzheimer's Australia, Blind Citizens Australia, the Australian Medical Association and National Council for Intellectual Disability.

The Advisory Group has also hosted a series of 'Your Say' forums on the ndis.gov.au website to give people with disability, their families and carers, community groups and service providers the opportunity to provide views and feedback on specific topics including the features of successful planning for people with disability and what qualities people would want in a disability support worker or service provider. Over the coming month, the forum will be used to seek feedback on aspects of the NDIS rules.

National Disability and Carer Alliance

The National Disability and Carer Alliance has three member organisations – Australian Federation of Disability Organisations, Carers Australia and National Disability Services. Each of these organisations is a national peak body and respectively they represent people with disability, carers of people with disability and disability service providers. Therefore, the Alliance is well placed to conduct consultations with the different sections of the disability sector.

The Department provided funding of \$840,000 to the National Disability and Carer Alliance to undertake grassroots engagement with people with disability, their families, carers and service providers around Australia on the National Disability Insurance Scheme (NDIS) under the Alliance 'Engagement Project'.

Phase One of the Alliance Engagement Project involved engagement forums in all states and territories in a mix of regional and metropolitan locations on broad NDIS policy issues (including the definitions of eligibility and reasonable and necessary supports), as well as an online survey.

The Alliance held 77 consultations, involving 2,056 people between August and December 2012. A summary of the outcomes from these consultations is provided at [Attachment E](#). They are also publicly available on the Alliance website.

The Alliance met with Minister Macklin and Senator McLucas in November 2012 to present the key themes arising from Phase One of their project.

Phase Two of the Alliance's Engagement Project will involve targeted engagement on identified focus areas, such as early intervention for children, people with mental illness and service delivery in Indigenous communities. Phase Three will include a series of roundtables with people with disability, carers and service providers throughout February 2013 that will specifically focus on key aspects of the NDIS Rules.

Co-design workshops in launch locations

The Agency is running co-design workshops in each of the launch locations involving people with disability, their families and carers, and sector representatives. Co-design is a process that allows government and stakeholders to work together so that the translation of policy can be shaped by what is desirable for people, what is possible for technology and what is viable for business.

In the first phase, a co-design session was run in each of the five launch locations. Approximately eight potential participants attend each session. The focus of these sessions was on how the Agency should look and feel, how people would prefer to make contact with the agency, how the planning process might work and what the Agency needs to do to ensure that it builds good relationships with participants. The next phase of Agency-led co-design related engagement will commence in mid-February 2013. The Agency is undertaking detailed planning for future engagement and communication in each launch site in conjunction with participating governments.

Consultation on the NDIS Bill

Departmental officers met with peak stakeholder groups in October 2012 to discuss an outline of the NDIS legislation. An Exposure Draft of the legislation was circulated to the peak groups and further consultations with them were held up until December 2012. The following groups were consulted through this process:

- o Australian Federation of Disability Organisations (AFDO)
- o First People Disability Network
- o Blind Citizens Australia
- o Brain Injury Australia
- o Children with Disability Australia
- o Disability Advocacy Network Australia (DANA)
- o Deaf Australia
- o Deafness Forum of Australia
- o National Council on Intellectual Disability
- o National Disability Services
- o National Ethnic Disability Alliance
- o Physical Disability Australia
- o Carers Australia
- o Women with Disabilities Australia
- o Mental Health Council
- o Vision Australia

The outcomes of these consultations are reflected in the Bill that has been presented to the Parliament. The Australian Government has also committed to continuing discussions with the states and territories on the Bill, and to consulting with stakeholders to inform the Bill.

Next Steps – NDIS Rules and Regulation Impact Statement

As a basis for further consultation with the sector and the public on the regulatory impacts of the National Disability Insurance Scheme (NDIS), COAG has released a consultation Regulation Impact Statement (RIS). This statement is available from the COAG website.

The Commonwealth is also working with states and territories, and with people with disabilities, their families and carers on the legislative instruments that will set out the operational aspects of the scheme (the NDIS rules).

Discussions on the development of the rules under the legislation are being supported by a consultation paper that seeks input from the community. The rules consultation paper is at [Attachment F](#). People with disability, their families and carers and other stakeholders will have the opportunity to have a say on these rules through the 'Your Say' online forum, ongoing work of the Commonwealth and state based Advisory Groups and the Alliance Engagement Project.

Attachment A

COUNCIL OF AUSTRALIAN GOVERNMENTS

High-level Principles for a National Disability Insurance Scheme

A National Disability Insurance Scheme

1. The Council of Australian Governments (COAG) has welcomed the release of the Productivity Commission's final report on Disability Care and Support and has agreed on the need for major reform of disability services in Australia through a National Disability Insurance Scheme. All governments recognise that addressing the challenges in disability services will require shared or coordinated effort.
2. This reform should take a social insurance approach that would share the costs of disability services and supports across the community. In addition, the reform should adopt insurance principles that estimate the cost of reasonable and necessary supports, promote an efficient allocation of resources based on managing the long-term costs of supporting people with disabilities and their carers while maximising the economic and social benefits. This would involve consistent application of eligibility criteria, and the timely and efficient delivery of reasonable and necessary supports, including early intervention. Actuarial modelling will be used to estimate and manage the costs of care and support across the life-course of individuals and monitor, evaluate and report on the overall performance of the National Disability Insurance Scheme.
3. A National Disability Insurance Scheme will fund reasonable and necessary individualised services and supports directly related to an eligible person's ongoing disability support needs.
4. COAG notes that design and implementation of a National Disability Insurance Scheme is the responsibility of all governments and that consideration of the Productivity Commission's recommendations provides a good starting point. The National Disability Strategy should also inform the design and implementation of a National Disability Insurance Scheme.
5. The development and implementation of a National Disability Insurance Scheme will be a shared responsibility of the Commonwealth and States and Territories. Governments agree this is a substantial and important reform that will fundamentally change the nature of disability care and support in Australia. Work will start immediately, but fully realising a National Disability Insurance Scheme will take time and require a careful and considered approach by all levels of government. The Commonwealth and State and Territory governments will work together through the Select Council of Treasurers and Disability Service Ministers (Select Council on Disability Reform) to build a National Disability Insurance Scheme which will deliver the following outcomes to eligible people with disabilities:
 - a. People with disability will be supported to participate in and contribute to social and economic life to the extent of their abilities;
 - b. People with disability and their carers will have certainty that people with disability will receive the individualised care and support they need over their lifetime;

- c. People with disability will be able to exercise more choice and control in their lives, through a person-centred, self-directed approach to service delivery with individualised funding;
 - d. People with disability, their families and carers, service providers, the public and governments will have greater transparency and certainty of funding for disability care and support;
 - e. Disability care and support will be more accessible;
 - f. Disability care and support will meet nationally consistent standards;
 - g. Disability care and support will be sustainably resourced; and
 - h. Disability care and support will contribute to governments' commitments to closing the gap on Indigenous disadvantage.
6. The Select Council on Disability Reform will reflect and give effect to the following design principles agreed by COAG when considering the Productivity Commission's recommendations and moving towards a National Disability Insurance Scheme. These principles do not direct governments' consideration of the Productivity Commission's recommendations in relation to the National Injury Insurance Scheme, which will be subject to a separate process lead by the Commonwealth Assistant Treasurer, however it will be important that the work progressing a National Injury Insurance Scheme is aligned to the National Disability Insurance Scheme work.
7. Principle 1: A National Disability Insurance Scheme should be needs based and provide people with disability access to individualised care and support. To achieve this, a National Disability Insurance Scheme should recognise existing best practice across the states and territories and build on this best practice through foundation reforms to:
- a. Provide certainty for people with disability in accessing high quality and effective services and support when they need them;
 - b. Be simple to understand, navigate and provide portability across jurisdictions and service providers;
 - c. Provide innovative responsive and coordinated services locally;
 - d. Support access to mainstream services such as education, transport, health, housing, aged care and employment services;
 - e. Recognise the essential support provided by families and carers and support them in their roles;
 - f. Recognise and enhance the significant role of the not-for-profit and private sectors in a well functioning disability services system;
 - g. Provide people with disability with better information and support to enable them to make informed choices and exercise control and choice over their care and support;

- h. Ensure the development of the sector is actively supported in a way that fosters continuous improvement, viability and sustainability;
 - i. Ensure equity of access by addressing the needs of people in regional and remote Australia and people from Indigenous and Culturally and Linguistically Diverse (CALD) backgrounds;
 - j. Promote innovation in services and the services system;
 - k. Provide appropriate safeguards to support and protect people with disability; and
 - l. Provide continuity of support to people with disability currently receiving services to ensure that they are not disadvantaged in the transition to a National Disability Insurance Scheme.
8. Principle 2: Resourcing arrangements for a National Disability Insurance Scheme should:
- a. Provide certainty of future resourcing recognising the projected ongoing growth in demand and the need for incentives for containment;
 - b. Provide adequate funding to address assessed needs;
 - c. Be fiscally sustainable for all levels of government;
 - d. Be based on an assessment of the costs of meeting reasonable and necessary care and support needs of an individualised funding approach;
 - e. Be transparent regarding contributions from jurisdictions;
 - f. Not create any disincentives for carers and family members to provide support;
 - g. Ensure that no jurisdiction is disadvantaged by:
 - i. historically high levels of funding for disability services, recent increased investment in disability services or additional investment in the lead up to the launch of a National Disability Insurance Scheme; and
 - ii. having already undertaken foundation reforms required to implement a National Disability Insurance Scheme.
 - h. Support a social insurance approach.
9. Principle 3: Governance for a National Disability Insurance Scheme must be transparent and accountable and ensure genuine ongoing involvement of all jurisdictions in determining governance, policy setting and scheme management. Governance arrangements should:
- a. Establish a National Disability Insurance Scheme that is administered in a way that manages life time costs of care and support through insurance principles, such as consistent application of eligibility criteria and timely and efficient delivery of reasonable and necessary supports, including early intervention, to ensure the ongoing financial sustainability of the scheme;
 - b. Maximise the benefits of a market-based approach to disability support services, including consideration of a costing structure that fosters competition and choice,

and supports an individualised and localised approach and takes account of legitimate cost variations for different locations and client groups;

- c. Ensure that there are nationally consistent eligibility criteria, standardised assessment tools, quality standards and a range of services and supports;
- d. Enable localised planning and access to efficient and responsive services, and be coordinated with mainstream services such as education, transport, health, housing, aged care and employment services;
- e. Equip and enable people with disability to the extent possible to choose and direct the services they receive and the manner in which they are provided;
- f. Ensure transparency of eligibility, assessment and resource allocation;
- g. Provide clarity around the roles and responsibilities of different levels of governments in the transition to and operation of a National Disability Insurance Scheme;
- h. Engage people with disability, their families and carers in the design and delivery of services;
- i. Facilitate national research and data collection and consolidation; and
- j. Ensure alignment with the policies, standards and services of a National Injury Insurance Scheme.

10. Principle 4: All jurisdictions commit to accelerated progress in the delivery of foundation reforms agreed by the Select Council in the period leading up to the establishment of a National Disability Insurance Scheme, together with simultaneous progress on resolution of governance and funding issues. This will ensure an effective transition to a National Disability Insurance Scheme which will deliver immediate improvements for people with disability in the interim. The implementation of a National Disability Insurance Scheme will recognise current systems, structures and coverage and ensure appropriate transition strategies. This will require:

- a. Ensuring continuity of support to people with disability currently receiving services to ensure that they are not disadvantaged in the transition to a NDIS;
- b. Ongoing development of the disability services sector capacity to meet the diverse and individual needs of people with disability, and to manage risk and operate effectively in a National Disability Insurance Scheme;
- c. Continuous improvement in specialist disability specialist support services in the lead up to a National Disability Insurance Scheme, including through reforms under the National Disability Agreement;
- d. A national workforce strategy to address qualifications, training and cross sector career mapping issues and other measures to establish the sector as an 'industry of choice' to ensure there is a skilled and responsive workforce to meet the care and support needs of people with disability, and assessment and local coordination roles under a National Disability Insurance Scheme;

- e. Robust evidence from trialling and evaluation;
- f. Appropriate legal and administrative reform, including data and information systems to support an insurance approach;
- g. Detailed analysis of the existing levels of investment to inform financing arrangements for a National Disability Insurance Scheme, including state and Commonwealth government funding, insurance based arrangements and other funding; and
- h. Detailed analysis of the cost structures underlying an individualised approach.

COUNCIL OF AUSTRALIAN GOVERNMENTS

Progress Report: Building a National Disability Insurance Scheme

All governments are committed to reforming disability services

On 10 August 2011, the Productivity Commission's report into disability care and support was released.

The Productivity Commission (PC) found that Australia's disability services system was underfunded, unfair, fragmented and inefficient. The report recommended that:

- A National Disability Insurance Scheme (NDIS) should be created to provide long-term care and support for all Australians with significant, ongoing disability who need it; and
- A National Injury Insurance Scheme (NIIS) should be created to provide long-term care and support on a no fault insurance basis for anyone who suffers a catastrophic injury.

The PC developed its recommendations after listening to people with disability and their families about the problems in disability services today and how they wanted future services to be delivered in Australia. The Commission held 23 days of public hearings, listened to 237 presentations and received over 1000 public submissions.

On 19 August 2011, the Council of Australian Governments (COAG), which is the peak intergovernmental forum in Australia, comprising the Prime Minister, State Premiers, Territory Chief Ministers and the President of the Australian Local Government Association, welcomed the PC's report and agreed on the need for major reform of disability services in Australia through an NDIS.

COAG has agreed that the PC's recommendations provide a good starting point for the design and implementation of an NDIS and has agreed on a set of high-level principles to guide its work.

An NDIS would change the way disability services are delivered

Under an NDIS, access to support for people with significant disability would no longer depend on how or where a person acquired a disability, where they live or how long they have been on a waiting list. They and their families and carers would have certainty about how their care and support needs would be met over their lifetime.

Under an NDIS, access to care and support would be portable within and across States and Territories. This means that there would be continuity of support for a person who is receiving support if they move to another State or Territory.

An NDIS would be 'person-centred', giving people greater choice and control over what supports and services they receive and who delivers them. As a result, service providers would need to be innovative and respond to the needs and preferences of individual clients. Services would be better coordinated and responsive to local needs, with improved linkages between disability services and mainstream and community services, including health, aged care, employment, education, housing and transport services. Support would be available to assist people with disability to make choices and navigate the range of services. An NDIS would also recognise the essential support provided by families and carers and support them in their roles.

Governments recognise that safeguards would need to be in place to ensure people with disability can access quality supports and services. Work is under way to develop safeguards, including

processes to hear and respond to complaints. The experiences and feedback of people with disability, their families and carers would also be at the centre of ongoing evaluation and improvement of the scheme.

Governments also recognise that an NDIS and the supports available under the scheme need to be simple to understand and navigate. This includes making sure the scheme does not place an unnecessary administrative burden on people with disability, their families and carers, or service providers.

Designing and implementing a scheme that will deliver these changes for people with disability is a large and complex task. At the moment, the States and Territories are primarily responsible for the delivery of disability services, with different arrangements in place in each State and Territory. This means the type and scale of change required to implement a nationally consistent scheme will be different in every State and Territory.

How are governments working together to design an NDIS?

The development of an NDIS is being led by COAG, reflecting the significance all governments place on improving the disability services and support system. COAG has established a Select Council of Treasurers and Disability Services Ministers (the Select Council on Disability Reform) to make recommendations to COAG on the overall design, governance and implementation of an NDIS, as well as threshold issues such as who will be able to receive funded support under the scheme and what funded supports will be available, what the scheme will cost and how it will be funded.

The Commonwealth has established an Advisory Group to help steer the development of an NDIS by providing advice to the Select Council on Disability Reform on foundation reforms required to deliver an NDIS. The Advisory Group will work closely with all governments and brings together a wealth of knowledge about the experience of people with a disability and carers and the challenges for the service sector and government administration. Some States and Territories have also established advisory groups.

In parallel, the Standing Council for Federal Financial Relations, (comprised of Treasurers from all governments), with advice from its own Advisory Group, which includes a diverse range of experts and key stakeholders, will consider the development of a National Injury Insurance Scheme (NIIS).

What's being done now to get ready for an NDIS?

The introduction of an NDIS would change how disability services and supports are currently delivered. This raises a number of important questions about how an NDIS should work for individuals.

How an NDIS would work for individuals

How would people access the scheme?

It is important that the scheme can be accessed locally. Local delivery would ensure the scheme is accessible to people with disability and responsive to local circumstances. The Select Council is considering how an NDIS 'gateway' would work and how it would assist people with disability in accessing support.

This includes looking at how people would access information about the scheme and be linked to community supports and mainstream services. It also includes looking at how individuals would be supported to navigate an NDIS (including working with locally-based coordinators).

Who would an NDIS be for?

Under an insurance approach (discussed later in this report), all Australians would be supported in the event of significant disability.

The PC recommended that the people who receive individually funded support under an NDIS should: have a significant disability that is, or is likely to be, permanent; have significantly reduced functioning in self-care, communication, mobility or self-management; and require significant ongoing support. The PC also recommended that people should receive individually funded support if they would benefit from early intervention support which is safe, cost-effective and would significantly improve their outcomes.

The Select Council is looking at what the PC's recommendations would mean for people with disability who need support and what this means for the cost of the scheme. As part of this work, the Select Council is considering the tools and criteria that should be used to determine who would receive individual support, to assess a person's support needs and identify the best response under an NDIS.

It is intended that an NDIS would provide continuity of support to people with disability currently receiving services, to ensure that they are not disadvantaged in the transition to an NDIS.

What support would people get from the scheme?

The support people receive from an NDIS would be based on their individual needs. The Select Council is developing a suite of national assessment tools to facilitate a consistent approach to assessing people's needs. This work involves defining how the assessment process should work, and evaluating existing assessment methods and tools used in Australia and overseas.

Any support provided by an NDIS would build on broader community supports, mainstream services (for example, health, aged care, employment, education, housing and transport services) and an individual's family support networks. An NDIS is not intended to replace the important care and support provided by families and carers, but to help make it more sustainable.

For some people, the support received from an NDIS would involve information and referrals to community supports and mainstream services. Assessment may also identify a one-off need for aids, equipment or specific supports which would be revisited at appropriate periods.

Some people with significant disability may also receive an ongoing, individually tailored support package. In all cases the aim is to provide support that is reasonable and necessary to meet the needs of the person with disability. The Select Council is working to refine the concept of 'reasonable and necessary', which was a term used by the PC in its report.

The Select Council is exploring how individualised funding would work under an NDIS, how support packages should be designed and what supports could be purchased. This work includes consideration of how aids and equipment should be provided and how positive outcomes from early intervention could be maximised.

The concepts of eligibility, needs assessment and 'reasonable and necessary' support are key elements of NDIS design and need to be considered in the context of the Select Council's other work on what the scheme will cost and how it should be funded and governed.

How would people get to exercise more choice and control?

Supports would be self-directed, meaning that people would have more choice and control over the supports they use and the way they are provided, including the type and nature of support they access and who provides them with the service they need. This could include a person choosing to

self-manage their funds, if they receive an ongoing package of support. For example, a person could choose to use funding that was previously used to purchase a place in a day service to buy other support and assistance which better matches their goals and interests, such as support to participate in a swim class at a local pool.

Governments are exploring how this would work in practice under an NDIS, and what supports would be needed to enable people to exercise the level of control and choice they want.

Building the infrastructure for an NDIS

The design and implementation of an NDIS is a complex reform, which will take considerable time. This is why it is important that work on the reforms needed to implement an NDIS (foundation reforms) occur at the same time as work on funding and governance arrangements for the scheme.

Applying insurance principles to the delivery of disability services

Governments have agreed that adequate, ongoing support for people with significant disability would best be delivered through the use of an insurance approach. Under such an approach, the unpredictable risk and unaffordable cost of severe disability for the individual would be distributed among the wider community as a shared responsibility.

There would be clear criteria about who can access funded supports under the scheme so that support is well-targeted and the scheme remains affordable and viable in the long-term. People's needs would be carefully assessed (and regularly re-assessed) so they get the right support at the right time. In undertaking these assessments, the scheme would take a long term view of people's care and support needs. This would include making sure people with disability get the right support earlier, rather than waiting until they reach crisis point.

Taking an insurance approach means the total cost of supporting everyone in the scheme over their lifetime would be estimated and carefully monitored to determine scheme funding requirements. There would need to be certainty that sufficient funding would be available to meet the assessed needs of all scheme participants over their lifetime.

There would also need to be efficient and effective systems to collect and analyse data to measure the performance of the scheme, including client outcomes. The Select Council is currently looking at what data and business information systems would be needed to support the scheme.

An insurance approach requires a disciplined focus on managing the costs and operations of the scheme to make sure it remains affordable in the long-term, while at the same time achieving good outcomes for people with disability. This means the scheme would need to be able to invest in early intervention and have a national research function to promote and share innovation and best practice across the whole scheme.

A key challenge in designing an NDIS will be delivering an affordable scheme which responds to the individual needs and aspirations of people with disability receiving support under the scheme. Assessing what support is 'reasonable and necessary' for each individual will be important in striking this balance.

Funding arrangements for an NDIS

In considering how the features of an insurance approach should be applied to an NDIS, governments will need to decide what funding arrangements are best able to ensure that sufficient funding is available year-to-year and in the long term to meet the needs of all scheme participants over their lifetime.

The PC estimated that an NDIS would cost between \$5-8 billion per year (once it is fully operational) in addition to the \$7 billion per year of existing State, Territory and Commonwealth

funding. Early work done by the Australian Government Actuary suggests that the additional cost of an NDIS is likely to be within the range estimated by the PC at about \$8 billion per year. This estimate is based on the model for an NDIS proposed in the PC's report.

Looking at the PC's estimates gives governments a good sense of the likely cost of the scheme, but further work on scheme design will be needed before the definitive cost is known. In particular, decisions about who would be able to receive funded support under the scheme, and what supports they would be able to choose, will have a significant impact on the final cost of the scheme.

States and Territories currently provide most of the funding for disability services, but the funding that would be required to pay for an NDIS is likely to be more than double the total current Commonwealth and State Government funding for disability services. COAG will be discussing funding options from mid-2012, recognising that governments must reach agreement on this matter to enable design work and implementation of the scheme to be finalised.

Governance arrangements for an NDIS

Governments also need to make decisions about who should manage and operate the scheme and how this should be done (known as 'governance arrangements'). This includes deciding what the roles of Commonwealth and State and Territory Governments will be.

In looking at a range of possible governance options for the scheme, the Select Council needs to consider:

- the important relationship between decisions on how the scheme will be paid for and the roles and responsibilities of the Commonwealth and State and Territory Governments in overseeing, managing and operating the scheme;
- what governance arrangements would best accommodate the key features of an insurance approach;
- what aspects of the scheme would need to be nationally consistent so that people with disability are treated fairly and consistently wherever they live across Australia;
- the importance of localised planning, decision-making and access to supports, to achieve the best outcomes for people with disability, their families and carers;
- how to make sure those directly responsible for managing the scheme can make decisions independently and focus on the sustainable and cost-effective provision of supports for people with disability, their families and carers; and
- how to monitor and manage costs across the whole scheme to make sure it remains affordable in the long term, while at the same time ensuring service quality and positive client outcomes.

Governments will also need to make sure the scheme aligns with arrangements for a National Injury Insurance Scheme, and that there are effective links between an NDIS and mainstream services, like health, employment and education.

Sector development

A key challenge in developing and implementing an NDIS will be making sure the disability services sector is equipped to meet the individual and diverse needs of people with disability.

The PC proposed that an NDIS should take a market-based approach to disability services to give people with disability the greatest possible choice of supports. The Select Council is considering how to maximise the benefits of a market-based approach to disability services to foster competition and choice. This includes considering how to recognise and enhance the significant role of the not-for-profit and private sectors under an NDIS, and how to make sure the development of the disability services sector is actively supported in a way that fosters continuous improvement, innovation, viability and sustainability.

The Select Council is also developing a national quality and safeguards framework to make sure people with disability receive high quality supports and services, and a national workforce strategy to make sure there is a skilled and responsive workforce to meet the care and support needs of people with disability.

Governments also recognise that an NDIS should be designed to make sure that people with disability are supported to participate in and contribute to social and economic life, including through improved linkages with community and mainstream services. Governments are considering the role of community and mainstream services, such as health, education and employment services, in supporting an NDIS. The National Disability Strategy will continue to have an important role to play in ensuring people with disability are able to access the supports they need in the community.

NDIS transition agency

The Commonwealth will establish a launch transition agency from July 2012 to coordinate the detailed design work for a launch of the scheme. Guided by the Select Council's decisions on policy and design, the agency will develop a practical plan to implement this significant reform. The Head of the Agency will report to the Select Council on Disability Reform on progress with launch design and preparedness. The Select Council remains responsible for NDIS policy, including development of options for funding, governance and scheme design, for consideration by COAG.

The Commonwealth has also dedicated ten million dollars for the NDIS Practical Design Fund for projects that will help to inform the development of the NDIS and prepare people with disability and their carers, the disability sector and workforce for its implementation. This Fund is currently being developed, with projects expected to commence later in 2012. This Fund will support organisations to undertake work which will both contribute to the development of an NDIS, as well as helping to prepare disability sector organisations and people with disability and their carers for significant change in the sector. The Fund is centred on research and learning for practical purposes. Projects will identify an issue or challenge which could affect the disability sector, workforce or people with disability and their carers as the NDIS is developed and implemented.

Conclusion

The PC's report into disability care and support was the result of extensive consultation.

Governments have a lot of work ahead to design a scheme. What's clear is that decisions cannot be made without working with people with disability, their families and carers and with the disability services sector. People with disability know what works, what doesn't and what's important.

Over the coming months, there will be several opportunities for people with disability, their families and carers to give their views on the issues covered by this progress report and about some of the big questions on the design of the scheme. The Advisory Group will work closely with government and key stakeholders and will provide opportunities for community engagement throughout 2012. A number of expert groups will also be formed to assist with the technical work needed to design and implement the scheme.

If you want to be part of the process, watch out for updates on the NDIS website - www.ndis.gov.au

Eligibility and reasonable and necessary support

At its meeting on 25 July 2012 the Council of Australian Governments (COAG) discussed a National Disability Insurance Scheme (NDIS) and proposals from the Select Council on Disability Reform for how eligibility and reasonable and necessary support under an NDIS might be defined. The Select Council's proposals built on the work of the Productivity Commission and were developed to describe in more detail how the scheme might work in practice.

As it stated in the communiqué from its meeting on 25 July 2012, COAG wanted people with disability, their families and carers, the workforce and disability sector and peak bodies to have a chance to comment on the proposed approach to eligibility and reasonable and necessary support under an NDIS. Your feedback will help identify if the statements make sense, or if they need to be changed before they are finalised.

This document has been produced to support this process. It outlines what the Productivity Commission said about eligibility and reasonable and necessary support, the proposed draft definitions, and poses questions which readers might find useful to focus their feedback.

Process

To ensure that your feedback is considered in the further development of these descriptions your response is required by **COB 28 September 2012**.

You can provide feedback via

- your state/territory based NDIS Advisory/Reference Groups;
- the National Disability and Carer Alliance Engagement project;
- the NDIS 'Your Say' online forum (www.ndis.gov.au); or
- NDISenquiries@fahcsia.gov.au

Feedback

Feedback will be used to refine these statements before they are finalised and turned into the laws, information materials, policies and practices that will be needed to start an NDIS in 2013.

A summary of the engagement outcomes, including stakeholder feedback will be made publicly available on the NDIS website at www.ndis.gov.au. There will be further opportunities for engagement on NDIS design including through the 'Your Say' online forum, ongoing work of the Commonwealth and State based Advisory Groups and the Alliance Engagement Project.

A schedule of NDIS engagement activity will be publicly available on the NDIS website.

Eligibility

The Productivity Commission's report into disability care and support has provided a starting point for Governments to design an NDIS.

What the Productivity Commission said on eligibility

The Productivity Commission's report proposed that all Australians would be covered by an NDIS should they require support from the scheme.

In one sense, the NDIS is for all Australians, since it would provide insurance against the costs of support in the event that they, or a family member, acquire a significant disability. (Productivity Commission Overview page 10)

In the Productivity Commission's terms one of the crucial benefits of an NDIS is that everyone is covered for the costs of long-term disability care and support, so people without a disability could feel confident that they or their families would be supported in the event of a significant disability (Productivity Commission Overview page 11).

Why eligibility for the scheme needs to be defined

An NDIS will be administered using an insurance approach to manage the life time costs of care and support in a financially sustainable way, and will share the costs of disability services and supports across the community. The scheme needs to ensure that support is well targeted so the scheme can be affordable and viable in the long-term.

Like other insurance schemes, such as existing transport accident insurance schemes, an NDIS needs clear criteria about who is eligible to receive support from the scheme. This is so the community can understand what to expect from an NDIS, and so the new NDIS Launch Transition Agency's decisions on who is able to receive support from the scheme are equitable, transparent and rigorous.

Factors to consider in defining eligibility

The Productivity Commission approach to describing who would receive support under an NDIS included consideration of the following factors:

- Residence;
- age;
- whether someone is affected by disability;
- the permanence of the disability;
- the impact of the disability on functioning; whether the person's needs are best addressed in other systems; and
- the need for significant ongoing support.

Each of these factors is important to eligibility for an NDIS in different ways.

- Residence means whether or not someone is an Australian citizen or a permanent resident in Australia. Most similar government schemes are available to Australian

citizens or permanent residents. There are approximately 22.7 million permanent residents/citizens in Australia.

- Age is important in determining eligibility because an NDIS is not intended to duplicate other service systems, such as the aged care system. The Productivity Commission proposed that an NDIS would be for people who have or acquire a disability before 65 years of age. The Productivity Commission further proposed that people who acquire their disability after age 65 will not be able to enter the scheme, but will instead be assisted by the aged care system. There are approximately 19.7 million people under 65 years of age.
- As an NDIS will support people with disability, the eligibility criteria need to identify the person's disability, for example from an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination of impairments.
- Since an NDIS is intended to provide long-term support, the eligibility criteria would need to consider whether the disability is permanent, or likely to be permanent. This includes impairments that are episodic, such as psychiatric impairments, where the level of impairment and support may vary but will be long term. There are approximately 2.6 million people with permanent disability under 65 years of age.
- There are approximately 992,000 people who are under 65 years of age, who have permanent disability, and who need assistance with mobility, self-care, communication and/or cognition.
- Not everyone who has a permanent disability and reduced functional capacity needs support through an individually funded package. Some will be supported through referral to mainstream services, disability support programs or be provided with a one off individually funded package. There are about 583,000 people that will be supported by the NDIS either with or without a funded package.
- People with a permanent disability who need assistance for activities such as getting into and out of bed, moving around in the community, caring for themselves, communicating and being able to manage their health and finances would be eligible for a individually funded package. There are about 410,000 people with permanent disability and severe functional limitation who will require development of an individual plan that includes a funded package which may include early intervention services where there is evidence that the intervention will improve their outcomes.

The draft eligibility statement

The Select Council has used the Productivity Commission's approach to eligibility to develop a working description of who would be eligible for the scheme. This will form the basis of further work on how the scheme would operate in practice and how eligibility criteria would be reflected in legislation, regulations or guidelines.

People with disability are in scope to receive support funded under an NDIS if:

1. *The individual resides in Australia and is:*
 - a. *an Australian citizen; or*

- b. *the holder of a permanent residency visa; or*
- c. *a New Zealand citizen who was an Australia resident on 26 February 2001 (SCV holder); and*
- 2. *The individual is less than 65 years of age on entry to an NDIS¹; and*
- 3. *The individual has a disability that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination of impairments; or is a child with a global developmental delay²; and*
- 4. *The impairment/s:*
 - a. *is permanent or likely to be permanent; and*
 - b. *results in a substantially reduced functional capacity of the individual to undertake activities of daily living; and*
 - c. *impacts on the individual's participation in the community or employment; and*
 - d. *may be of a chronic episodic nature and result in the need for ongoing or long term episodic support; and*
- 5. *The support needs will persist for the foreseeable future and are not more appropriately met by other systems including education, health and/or palliative care.*

This description of eligibility would identify the people who are potentially entitled to receive support under an NDIS. It is likely the scheme will use a needs assessment process to consider the severity of the person's activity limitation and the intensity of their support needs to determine the level of support that is provided.

Funded support under an NDIS would be for people where a needs assessment indicates that the severity of their disability impacts on their ability to do normal day-to-day activities, and means that they need support. This could be as simple as getting help with a piece of equipment, such as a device to help someone with a vision impairment get access to information, and training to use the device. In addition, there are a group of people whose disability has a severe impact on their lives, and for whom the intensity of their support

¹ Schedule F, part 6, of the National Health Reform Agreement (except in Victoria and Western Australia), details that the Commonwealth is responsible for:

- a. regulating packaged community and residential aged care delivered under Commonwealth aged care programs;
- b. funding packaged community and residential aged care delivered under Commonwealth aged care programs for people aged 65 years and over (50 years and over for Indigenous Australians);
- c. funding and regulating basic community care services for people aged 65 years and over (50 years and over for Indigenous Australians); and
- d. funding specialist disability services delivered by the States in accordance with their responsibilities under the National Disability Agreement for people aged 65 years and over and 50 years and over for Indigenous Australians.

In Victoria, health and aged care services for people over the age of 65 are jointly funded by the Commonwealth and Victorian Governments, and administered by the Victorian Government.

² 'Global developmental delay' means a delay in a child's development (that is slower than other children of the same age) in the majority of areas of development. That is, movement, manipulating objects, speech and language, understanding and learning, and social skills.

needs means that they require an individually tailored, funded support package of supports. The Productivity Commission estimated that about 410,000 people have a permanent disability and need assistance with activities of daily living that are not best addressed in another system, and whose reasonable and necessary support needs include an individually tailored, funded support package.

The statement is intended to include people with severe and permanent (or likely to be permanent) psychiatric disability with significant, long-term continuous or episodic support needs who require assistance in order to participate in the community. An NDIS would provide non-clinical support (such as assistance with planning and decision making) but responsibility for clinical interventions would remain with the mental health sector.

Focus questions

Governments are seeking feedback from people with disability, their families and carers, the workforce and disability sector and peak bodies about the description of eligibility that has been developed by the Select Council. This feedback will be used to inform the final approach to eligibility to be agreed by COAG. You are welcome to provide general comments, and/or to respond to the example questions below:

1. Does this description of eligibility cover all the things that you think a National Disability Insurance Scheme would need to know about you to determine whether you should be eligible to receive support under an NDIS?
2. Are there additional questions that an NDIS should ask people before deciding if they are eligible to receive support?

Reasonable and Necessary Support

What the Productivity Commission said on reasonable and necessary support

The concept of 'reasonable and necessary' support was used by the Productivity Commission to describe what support people could expect from a National Disability Insurance Scheme. The Productivity Commission argued that

A key point of distinction between existing arrangements and those proposed under a National Disability Insurance Scheme (NDIS) would be the obligation for the scheme to deliver the package determined by the independent assessment of need, rather than the present arbitrarily rationed amount. This feature is an essential element of avoiding the chronic underfunding that has beset the current disability system. However, that does not mean that the provision of supports will be unconstrained. Indeed, in other, better resourced schemes – such as no-fault accident insurance schemes that provide lifetime care and support for catastrophic

injuries – service provision is ‘bounded’ by the concept of reasonable and necessary. (Productivity Commission, page 257)

Why a statement of reasonable and necessary supports is needed

A clear statement of what ‘reasonable and necessary support’ means is needed so that the community can understand what to expect from an NDIS, and so that decisions by the NDIS Launch Transition Agency are equitable, transparent, and rigorous. As it works with people with a disability, the NDIS Launch Transition Agency will have to make consistent decisions about what support people will get under an NDIS. These decisions will need to balance what support is ‘necessary’ to address the impact of a person’s disability on their participation in the community or employment, and what is ‘reasonable’ taking into consideration factors such as cost effectiveness, value for money of the support, efficacy of the support and relevant community standards (such as the expectation that everyone should have access to support for personal care if they need it, and community expectations about what is reasonable to ask from carers and families).

Factors to consider in defining reasonable and necessary supports

The Productivity Commission approach to describing what would be ‘reasonable and necessary’ included consideration of the following factors:

- The benefit to the participant;
- The appropriateness of the support or service request;
- The appropriateness of the provider;
- Cost effectiveness considerations; and
- Whether the support or service would be most appropriately provided through an NDIS.

The Select Council has used the Productivity Commission’s approach to develop a working description of reasonable and necessary support would form the basis of further work on how the scheme would work in practice and how eligibility criteria would be reflected in legislation, regulations or guidelines.

Reasonable and necessary supports:

- a. are designed to support the individual to achieve their goals and maximise their independence;*
- b. support the individual’s capacity to undertake activities of daily living to enable them to participate in the community and/or employment;*
- c. are effective, and evidence informed;*
- d. are value for money;*

- e. *reflect community expectations, including what is realistic to expect from the individual, families and carers; and*
- f. *are best provided through an NDIS and are not more appropriately provided through other systems of service delivery and support, including services that are offered by mainstream agencies as a part of its universal service obligation to all citizens.*

It is important to note that an NDIS would not be responsible for providing support that is more appropriately provided through the health, education, employment, housing, transport, and income support systems.

- People who require primary care and hospital (inpatient and outpatient) based services and medical and pharmaceutical products will continue to receive these services from the health system. People who require palliative, or end of life care will receive assistance from that system rather than funded assistance from an NDIS.
- Students who require 'reasonable adjustments' to participate in education, such as structural modifications for buildings to ensure better accessibility, aids and appliances to increase educational opportunity, and teacher aides should have those needs met through the education system. However, an NDIS would have a role in meeting some of the needs of students, such as aids, appliances and services that would be needed regardless of whether a person was attending school or not (e.g. personal attendant care or a wheelchair).

An NDIS would also have a role in connecting people with support needs which are more appropriately met by other systems, such as the health, palliative care, aged care, employment, public housing or education systems. Referrals between systems should maximise outcomes for people and should be as seamless as possible.

Focus questions

Governments are seeking feedback from people with disability, their families and carers, the workforce and disability sector and peak bodies about the description of reasonable and necessary support that has been developed by the Select Council. This feedback will be used to inform the final approach to reasonable and necessary support to be agreed by COAG. You are welcome to provide general comments, and/or to respond to the example questions below:

1. Are there supports that you think are important to include in an NDIS that would be excluded by this description?
2. Are there additional points that are needed to make sure that the support provided under an NDIS meets the reasonable and necessary support needs of people with disability?

3. Does this description of reasonable and necessary supports, combined with the eligibility statement, help you to understand who will be supported in an NDIS and what supports might be provided to them? If not, how do you suggest that the description be made clearer?

The NDIS Advisory Group

The NDIS Advisory Group was announced by the Prime Minister on 10 August 2011.

The Advisory Group has helped steer the development of the NDIS by providing advice on progress with the foundation reforms required to improve the system of care and support for Australians with disability and their carers. The Advisory Group has worked closely with all governments and brings together a wealth of knowledge about the experience of people with a disability and carers and the challenges for the service sector and government administration. Some States and Territories also established advisory groups.

The Advisory Group includes people with expertise in social insurance principles, disability policy, service provision, performance monitoring, training and curriculum development, academia and research, psychological and intellectual disability, indigenous disability services, young people and children with disability.

The members of the Advisory Group are Dr Jeff Harmer AO, Dr Ken Baker, Mr Bruce Bonyhady AM, Dr Rhonda Galbally AO, Dr Lorna Hallahan, Ms Joan McKenna-Kerr, and Ms Fran Vicary.

NDIS expert groups

National Disability Insurance Scheme (NDIS) expert groups were established in May 2012 to help the Australian Government design a scheme that meets the lifetime care and support needs of people with significant and permanent disability.

The expert groups work under the NDIS Advisory Group and advise on the design of key elements of the scheme including eligibility and assessment, quality safeguards and standards, a national approach to choice and control for people with disability and workforce and sector capacity.

The expert groups include people with disability, their carers, advocates, service providers and other sector experts and bring a wealth of knowledge and experience to help people with disability, their families and carers, and the disability service sector, get ready for this change and to make sure the scheme works for them.

The NDIS expert groups have met regularly since their establishment on 30 May 2012. Some key outcomes include:

- the National Approach to Choice and Control Expert Group has provided advice on high level scheme design, the development of the Launch Transition Agency to officials and the consultancy work on a control and choice policy framework;
- the Eligibility and Assessment Expert Group provided advice on the role of the assessment in goal based planning, high level scheme design, the development of the Launch Transition Agency to officials and provided input to the 'Eligibility' and 'Reasonable and Necessary Support' engagement materials;

- the Workforce and Sector Capacity Expert Group provided a paper to the Advisory Group, “A Sustainable Workforce Strategy for the NDIS” which provided an analytical framework for progressing work on a sustainable workforce to support the NDIS roll out. In addition the Expert Group met with people with disability who are managing individual packages on the workforce implications.
- the Quality, Safeguards and Standards Expert Group have met with additional experts from across the country, including people with expertise in advocacy; the law; and people with lived experience of disability. These discussions have informed a paper on the key principles and recommendations to be considered in the development of policy and legislation for an NDIS, which has been prepared by the Expert Group.

National Approach to Control and Choice

- Jeff Harmer, NDIS Advisory Group (co-chair)
- Fran Vicary, NDIS Advisory Group (co-chair)
- Robbi Williams, Julia Farr Association
- Kirsten Deane, National Disability and Carers Alliance
- Lesley Hall, Australian Federation of Disability Organisations
- Sally McManus, Australian Services Union
- Samantha Jenkinson, National People with Disability and Carers Council
- Ara Cresswell, Carers Australia
- Vicki O’Halloran, Somerville Community Services Darwin
- Daniel Leighton, Inclusion Melbourne

Eligibility and Assessment

- Rhonda Galbally, NDIS Advisory Group (co-chair)
- Joan McKenna-Kerr, NDIS Advisory Group (co-chair)
- Ros Madden, University of Sydney
- Janet Dore, Transport Accident Commission
- Robbi Williams, Julia Farr Association
- Tim Moore, Carers Australia
- Graeme Innes, Australia’s Disability Discrimination Commissioner
- Frank Quinlan, Mental Health Council of Australia
- Suzanne Lulham, New South Wales Lifetime Care and Support Authority
- Lesley Hall, Australian Federation of Disability Organisations

Quality, Safeguards and Standards

- Lorna Hallahan, NDIS Advisory Group (co-chair)
- Bruce Bonyhady, NDIS Advisory Group (co-chair)
- Stephanie Gotlib, Children with Disability Australia
- Margaret Reynolds, University of Tasmania
- Marita Walker, Perth Homecare
- Sally Robinson, Southern Cross University
- Kevin Cocks, Queensland Anti-Discrimination Commissioner
- Kelly Shay, United Voice

Disability Workforce and Sector Capacity

- Ken Baker, National Disability Services (co-chair)
- Rhonda Galbally, National People with Disabilities and Carer Council (co-chair)
- Sally McManus, Australian Service Union
- Gordon Duff, National Disability Services
- Damian Griffis, First Peoples Disability Network
- David Barbagallo, Endeavour Foundation
- Sue Lines, United Voice
- Samantha Connor, CY O'Connor Institute
- David Meldrum, Mental Illness Fellowship of Australia
- Kim Windsor

Acknowledgements

We are very grateful to the people who participated in the consultation process and gave their time and expertise to produce outstanding quality input. We also particularly want to acknowledge FaHCSIA for funding and supporting every stage of this important project.

November 2012

Contents

The report is structured around seven key NDIS themes, identified by the Alliance and FaHCSIA prior to the consultations:

- Assessment and Eligibility
- Supports
- Review & Complaints
- Involvement of people with disability and carers in the design and implementation of the NDIS
- Planning
- Control and Choice
- Innovation

Issues Raised

The findings in this document are the outcomes of 77 Alliance NDIS consultations held in the second half of 2012. The consultations involved 2,056 people in 55 forums and 22 face to face and teleconference meetings held across every state and territory in Australia.

The issues raised in this report are high level overviews only and are a compilation of the common themes raised in all the consultations to date. The report provides a single and united voice for people with disabilities, families and carers and service providers. Issues that were raised or emphasised by any single group (people with disabilities, families, carers or service providers) were captured separately in the individual consultation reports provided to FaHCSIA.

A Single Voice: the National Disability and Carer Alliance

The National Disability and Carer Alliance (the Alliance) was formed in 2009 by the Australian Federation of Disability Organisations, Carers Australia and National Disability Services to pursue the structural and systemic changes necessary to transform the lives of people with a disability, their families and carers in this country.

Further Information

Any further detail or clarification required on any issue can be obtained by contacting the Alliance Community Engagement Manager, Roland Naufal

National Disability Insurance Scheme

Universal Support

It is difficult to overstate the level of support provided in the public forums for both the concept and the intent of the NDIS. The 2,056 people engaged in the consultations provided overwhelming support for the NDIS and widespread enthusiasm for its implementation.

NDIS Outcome

The increase in funding for the NDIS needs to result in a radical overhaul of the existing disability service system to person centred outcomes that integrate people with a disability. The NDIS must not just support growth in the current system.

Greater Recognition

There needs to be greater recognition of people with high levels of sensory or cognitive impairments or very low literacy skills in the design of the NDIS. It is expected that this will apply to over 50% of people in Tier 3.

Communication

People need useful, up-to-date information available in a variety of accessible formats. Information must be available through a variety of entry points (not just the internet) and should be available locally. Language is important, it needs to be accessible and in plain English where possible. The use of an Internet hub to promote information collection and dissemination requires further consideration.

Assessment & Eligibility

Assessment Focus	Assessment should be individualised, flexible, collaborative, respectful and responsive.
Assessment Focus	Assessment should be goal oriented and based on function rather than just medical diagnosis.
Assessment Focus	The process must be holistic and take a whole of life focus. The assessment will often need to incorporate the impact of disability on the wider family and linkages between the NDIS and other systems of support.
Eligibility	Eligibility: 410,000 people, <i>is it right, is it enough?</i> Participants expressed a concern that NDIS eligibility would continue a situation of competition for resources for those left outside of the scheme.
Eligibility	Concerns were raised by a large number of participants about the impact of the proposed 65+ age cap. Concerns were also raised about the intersection between the NDIS and the aged care system, and how people were going to shift between the two systems without losing vital supports. Issues raised included the willingness, capacity and capability of the aged system to adequately support people with a disability, carers and families.
Assessment Process	The assessors will need the attitudes, skills and experience (strengthened by lived experience) to embrace diversity in all its forms including: disability types, carer and family needs, cultural variations, gender, sexuality and geographic disadvantage. Assessors need to be experienced with, and knowledgeable about, people with a disability. They should get to know the person with disability: who they are and what they require.
Assessment Process	Reassessment should be timely, but only as required and available on request.
Assessment Process	<i>A one stop shop</i> approach to assessment is desired.
Assessment Process	Using and sharing of existing information about individuals was strongly supported (electronically) but the information must be owned and controlled by the person with disability.

Assessment Process

Episodic issues pose particular concerns; where disabling conditions can become more, then less, severe.

Assessment & Eligibility ctd

Assessment Process

The system will need to recognise the complex and inter-dependant dynamics of disability, family and community. Transformation is required from the current approach where people with a disability are often viewed as a burden. It will be important to allow flexibility in key rules/approaches to recognise this complexity and for the system to develop over time. Approaches developed need to:

- Be person centred
- Acknowledge families of children require support until and during a child's transition to adulthood
- Adults with a disability will need to be supported to have independent assessments with an empowerment approach
- We need to ensure the endpoint of assessment is a single integrated package of support.

Supports

Support Focus Support services should promote inclusion and support the person with a disability being valued in their community and as independent as possible.

Support Focus Value for money should be defined in a *long term outcomes* framework.

Infrastructure Infrastructure funding in the insurance system is a concern: *where will the funding come for infrastructure required by service providers, community, society and to service Tier 2 clients?*

Infrastructure How will accommodation be funded?

Service Range *We do not want lists of things we can and cannot have.* People want flexible responses that best meet the needs of people with disabilities, families and carers. However, a substantive connection between the plan and funded service needs to be made.

Service Range Many people want accessible, flexible, quality and affordable family support (often calling it “respite”) but do not know how this will be funded in the NDIS.

Support Systems There is concern about the extra NDIS funding causing demand driven inflation for goods and services. However, there is widespread acknowledgement that the system needs to pay support workers better.

Support Systems There was a strong support for a tribunal or independent arbitrators if there is a disagreement about what is *reasonable and necessary*. People will need to be well informed about, and supported in, this process to ensure their rights are respected.

Support Systems Many suggested a worker database system, so that appropriate staff could be sourced from a central electronic register.

Support Systems

Workforce development is essential: from professional development to improved retention and recruitment.

Supports ctd.

Particular
Emphasis

Services will need to take into account the differing needs of the full diversity of people with a disability, their families and carers including diversity in disability types, cultural variations, gender, sexuality and geographic disadvantage.

Particular
Emphasis

Rural and remote limitations cause many barriers including the concern that the market will not provide adequate services to people with diverse needs in rural and remote locations. There needs to be greater allowance for the increased costs of disability supports in regional and remote areas and recognition of the increased travel times to access services.

Particular
Emphasis

Key transitions are often where systems fail people with disabilities and transitions are often when people need most assistance: eg into school, adolescence, into and out of employment, ageing and for ageing carers.

Review and Complaints

Review Focus Individualised: The reviews and complaints system must focus on individual issues, needs and outcomes.

Review Process Independent: A review body completely independent from the funding agency is seen as essential.

Review Process Timely: Issues need to be dealt with in a timely manner.

Review Process Supported: Some people will need independent support to use the review process perhaps including a system of lay advocates.

Review Process Enforceable: The system needs the ability to enforce its rulings.

Review Process Accessible: The process needs to at no cost, without lawyers, be welcoming with a variety of venues for hearings. The process and results need to be widely publicised.

Review Process Transparent: The process requires a defined framework including: *how to use it* and *what to expect*.

Review Process Feedback: The process will need to include a process to ensure systems change based on feedback for all parties based on learnings from reviews and complaints.

Involvement

Involvement of people with disability and carers in the design and implementation of the NDIS

Involvement Focus	<i>Nothing about me without me</i>
Involvement Focus	People with lived experience are essential at all levels to the NDIS system with an affirmative action approach required to employ staff with lived experience at all levels. All people employed need to operate within the value base of the NDIS with a focus on community participation.
Capacity Building	Education and resources are required to build the capacity of people with disability and carers to participate in key decision making processes.
Resourcing Involvement	Agencies and organisations need to actively support people with disability and carers to be actively involved in the design and implementation of NDIS. This requires provision of transport support, family support and central, accessible venues.
Local Networks	It is vital the NDIS not be driven from the top down. The importance of local networks as a building block of involvement is central to success.
Existing Networks	Involvement will be enhanced if the system embraces existing organisations that already involve people with disabilities, families and carers in decision making.
Tailored Engagement	People with disabilities, families and carers must choose their own level of engagement with the system.
Ongoing Engagement	The ongoing funding of broader processes of engagement and consultation of people with disabilities, families and carers is required. A range of mechanisms are needed that are more inclusive than just an advisory group; all stakeholders should be encouraged to provide feedback. A shift is required in current organisational and community culture towards a broad culture of inclusion and involvement.
Transition Support	There should be independently facilitated user groups in each launch site giving feedback every month as the NDIS rolls out. Separate opportunities are needed for people with disability, carers and service providers to input. These groups would also be useful forums to share information and experiences between peers.

Service Providers

The NDIS also needs to support the capacity building and ongoing engagement of disability service providers in the design and implementation of the NDIS.

Planning

Planning Focus *Person centred collaboration amongst equals.*

Planning Focus Individual planning should be based on choice, goals and aspirations. Planning should focus on barriers, not individual dysfunction. Planning must be positive.

Planning Focus People with disability must own the planning process. However, families and carers also have needs and aspirations that need to be acknowledged.

Planning Focus The planning process should be rights based and person centred.

Planning Focus Planning should be based on life domains (eg social, physical, economic, educational).

Planning Focus Planning should focus on early intervention; the early application of supports at all ages.

Planning Systems People with disabilities, families and carers should have a choice about who assists them in planning. Peer support in planning is important to many.

Planning Systems Capacity building for people with a disability, families, carers, service providers, community and systems is required to facilitate better planning at all levels.

Planning Systems Feedback and evaluation of outcomes is required at the individual and systems levels.

Planning Systems Good tools and resources need to be developed to facilitate planning.

Planning Systems Planning should be based on developing flexible pathways for the individual.

Planning ctd

Particular Emphasis	Significant attention is required to ensure there is no disadvantage for individuals in the transition from current funding systems to the NDIS.
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Particular Emphasis	Planning for complex support needs is currently inadequate and will require additional support and resources.
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Particular Emphasis	The interface of the NDIS with the justice system requires particular attention.
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Particular Emphasis	Planning for people with multiple disabilities is currently inadequate and will require additional support and resources.
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Communication	Information about planning will be required in diverse formats and mediums. Attention to the processes of collection and dissemination of information is essential.
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Emergency Planning	How will the system have the capacity and flexibility to respond to crisis & emergency?
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Control and Choice

NDIS Aspirations	The NDIS should support people with disability to pursue the same options as everyone else in the community.
NDIS Aspirations	The NDIS should have a human rights, entitlement basis underpinned by the UN Convention on the Rights of People with a Disability with a particular emphasis on Article 19: <i>Living independently and being included in the community.</i>
Individual Aspirations	There may be a difference between community expectations (often low) and the aspirations and hopes of people with disability. The concept of choice should include the notion of dignity of risk; allowing people to take positive risks in their lives.
Advocacy	Independent, individual and systemic advocacy is needed to support control and choice and must include the lived experience of people with disabilities, families and carers.
Capacity Building	Education and support is required to exercise control and choice, many people have not experienced the ability to make choices.
Capacity Building	Enhanced support is required for people with limited decision making abilities to be able to exercise control and choice. People need access to supported decision making processes.
Flexibility	People with disabilities, families and carers want as much flexibility as possible over spending decisions in their individual budgets. However, there needs to be appropriate, but not excessive, accountability for how funding is spent.
Workforce	Many individuals, carers and families want to be employers, many do not.
Workforce	The quality of staff people with a disability are able to employ is mission critical to the enactment of control and choice.
Market Concerns	There are many concerns over the vulnerability of some people with disability in a market based system and how the market will operate in areas that provide few incentives; safeguards are required.

Innovation

Focus	People with disability should be in the driver's seat when it comes to innovation. <i>They should be asked what they want to do with their lives; that's what should bring about change.</i>
R&D	Innovation should be informed by data collection and research and that data should be widely available
R&D	It is important for the NDIS to invest in research and foster academic links and draw on other the experience of other sectors.
R&D	Look overseas for innovative models. <i>Are others doing it better? If they can do it, why can't we?</i>
Process	Ongoing forums that foster dialogue about innovation are required between people with disabilities, families, carers, service providers, government and businesses.
Process	Seed money is required to foster innovation. Expect failures, learn from experience.

National Disability Insurance Scheme Rules Consultation Paper

Introduction

What is the National Disability Insurance Scheme?

The National Disability Insurance Scheme (NDIS) will transform the way disability services are provided in Australia.

The NDIS will provide eligible people with disability with the reasonable and necessary support that they need. It will give all Australians the peace of mind to know that if they have or acquire a disability that means they need care and support in everyday life, or if they would benefit from early intervention support or therapies, they will receive that assistance.

The NDIS will start in launch locations before being rolled out more broadly. The first stage of an NDIS will commence from July 2013 in launch sites in South Australia, Tasmania, the Hunter launch area in NSW and the Barwon area of Victoria. The Australian Capital Territory will commence in July 2014. This approach will ensure that the implementation of the scheme is informed by feedback from people with disability, their families and carers, and service providers and community organisations and by the lessons of launch.

The National Disability Insurance Scheme Launch Transition Agency (the Agency) will be established by the National Disability Insurance Scheme Bill (the Bill) to deliver the first stage of the scheme. The Agency will also carry out a range of functions including developing the community sector, building disability awareness, and undertaking research.

The NDIS Bill

The National Disability Insurance Scheme Bill 2012 (the Bill) was introduced into the Australian Parliament in November 2012.

The legislation sets up the legal framework for the establishment and operation of the NDIS and the Agency. When passed by the Parliament, the Bill will enable the scheme to be launched in five sites from July 2013.

Key matters covered by the Bill include:

- the establishment of the Agency to administer the NDIS launch, including a Board and Advisory Council;
- the principles and objects on which the scheme is based;

- how people can become participants;
- the personal planning process that enables people to identify what they need and to choose the type of supports and services they use, who provides them, and how they are designed and provided;
- arrangements to enable people to purchase their own supports if they wish;
- circumstances and processes to support or substitute decision making where needed;
- registration of providers of services;
- treatment of compensation payments;
- the provision and protection of personal information; and
- a process to review decisions.

The Senate Committee on Community Affairs is currently inquiring into the Bill, and Commonwealth, State and Territory Governments are continuing to work through the detail of the Bill. Amendments could be introduced to the Bill before it is voted on by the Australian Parliament.

Copies of the legislation and the explanatory memorandum are available at the [Australian Parliament House website](http://www.aph.gov.au) at www.aph.gov.au. An easy English version of an overview of the Bill is also available on the [NDIS website](http://www.ndis.gov.au) at: www.ndis.gov.au.

About this paper

The NDIS Bill sets up the framework for the scheme. Further detail on the way the scheme operates will be set out in legislative instruments known as the NDIS Rules.

The purpose of this paper is to explain what is intended to be covered in the NDIS rules and to give people an opportunity to provide feedback. Details on how to provide feedback on the paper are set out in the last section of the paper.

The principles of the NDIS

The objects and principles explain what the legislation is intended to achieve and how it is to be achieved.

The NDIS rules must also reflect these objects and principles.

The objectives of the NDIS as outlined in the Bill (Clause 3)

The objects of this Act are to:

- (a) provide for the National Disability Insurance Scheme in Australia; and
 - (b) support the independence and social and economic participation of people with disability; and
 - (c) provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and
 - (d) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and
 - (e) facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and
 - (f) promote the provision of high quality and innovative supports to people with disability; and
 - (g) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability; and
 - (h) give effect to certain obligations that Australia has as a party to the Convention on the Rights of Persons with Disabilities.
- (2) These objects are to be achieved by:
- (a) providing the foundation for governments to work together to develop and implement the National Disability Insurance Scheme launch; and
 - (b) adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability.
- (3) In giving effect to the objects of the Act, regard is to be had to:
- (a) the progressive implementation of the National Disability Insurance Scheme; and
 - (b) the need to ensure the financial sustainability of the National Disability Insurance Scheme.

Choice and control for people with disability is central to the NDIS. This means that in the NDIS, people with disability have the right to make their own decisions about things like:

- the type of supports and services they use;
- who provides them;
- how they are designed and provided; and
- how supports are able to be managed; and
- how their funding is managed.

General principles of the NDIS as outlined in the Bill (Clause 4)

- 1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.
- 2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.
- 3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.
- 4) People with disability should be enabled to exercise choice and control over the purpose, planning and delivery of their supports.
- 5) People with disability should be enabled to obtain access to reasonable and necessary supports, including early intervention.
- 6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect or exploitation.
- 7) People with disability have the same right as other members of Australian society to pursue any grievance.
- 8) People with disability should be able to determine their own best interests, exercise informed choice and engage as equal partners in decisions that will affect their lives, to the fullest extent of their capacity.
- 9) People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise control and choice is maximised in a way that is appropriate to their circumstances.
- 10) People with disability should have their privacy and dignity respected.

- 11) Reasonable and necessary supports for people with disability should:
 - (a) address the effect of an impairment or impairments on their capacity to undertake everyday activities, including by enabling them to participate in and contribute to social and economic life to the extent of their ability; and
 - (b) allow them to achieve their goals, objectives and aspirations, to the extent possible.
- 12) The vital role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and valued.
- 13) Access for people with disability to supports outside the NDIS, and assistance in the integration of such supports with the supports provided under the NDIS, should be facilitated.
- 14) Innovation, quality, continuous improvement and effectiveness in the provision of supports to people with disability are to be promoted.
- 15) It is the intention of the Parliament that the Ministerial Council, the Minister, the Board, the CEO and any other person or body is to perform functions and exercise powers under this Bill in accordance with these principles, having regard to:

- (a) the progressive implementation of the launch of the NDIS; and
- (b) the need to ensure the financial sustainability of the NDIS.

The different functions of the NDIS

The NDIS will provide eligible people with significant and permanent disability with the care and support they need in everyday life.

The NDIS will also perform other important functions. For some people with disability, the Agency will provide assistance by referring them to community based and mainstream organisations that can best support their needs.

The NDIS will provide all people with disability, their families and carers with information and referrals, raise community awareness of the issues that affect people with disability, and facilitate greater community inclusion of people with disability.

These roles mean that the Agency will be active in local communities. The Agency will actively foster community based supports for people with disability, and help them access and engage with mainstream and local services. It will do this through local area

coordination, which could include providing some funding to community based organisations which provide support that people with disability can access as they need it .

Another role for the Agency will be to ensure that people with support needs which are more appropriately met by other systems, are connected with those systems, such as the health, palliative care, aged care, employment, public housing or education systems. Referrals between systems will seek to support people in transition, maximise outcomes for people and be as seamless as possible.

The rules to be developed for this part of the Bill will guide the Agency's activities in local engagement, including what sort of information it will need to make available to people and how it does this, as well as more technical issues such as the conditions under which an organisation is funded to provide a service for people with disability.

Rule

1. The rule may prescribe matters for and in relation to this chapter (relating to the types of assistance for people with disability provided by the Agency). (Clause 17)

Questions

What sorts of general information and referral services should the Agency provide for people with disability who approach the NDIS?

What guidance should the rules provide the Agency about how to support people in referring them to community or mainstream supports, or to other support systems?

What guidance should the rules provide the Agency about funding of persons or organisations so that those persons or organisations may assist people with disability to realise their potential, and participate in, all areas of life

Becoming a participant

The legislation sets out the criteria which will be used to decide who will be eligible to receive support from the NDIS and become a *participant* of the scheme. This is to assist the community to understand what will or will not be covered by the NDIS, and why, and to ensure that the Agency's decision-making processes are equitable, transparent and rigorous.

Age requirements

Age is important in determining who will become a participant because the NDIS is not intended to duplicate other service systems such as the aged care system. Therefore people who need disability support for the first time after the age of 65 would have their needs met through the aged care system. However, people who receive support under the NDIS and turn 65 can choose to remain in the NDIS or move to the aged care system.

In addition to being under 65 when a request for support is made, there may be specific age requirements that must be met in some of the first launch sites that are targeted at particular age groups. For example, in South Australia, the scheme will target children, and in Tasmania, the scheme will work with young people between the ages of 15 and 24.

The rules for this section will need to set out the age requirements for participants in different launch sites.

Rule

2. Age requirements for specific locations within Australia during launch. Clause 22(1)(2)

Question

Should the rule also set out the types of information the Agency will need to establish that a person meets the age requirements?

Residence requirements

Australian citizens or permanent residents in Australia will be able to receive support from the NDIS. Once the scheme is fully implemented across the country, NDIS services will be fully portable within Australia.

During the first stage of implementing the scheme, participants will need to be living in the specific launch sites, such as in the Hunter area of New South Wales, or the Barwon area of Victoria, or South Australia. The Agency will need a simple way to confirm that a person who is applying to enter the scheme is a resident of one of these locations at launch. The rules will set out the length of time that a person needs to have lived in a particular place to meet this requirement and clearly define the boundaries of each launch site.

Rules

3. What alternative or additional criteria may be used to determine that someone is resident in a launch site. Clause 23(1)(c).
4. On what date or date in a time period should a person need to be living in a launch location to be considered a resident Clause 23(3)(a)
5. How long a person may need to have lived in a particular location to be considered a resident. Clause (23) (3)(b)
6. Whether a person needs to continue to live in a launch site to be considered a resident. Clause 23(3)(c)

Questions

What factors should be taken in to account in deciding whether a person meets the residence requirements? What types of evidence are appropriate to determine if a person meets the residence requirements?

What boundary issues between launch and non launch locations are likely to arise and how could these be resolved in developing the rules?

Continuity of support

In the transition to the new scheme, the legislation provides arrangements to ensure continuity of support for people currently receiving disability support in the launch sites. People who may not meet the NDIS eligibility requirements but are currently receiving regular disability support in launch sites will continue to receive support consistent with their currently agreed arrangements if the funding for this support is transferred – or phased out and funding redirected – to the NDIS in a launch site . This is so that the transition to the NDIS from existing disability service systems does not disadvantage people.

The NDIS rules will set out the specific programs where support will need to continue to be provided and how long a person will need to have been receiving that support to be eligible to become a participant in the NDIS. For example, each State or Territory with a launch site already provides specialist disability support to residents in that location. In some cases there might be people who have been receiving support through these programs who would not ordinarily meet the disability, residence or age requirements of the NDIS. If support is no longer available to a person because funding for a program is transferred to the NDIS, then the NDIS will continue to support that person.

Rule

7. The time period during which the previously existing supports need to have been received, and the programs under which the previously existing supports need to have been delivered, for a person to meet the access criteria and be eligible for the NDIS. Clause 21(2)(b)

Question

What factors should be considered in deciding whether the NDIS should provide continuity of support to someone who has been receiving assistance under other programs, but who would not otherwise be eligible for NDIS support?

Disability requirements

The NDIS is designed as a scheme to support people whose disability or impairment is or is likely to be permanent, and results in substantially reduced capacity to undertake day-to-day functioning including communication, social interaction, learning, mobility, self-care or self-management, or who will benefit from an early intervention approach (see Section 4.3) The NDIS Bill outlines a number of factors to be taken into account in determining whether a person meets the disability requirements to be eligible to access individually funded supports.

The disability requirements in the Bill (Clause 24)

- (a) The person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and
- (b) the impairment or impairments are, or are likely to be, permanent; and
- (c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:
 - (i) communication;
 - (ii) social interaction;
 - (iii) learning;
 - (iv) mobility;
 - (v) self care;
 - (vi) self management; and

- (d) the impairment or impairments affect the person's capacity for social and economic participation; and
- (e) the person's support needs in relation to his or her impairment or impairments are likely to continue for the person's lifetime.

This means that the rules must set out how the Agency will determine the factors or circumstances where impairments may be considered permanent, whether impairments result in substantially reduced functional capacity or psychosocial functioning, and the criteria to determine or circumstances where impairments may affect a person's social and economic participation. The criteria set out in the rules will be based on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF). As well, the rules may set out whether an individual who has an existing assessment relating to these disability requirements can use that assessment.

Rules

8. The criteria to be used to determine that the impairment or impairments are permanent or likely to be permanent. Clause 27(1)(a)
9. The criteria to be applied to determine that one or more impairments substantially reduce a person's functional capacity, or their psychosocial functioning, in relation to one or more activities such as communication, mobility, or self-care. Clause 27(1)(b)
10. The criteria to be considered in assessing whether and to what extent social and economic participation has been affected. Clause 27(1)(c)

Questions

What criteria/factors should be taken into account in determining whether a person meets the disability requirements?

Should there be any guidelines on people being able to provide existing assessments to meet the disability requirements?

What should be considered in developing a rule on the types of persons who should conduct assessments?

What should be considered in developing a rule on the kinds of assessments that could be provided or undertaken as part of meeting the disability requirements?

How can we make sure the rules determine disability on the basis of a functional assessment of what a person can or aspires to do, rather than on the basis of diagnosis?

Early intervention requirements

The legislation sets out the early intervention requirements that a person may satisfy as an alternative to satisfying the disability requirements described in Section 4.4. A person may not meet the disability requirements, but may still need support to help minimise the impact of a disability from its earliest manifestation. Through early intervention, the scheme is able to fund supports that help minimise the impact of a person's disability, help to improve their functioning or prevent the deterioration of their functional capacity over their lifetime, reduce the need for future support and build the sustainability of each individual's support network, particularly that of their immediate family.

Some examples of early intervention strategies include therapy to slow or delay the impact of degenerative conditions, investment in environmental supports that would allow a person to remain in their own home rather than be forced to move to a residential facility, or early childhood early intervention programs to address developmental delay.

The timing and duration of early intervention and the nature of interventions will be informed by the available evidence and depend on a range of factors including the individual's goals, the particular disability, the type of intervention and the individual's particular circumstances. The scheme will also be able to support innovative approaches which do not yet have a clear evidence-base, and which can be tested within the NDIS.

The rules will set out how the Agency to determine whether an early intervention, or a particular type of intervention is likely to be beneficial for an individual. The rules could set out, for example, that where there is evidence that if people can get help in the early stages of particular degenerative conditions to manage the impact of, say, a loss of function, then the NDIS would provide that support.

Rules

11. Criteria for determining if early intervention supports are likely to reduce a person's future need for supports in relation to disability. Clause 27(1)(d)
12. The criteria to be considered in assessing whether a support is likely to mitigate, alleviate or prevent of an individual's function capacity to undertake communication, social interaction, learning, mobility, self-care or self-management. Clause (27(1)(e)
13. Criteria for determining if early intervention supports are likely to strengthen the sustainability of the informal supports available to the participant, including through building the capacity of a carer. Clause 27(1)(f)

Questions

What criteria would be useful for considering the benefits of early intervention for mitigating or preventing deterioration in a person's functional capacity to undertake activities such as mobility, self-care or self-management?

How can the support provided by families and other carers be made more sustainable by early intervention?

How should the rules support innovative approaches to early intervention and balance this with the need to get the best outcomes for people with disability and for the scheme to be accountable and sustainable?

What criteria should be included in the rules to assist determining if an intervention strengthens the sustainability of informal support?

What criteria should be applied to determine 'evidence-based' assessment of the benefits of early intervention?

Participants' Plans

Once a person has met the age, residence, and disability or early intervention requirements, they become a participant in the NDIS. At the centre of the NDIS is an individual plan for each participant. This plan sets out a participant's support needs, as worked out through a planning process with the Agency. The plan will have two parts:

- the statement of goals and aspirations, which will be developed by each participant to set out their goals and objectives and personal circumstances; and
- the statement of supports, setting out any supports provided or funded by the Scheme, as well as any relevant informal or mainstream supports.

The legislation details how individuals will be able to develop their plans with the Agency, how the plans come into effect and how the plans are managed and reviewed. It also details how payments may be made and acquitted.

Importantly, the legislation works to make sure that the support for each person is designed specifically for them and that they have full opportunity to choose their supports and control their provision. The development of plans will be guided by the following principles:

Principles in the Bill (Clause 31) relating to participant plans

The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

- (a) be individualised; and
- (b) be directed by the participant; and
- (c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and
- (d) where possible, strengthen and build capacity of families and carers to support participants who are children; and
- (e) consider the availability to the participant of informal support and other support services generally available to any person in the community; and
- (f) support communities to respond to the individual goals and needs of participants; and
- (g) be underpinned by the right of the participant to exercise control over his or her own life; and

- (h) advance the inclusion and participation in the community of the participant with the aim of achieving his or her individual aspirations; and
- (i) maximise the choice and independence of the participant; and
- (j) facilitate tailored and flexible responses to the individual goals and needs of the participant; and
- (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.

The planning process will acknowledge the circumstances and goals of each individual with a disability. The process recognises that some people will approach the Agency with clear goals for their social and working life while other people may not have thought about their future in this way before. All participants will be able to ask for assistance from the Agency with the planning process. The Agency can also work with the participant to help build their capacity to design the supports that meet their preferences and to self-manage their package.

As part of the planning process, the NDIS will assess a person's support needs. These assessments will use a consistent set of tools for identifying a person's needs and any potential risk or need for safeguards. Where people already have existing assessments, including people who are already receiving disability supports under other systems, they may wish to provide those assessments to the Agency. Some people may not have relevant existing or previous assessments or may wish to test whether they should receive additional support.

Consideration of the participant's living arrangements and informal supports will reflect discussions with both the participant and their carers, and will take account of the carers' circumstances, capacity and plans relevant to their caring role, and the sustainability of informal caring arrangements. The Agency will work to make informal caring arrangements sustainable, and provide certainty to informal carers that the person they are caring for will get reasonable and necessary supports into the future. However, the NDIS will not replace all informal care.

Reasonable and necessary supports

As the Agency works with people with a disability, it will have to make consistent decisions about what support people will get under the NDIS. These decisions will need to balance what support is 'necessary' to address the impact of a person's disability on their participation in the community or employment, and what is 'reasonable' taking into

consideration factors such as value for money of the support, efficacy of the support and relevant community standards (such as what support it is reasonable to expect of families and carers. .

A clear statement of ‘reasonable and necessary support’ is included in Clause 34 of the Bill. This is to assist the community to understand the types of support the NDIS will provide and to ensure that the Agency’s decision-making is equitable, transparent and rigorous.

Reasonable and necessary supports as outlined in the Bill (Clause 34)

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:

- (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant’s statement of goals and aspirations;
- (b) the support will assist the participant to undertake activities, so as to facilitate the participant’s social and economic participation;
- (c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;
- (d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;
- (e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;
- (f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:
 - (i) as part of a universal service obligation; or
 - (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability;
- (g) the support is not prescribed by the National Disability Insurance Scheme rules as a support that will not be funded or provided under the National Disability Insurance Scheme;

(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.

The Bill sets out the criteria to determine whether a support to be provided or funded by the NDIS is reasonable and necessary. The rules will set out how these criteria are applied, the methods that will be used for determining which supports are funded or provided and what criteria might be used to decide this. The rules will also need to set out how the Agency will take into account any lump sum or periodic compensation payments in deciding on the reasonable and necessary supports that will be provided by the NDIS. The rules will also outline how the Agency should determine whether the support provided or funded by the NDIS would be more appropriately provided by another system of support such as in a school, or by the health system.

There will also be rules that clarify supports that will not be funded or provided under the NDIS, and also there will be rules which set out the supports that will not be funded or provided for some participants. These need to be developed in a way that allows people maximum choice about the care and support they receive so that people can be innovative in how they work out the package of supports that works best for them, and provides them with the best help to achieve their goals.

Rules

14. The methods or criteria for deciding which supports will be funded or provided. Clause (35 (1)(a)
15. The supports that will not be funded or provided under the NDIS. Clause 35(1)(b)
16. The supports that will not be funded or provided under the NDIS for certain participants. Clause 35(1)(c)
17. The methods or criteria for assessing the supports that will be funded may also include methods or criteria relating to the manner in which the supports are to be funded and by whom these supports will be provided. Clause 35(2); 35(3)
18. The methods or criteria for providing supports may also include methods on how to take in to account compensation payments. Clauses 35(4); 35(5)

Questions

What methods or criteria should be used to determine those supports that would not be provided or funded by the NDIS, based on the criteria set out in clauses 34 and 35 of the Bill?

Are there any issues that are not covered by these proposed topics for determining reasonable and necessary supports that should be?

Management of Plans

The NDIS is designed to give people with disability control over the management of the funding in their support package. People can choose their own support providers and can also choose whether to self-manage their funding or ask another person or organisation (including the Agency) to manage some or all of their funding.

The process of making decisions about how a person's supports are managed is to be as inclusive and flexible as the person with a disability desires. It should be directed by the person, and include others that the person wishes to be involved (e.g. family members, friends, advocates, and support providers). It will be able to be reviewed as a person's needs change over time.

The NDIS starts with the presumption that people with disability have the ability and the right to make their own decisions and exercise choice and control over their supports. Consistent with the principles set out above, limits on choice and control will be restricted to activities or items that are illegal, significantly detrimental to health, or where activities or items are demonstrated to harm the well-being of the individual.

Some people with disability who choose to self-manage their plans will still need support to manage their plan. Others may only need assistance with some aspects, or none at all.

There are some limited circumstances set out in the legislation where self-management may not be appropriate, for example, if the participant is unable to make informed decisions on the administrative and financial aspects of spending the funding provided to purchase the supports.

There may also be limited circumstances where it would not be appropriate for a participant to continue to manage his or her plan without support. These circumstances could include, for example, situations where the participant experiencing difficulty with the requirements for self-management of a plan, is expending funds other than in accordance with the plan or has had a significant temporary or permanent change in their personal circumstances. In these cases there would be a meeting with the individual to review their circumstances and agree on revised management arrangements for their plan.

NDIS rules will prescribe the criteria to be taken into account when the Agency is considering whether self-managing funding would present an unreasonable risk for the participant. Also, for full transparency there will be rules that set out particular matters that must not be managed by a participant.

In recognition that people's life circumstances can change, the legislation provides that participants can initiate a review of their plan at any time. There may also be circumstances where the Agency would conduct a review of the plan. These circumstances will be set out in the rules.

Rules

19. Criteria for determining whether a participant managing a matter would present an unreasonable risk to the participant. Clause 44(3)
20. Particular matters within a participant's plan that must not be managed by the participant. Clause 44(2)(b)
21. Circumstances which would require a review of a participant's plan to be automatically triggered. Clause 48(6)

Questions

What criteria should be used by the Agency in deciding whether there is an unreasonable risk for the participant in self-managing funding?

What flexibility should a person have in making changes to their support arrangements without requiring a review of the plan?

What circumstances should trigger an automatic review of a person's plan?

What matters within a participant's plan must not be managed by the participant?

How can the concept of 'dignity in risk' inform the development of these rules?

Information sharing

The NDIS will need to collect information from participants and prospective participants that is private and confidential. The legislation sets out the circumstances in which a person may be required to give information to the scheme.

The Agency must handle all the information it collects very carefully. This is required by the legislation because the protection of personal information and a person's right to privacy is paramount. The legislation covers the collection and handling of protected information, and creates a series of offences related to unauthorised access, use or disclosure of protected information.

The legislation also includes provisions that ensure that State or Territory laws that would prevent a person from disclosing information or providing documents to the NDIS are respected, for example laws relating to whistleblowers' protection.

The legislation ensures that the Agency CEO can disclose protected information only in exceptional circumstances. The NDIS rules will provide guidance on disclosure of information by the NDIS to facilitate information sharing between the Agency and other Commonwealth agencies and State or Territory departments. The legislation also gives the CEO of the Agency powers to release information in the public interest. The rules will identify circumstances in which the CEO would exercise this power in the public interest. One example might be where it is legally required for the investigation of a criminal offence.

Rules

22. Prescribing State or Territory laws under which a person would not be required to provide information to the Agency. Clause 58(2)
23. Making provision for the Agency to disclose information in the public interest. Clause 66(2)
24. Making provision for the Agency's CEO to disclose information to the head of a Commonwealth or State or Territory authority. Clause 67

Questions

Under what circumstances would you consider it reasonable for the CEO of the Agency to disclose information to a Commonwealth or state or territory authority?

Are there any other protections for information that are not covered?

How do we strike the right balance between making sure people don't have to repeat their story and personal information, and making sure people's' privacy is respected at all times?

Registered providers of support

Participants in the NDIS need to be able to choose supports that are of the standard and quality required to best support people with disability. During launch, the Agency will seek to use existing practices in states for quality control, safeguards, and qualifications of employees wherever possible.

Under the legislation, service providers will need to be registered in order to provide supports to people who have requested that the Agency manage all or some of their support. The legislation allows the Agency to register an organisation to provide supports and/or plan management. There will be rules related to the approval of registered providers of supports, including plan management.

The registration process could also include service providers showing that they have met relevant quality standards including governance, business and accounting practice, complaints handling, and auditing processes.

It is also important that the process for the registration of registered providers of supports promotes the policy objectives of the Bill to enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports.

Rules

25. Criteria for registering or revoking the registration of a service provider to deliver supports or a class of supports, including whether compliance with safeguards or quality assurance standards and procedures or qualifications of employees is required. Clauses 70(1)(d); 72; 73(1)
26. Prescribing the consequences of registered providers failing to comply with the NDIS Act, regulations or rules. Clause 73(2)(a)
27. The requirements for registered providers including governance, business and accounting practice. Clause 73(2)(b)
28. The obligations of registered providers in relation to the monitoring of compliance, complaints handling and auditing requirements. Clauses 73(2)(c); 73(2)(d); 73(2)(e)

Questions

What would be appropriate criteria for registering a service provider to deliver different types of supports?

How can the Scheme ensure that providers don't have to go through a lot of red tape, while also ensuring that services are of a standard and quality to best support people with disability?

What registration information should the agency collect from registered providers of supports that will promote the policy objectives of the NDIS Act to enable people with disability to exercise choice and control?

What registration information should the agency collect from registered providers of supports that will build data for public evidence based decision making?

Note: The implications for businesses and the not-for-profit sector of the NDIS legislation and regulations will also be addressed through a regulation impact statement process as the Council of Australian Governments considers the details of the policy development of the NDIS.

Children

The scheme's lifelong approach and capacity to provide early intervention supports are designed to improve life outcomes for children, and to ease pressures on their families. The priority will be on assisting families to care for children with disability in a way that is sustainable for the family in the long term. Reasonable and necessary supports will be provided in the context of each child's family circumstances. In developing a child's plan, the NDIS will take account of what is reasonable to expect from parents and families in the care for children.

The legislation sets out the arrangements for children in a number of areas of the scheme. Children will be a focus for early intervention and the criteria used to define the early intervention requirements will need to reflect this.

The legislation provides for children to be represented by parents, guardians or other appropriate people in all aspects of the scheme's operations. As far as possible the duties and responsibilities of parents acting on behalf of a child who is a participant in the scheme are the same as for parents generally. However in line with best practice in relation to decision making for all children, parents of a child with disability will be expected to promote the best interests of the child.

The NDIS rules will set out the criteria for decisions relating to the appointment of a person other than a parent to make decisions relating to care and support for a child, for determining when a child is capable of making their own decisions, and other situations which may arise.

Rules

29. Criteria for appointing someone other than the person with parental responsibility to act on behalf of a child. Clause 74(6)(a)
30. Criteria for deciding whether a person managing the funding for supports would present an unreasonable risk to the participant (child). Clause 74(6)(b)
31. Criteria to use when making a determination as to whether a child is capable of making decisions. Clause 74(6)(c)
32. Criteria for determining who has parental responsibility when there is more than one potential person. Clause 75(4)
33. Prescribe other duties to support decision-making by the child or give appropriate weight to the views of the child. Clauses 76(4)(a); 76(4)(b)

Questions

What criteria would a decision-maker need to take into account to appoint someone other than a parent to act on behalf of a child or young person?

What criteria should be considered in deciding to exclude a child or young person under the age of 18 from being involved in decisions about the support they receive?

What additional supports should be given to a decision-maker to ensure that a child or young person under the age of 18 is involved in decisions about the support they receive?

What additional supports should be given to a child or young person under the age of 18 to ensure that they are involved in decisions about the support they receive?

What additional supports should be given to a parent or guardian to ensure that a child or young person under the age of 18 is involved in decisions about the support they receive?

How can we best reflect the fact that as children and young people with disability get older, like all children and young people, they may want to have more say in what they do, and the care and support they receive?

What is the best way for children and young people to be encouraged to express their views about the support that they receive?

How can we best ensure that the views of children and young people under the age under 18 are regularly reviewed without being obtrusive?

Supporting decision-making

In the NDIS people with a disability are presumed to be able to exercise choice and control over the care and support they receive.

In any individual's life there may be a range of family, carers and other significant persons who provide support, advice and assistance in decision making. In some circumstances, people with disability may need to be more formally supported in their decision making by a family member, someone else with a close relationship to the person with disability, or a nominee. While there will be some situations in which people with disability are unable to make decisions even with supports in place, in all circumstances the Agency will seek to put people with disability at the centre of decision making, and to involve family members and carers where that is appropriate.

In circumstances where a person is unable to make decisions, options include:

- in the first instance, a nominee (substitute decision-maker) arrangement initiated by the person and accepted by the Agency/CEO or, if necessary, a nominee arrangement initiated by the Agency/CEO, taking into account the person's wishes;
- recognition of formal legal arrangements that are in place for people without legal capacity such as the Public Trustee and guardianship arrangements;
- in strictly limited circumstances, the Agency/CEO making a decision to assign an appropriate person to act as the person's representative when the person with disability is unable to be supported in their decision making and unable to consent to a nominee (without the need for that person to apply for formal guardianship); and
- consistent with other areas of law and administration, parents will be legally responsible for children under the age of eighteen in an NDIS.

Supported or substituted decision-making in the NDIS must be handled with great care to protect the right of people with disability to exercise choice and control over those decisions that impact on their lives. A set of principles has been included in the legislation to guide the operation of the scheme.

General principles guiding actions of people who may do acts or things on behalf of others, as set out in the Bill (Clause 5)

It is the intention of the Parliament that, if this Bill requires or permits an act or thing to be done by or in relation to a person with disability by another person, the act or thing is to be done, so far as practicable, in accordance with both the general principles set out in clause 4 and the following principles:

- (a) people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves;
- (b) people with disability should be encouraged to engage in the life of the community;
- (c) the judgements and decisions that people with disability would have made for themselves should be taken into account;
- (d) the cultural and linguistic circumstances of people with disability should be taken into account;
- (e) the supportive relationships, friendships and connections with others of people with disability should be recognised.

The legislation sets out the process for appointing a plan management or correspondence nominee for a participant. This can be requested by the participant or be on the initiative of the Agency taking into account the participant's wishes. The role and responsibilities of nominees are also set out in the legislation.

The Agency will not assume that people with disability who require support in their decision-making or have substituted decision-making will always need that support. The Agency will seek to build people's skills, experience and confidence to make choices and take greater control over their support arrangements. The Agency will also recognise that the capacity of some people with disability (in particular, some people with psychiatric disability) to make decisions may vary over time.

The NDIS rules will include practical approaches to ensure that actions taken by others on behalf of participants follow the principles in the legislation. The rules will provide guidance to ensure that only appropriate people are appointed as nominees and that the decisions made on behalf of the person are, as far as possible, those decisions that the decision-maker believes the person would make if they had the capacity.

Rules

- 34. Criteria to be considered in deciding to appoint a nominee. Clause 88(6)(b)
- 35. Requirements and matters to consider in the appointment, suspension or cancellation of nominees. Clauses 93(a); 93(b)
- 36. Prescribing who must not be appointed as a nominee. Clause 88(6)(a)
- 37. Prescribing additional duties of nominees to support decision making by the participant personally or to give appropriate weight to the participant's views. Clauses 80(4)(a); 80(4)(b)

Note: The NDIS rules will need to take account of differing arrangements for assisted or substituted decision making across State and Territory jurisdictions.

Questions

What criteria should guide the decision to appoint a nominee?

What criteria should be used to select an appropriate nominee?

How can a nominee demonstrate thorough knowledge and understanding of the participant's wishes, goals and life aspirations?

How can we test that the decisions of a nominee are reasonably those the person would have made if they had the capacity to do so?

What should be in place to allow these arrangements to change?

Who should not be appointed as a nominee?

Other than duties to support decision making by the participant personally or to give appropriate weight to the participant's views, what additional duties should be prescribed to nominees?

Should the appointment of nominees be for a fixed period or should there be a regular review of the arrangements to ensure the person with disability is satisfied with their nominee arrangements?

How can we ensure that the nominee arrangements continue to build the decision making capacity of people with a disability.

Compensation

The legislation is intended to ensure that where a person receives a compensation payment which includes an amount for the future cost of care and support, this amount is taken into account by the Agency in assessing the reasonable and necessary supports that person is entitled to receive through the scheme.

The legislation proposes that the Agency has the power to require a person to try to secure compensation where it believes that person is entitled to compensation in respect of the costs of supports that may be funded by the NDIS, where it is reasonable to do so.

The provision of support and assistance under the NDIS is not intended to replace existing entitlements to compensation. The Courts will continue to determine and award compensation payments in cases where there is a legal right to compensation.

The NDIS rules will set out how the Agency will determine reasonable and necessary supports when dealing with lump sum payments and periodic compensation payments that specifically include an amount for the cost of the supports. The rules will also need to cover lump sum compensation payments that do not specifically include an amount for the cost of supports.

Rules

38. The treatment of compensation payments in determining reasonable and necessary supports provided by the NDIS. Clause 35(4)(5)
39. Criteria for taking into account other amounts that a participant (or prospective participant) did not receive by way of compensation payments because they entered into an agreement to give up their right to compensation. Clause 35(5)
40. The Commonwealth, State or Territory laws to be set out in the NDIS rules that need to be considered in determining what if any, past NDIS payments can be recovered from a compensation payment made after the NDIS amounts were paid. Clause 106(5)(b)(iv)

Question

How should compensation payments for care and support be treated in working out how much care and support should be provided by the NDIS?

Conclusion

Over the coming months, the Commonwealth Government will continue to work with States and Territories on the legislation, and consult people with disabilities, their families and carers on the Bill, before it is voted on by the Commonwealth Parliament in time for the launch of the NDIS from the middle of 2013. This includes developing the rules that underpin the legislation to be considered by Parliament.

Your input to this reform process is extremely important. We want to hear from people with disability, their families and carers so we can build a system that meets your needs.

All comments received through the NDIS consultation processes will be considered. We encourage you to contribute to this process and thank you for taking the time to consider and provide input to this important reform.

How to provide feedback

The Government is offering a number of opportunities to gather the views and insights of stakeholders on the issues set out in this paper.

Feedback

The Government welcomes direct feedback on questions in the paper which can be submitted through a dedicated link on the NDIS website www.ndis.gov.au. It will not be possible to provide individual responses to your feedback, but all responses will be read and considered in the development of the rules throughout the first quarter of 2013.

You can also email a written response to our email address at:

NDISengagement@fahcsia.gov.au or via the postal address:

ATTENTION: SECRETARIAT

NATIONAL DISABILITY INSURANCE SCHEME

PO BOX 6555

CANBERRA ACT 2600

The Government will also be conducting consultation sessions with peak stakeholder groups in the disability sector.