National Disability and Carer Alliance

Summary Report

Key Issues Raised in the Alliance

NDIS Community Engagement Project

Nothing About Me Without Me: Person Centred Collaboration Amongst Equals

The "Wordle" above is a pictorial depiction of the words used in this document. The bigger the word, the more times it occurs in this document.

Acknowledgements

November 2012

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

- Assessment and Eligibility
- Supports
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- 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 at roland.naufal@disabilitycareralliance.org.au

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, *is it right, is it enough?* 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	*A one stop shop* 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	*Nothing about me without me*
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.
Particular Emphasis	Planning for complex support needs is currently inadequate and will require additional support and resources.
Particular Emphasis	The interface of the NDIS with the justice system requires particular attention.
Particular Emphasis	Planning for people with multiple disabilities is currently inadequate and will require additional support and resources.
Communication	Information about planning will be required in diverse formats and mediums. Attention to the processes of collection and dissemination of information is essential.
Emergency Planning	How will the system have the capacity and flexibility to respond to crisis & emergency?

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: *Living independently and being included in the community.*
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. *They should be asked what they want to do with their lives; that's what should bring about change.*
R&D	Innovation should 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. *Are others doing it better? If they can do it, why can't we?*
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.