

NDIS Impact, Needs and Planning Project

Stakeholder Consultations Report

December 18, 2016

Prepared for the Central and Eastern Sydney Primary Health Network by:

Dr Mark Bagshaw

Managing Director

innov8 Consulting Group

mark.bagshaw@innov8group.com.au

+61-2-9011-7588

Background

The National Disability Insurance Scheme (NDIS) is undoubtedly one of, if not the most significant advancements in Australia for people with disability, arguably in Australia's history. The NDIS model is based on six key changes to the way Australia delivers disability support, including a threefold increase in funding and a business model that offers people with disability choice and control over the services they purchase in a market-driven system.

At the same time the Australian primary health system is undergoing a period of significant change. Arguably the most significant recent change to the structure of primary health care in Australia was the establishment of 31 Primary Health Networks across Australia, including the Central and Eastern Sydney Primary Health Network (CESPHN). A significant element guiding the work of the PHNs is a focus on holistic, person centred health care, which is very much in alignment with the key design element of the NDIS based on the concept of "user choice and control".

It is in this context that the Central and Eastern Sydney Primary Health Network is commissioning the development of a NDIS Operational Plan. The project will explore the demographics and needs of people with disability within the CESPHN catchment, and will map the disability supports currently available to people with disability and identify gaps that may be filled by the primary health system. Its key deliverable will be a NDIS business plan for the CESPHN.

This is a significant and important project that has the potential to contribute a great deal to the successful implementation of the NDIS. CESPHN has engaged the innov8 Consulting Group in collaboration with the Centre for Disability Studies at Sydney University to undertake this project.

To ensure that the project best meets the needs of all the stakeholders, the project undertook a combination of one-on-one telephone interviews with selected key stakeholders from the disability and primary health sectors, and a series of five Stakeholder Workshops.

This report summarises the findings of the Stakeholder Consultations.

Stakeholder Consultation Objectives

Our consultation process was focused on current and potential future primary health needs of people with disability with the NDIS in place, and consisted of a series of half day workshops involving people with lived experience of all key types of disability, and also included key disability service, accommodation and support organisations, peak bodies, LHDs, FaCS, GPs, Indigenous and CALD organisations, consumers and carers, the National Disability Insurance Agency, as part of this process.

Central to the consultation process was a series of five 4-hour workshops involving invitees from each of the groups listed above. The first four of those workshops aimed primarily to uncover the core issues faced by each of the stakeholders in the

delivery of integrated, person centred primary health support for people with disability, and to explore the challenges and opportunities represented by the introduction of the National Disability Insurance Scheme.

The final “Experts Group” workshop involved a diverse mix of all stakeholder groups, and was conducted as a structured *Visioning Workshop*. A key component of the workshop is a technique we call “feed-forward imaging” through which we create the key elements of our vision for the future. Project Director, Dr Mark Bagshaw, led the workshop.

In addition to the workshops, over 40 telephone discussions were held leading up to, and subsequent to the workshops, providing an opportunity for those who were unable to attend a suitable workshop to contribute to the consultation process.

The workshops were very well attended across the board, despite difficult timing so close to Christmas and also taking into account the “burnout factor” often described particularly by people with disability, who sometimes describe themselves as one of the most highly researched groups in our community. This level of engagement bodes well for the future of CESP HN’s efforts to improve primary health support for people with disability.

The following table lists each of the stakeholder workshops:

Date	Location	Focus	No. of attendees
29 November 2016	CESPHN Ashfield office	General disability	18
30 November 2016	Sydney University	Intellectual disability	27
1 December 2016	CESPHN Ashfield office	Primary and allied health professionals	27
6 December 2016	Club Redfern, Redfern	Aboriginal disability	23
13 December 2016	CESPHN Ashfield office	Experts group	21

A full list of attendees can be found at *Appendix A: Workshop Attendees* on page 8.

Learnings

The workshops are provided a wealth of information that will feed into the recommendations and business plan. It quickly emerged that there are a set of common themes that were raised across all the stakeholder workshops and other discussions, and equally there were themes that emerged as key issues and

concerns for some of the stakeholders but not others. This pattern is common in projects of this type.

However, unlike many other similar projects where certain themes arise strongly across different stakeholder groups but significantly different (and often strongly held) views are expressed by different stakeholders about the themes, the general pattern and responses from the workshops and other discussions indicates a great deal of synergy in thinking amongst the stakeholders.

In these areas where a subset of stakeholders have strong views but others don't, detailed feedback points to a dynamic that might best be described as "they don't know what they don't know". Evidence of this emerged on several occasions when one group of stakeholders was being briefed about the issues that emerged from discussions held with other stakeholders, and they responded with phrases like "that's interesting, I had never thought about it from that perspective". This dynamic relates directly to a key finding from our consultations related to the urgent need for education about a range of issues across all sectors.

Common Themes

Several themes kept emerging from virtually all our discussions:

1. Education is desperately required across all stakeholder groups, albeit education about different topics for different groups:
 - Primary and Allied Health professionals expressed an urgent need for education in two areas: a) disability and the whole of the dynamics of disability, and b) the NDIS – what it is, how it will work, and the role of primary and allied health in its delivery,
 - People with disability called for significantly improved education for themselves and the community about the NDIS, and also expressed a need for better education and information about Australia's health system and about primary and allied health services in particular;
2. Cultural change is at the heart of the reform processes currently underway in Australia's disability support system represented by the NDIS, and across the entire health system. There was consensus across all of our discussions that the need to drive cultural change in line with the concepts of "user choice and control", "person-centred support", "codesign", "empowerment of people with disability" and an "aspirational view of the capacity of people with disability" is of utmost importance;
3. The fragmented nature of Australia's disability support system and its health system has long been identified as a significant issue for people with disability who have often spent a significant amount of time and effort finding and organising the supports they need to participate in Australian society. A core element of the design of the NDIS aims to address this issue through the development of Individual Support Plans tailored to each individual's needs, leading to an NDIS funding package to pay for those supports. While this is recognised as one of the most significant positive

developments of the NDIS, people with disability and inevitably require support that is not directly funded by the NDIS, including support from the health system, access to education, transport, work opportunities etc. Participants in our consultations who know about and understand the National Disability Strategy (NDS) reinforced the fact that the NDS is Australia's integrated disability support plan, and they highlighted the need for the NDS to be elevated in its prominence in the disability reform process.

Other Themes

In addition to the common themes described above, a number of important themes emerged that need to be recognised, understood and addressed. Key themes in this category were:

1. The specific needs of aboriginal communities and ethnic communities are not well understood, one result of which is that a “one size fits all” approach is often applied to health and disability services, producing services and supports that do not take into account the unique needs of these communities;
2. The level of interest and engagement from the primary and allied health professionals who took part in the consultations demonstrated a strong recognition of the importance of these issues, and a willingness to improve the support they provide to people with disability. However, the time and cost of doing so for people whose roles are already resulting in significant work pressures was often raised as a significant challenge;
3. The consultation participants who have been close to the NDIS trials and the early rollout of the NDIS described a significant challenge we all face designing, building and delivering such a massive reform. While the importance of this CESPHE project was recognised by all (including the reality that this project will be of value across the national Primary Health Network structure), the challenge associated with gaining and keeping focus of key stakeholders on this project was appropriately highlighted.
4. The paucity of data related to people with disability overall, and the lack of connection and integration of the data that is available, has long been identified as a key issue facing those involved in disability reform globally. Gaining access to “person-centric”, whole of life information about each individual with disability – an essential requirement to build a person-centred disability and health support system for people with disability – is a significant challenge for the National Disability Insurance Agency and its actuaries in particular. It is also a challenge for the health system as it strives to understand where and how acute, primary and allied health services fit into the overall lives of people with disability.

The remainder of this report provides more detailed summaries of the information gathered at each of the workshops. This information will form a primary input to

the next stage of the project – Analysis and Design – leading to the final Project Report and Business Plan.

General Disability

National Disability Strategy

- Needs coordination and ownership
- Promotion and education about NDS required
- Create better structural/individual linkages through Strategy
- Create digital framework

Primary/Allied Health education

- GPs in particular need for education about disability
- “Whole of Life” perspective required on education
- Time required for education a major issue, particularly for GPs
- Education about NDIS a key immediate priority – scheme characteristics, referral pathways

Mapping the health journey for people with disability

- Particular issues about prevention and inadequate post discharge support
- Important role for peer support
- Impact/role of the NDIS?

CALD communities

- “Gross” lack of understanding of cultural issues: language; cultural view of disability

Codesign essential

- The need for codesign is central to international and national disability reform processes
- Codesign for the NDIS so far has been limited

Intellectual Disability

Inconsistent knowledge of intellectual disability

- Can be hard to find knowledgeable primary/allied health professional
- Cultural awareness as important as understanding of medical aspects
- Need to find the right balance
- Link between ID and mental health poorly understood
- Capacity of person with ID often undervalued

Exiting services

- Insufficient post-discharge support, lack of safety net
- Need to form close link with NDIS
- Need for person centred, whole of life approach

Closure of ADHC

- Services changing form, disappearing altogether
- NDIS eligibility – some slipping through the cracks
- Who is responsible for what?

Attitudinal change

- Communities underestimate capacity of people with intellectual disability
- Need for campaign across all disabilities
- Disability is everyone's responsibility

Primary and Allied Health Professionals

Lack of skilled workers in the disability sector, and disability skills in the primary/allied health sectors

- Will slow sector development, impact quality of support
- Risk of unsafe services
- Disability sector needs incentives to attract good staff
- Need for ongoing education – education strategy
- Particular focus on young health professionals
- Training focused on person-centred service delivery and user choice and control
- Opportunity for mentoring (provide financial incentives)
- Opportunity for clinical placements in the disability sector

Overlapping roles of the health and disability sectors

- Duplication across health/NDIS – not recognised in COAG agreement
- Inadequate access to disability services can create health problems
- Changing eligibility causing confusion

NDIS information

- Education package for primary/allied health professionals: “NDIS for Dummies”, short instruction videos
- Need to combine information about each person – NDIS participant, My Health Record

Aboriginal Disability

Unique dynamics of aboriginal disability population

- Much younger population
- Disability often not recognised as such
- High percentage of aboriginal population have disability
- Significant cultural issues and unhealed wounds from the past

Focus on youth

- Disability often criminalised among young aboriginal population

- Desperate need for early intervention
- Screening tool required urgently – triggered in schools, Primary/Allied health, legal system
- Generational disadvantage – community capacity building required

Knowledge of aboriginal-specific disability issues

- Training required across primary/allied health
- Training needs to start at university
- Child protection workers need disability training
- Aboriginal Medical Service doesn't understand disability

Co-design, Co-manage, Co-deliver

- Empower aboriginal people
- Need to identify/train/empower “champions” – aboriginal people, primary/allied health
- Disability is everyone's responsibility

NDIS

- Establishing effective linkages with Aboriginal communities, primary/allied health, NDIS essential

Experts Group

The Experts Group Workshop was run differently to the previous four workshops. The workshop began with a “Strategic Visioning” exercise during which the workshop participants were asked to envisage a future in which Australia had been so successful in its disability reform process that it had won a Nobel Peace Prize for disability reform. Each participant was asked to imagine they had been asked to receive the award on behalf of the Australian people, and had been asked to deliver a 20 minute presentation describing the things we did to achieve such profound success. Participants were prompted through a series of questions aimed at clarifying the critical success factors.

Each participant then selected their top three ideas, which they then shared with all of the workshop participants. Ideas were categorised and ranked through a “meta planning” process that resulted in identifying four key priority areas for reform. They were:

1. Education & Awareness (10 votes)
2. Inclusive Culture (7 votes)
3. Integrated Systems (6 votes)
4. Empowerment (6 votes)

In the second half of the workshop the group was divided into four subgroups, and each developed a high level plan for one of the four priority areas. The detailed notes taken from this workshop will be a key input to the analysis and design process.

Appendix A: Workshop Attendees

General Disability Workshop, 29 November 2016, CESP HN Ashfield office

Full Name	Organisation	Position
Navid Anthony	Advanced Diversity Services	Senior Manager, Aged and Disability Services
Hawanatu Bangura	Ethnic Community Services Cooperative	Advocacy Team Leader for PWD
Bruce Blackshaw		Person with disability
Mark Burgess	St Vincent de Paul	
Jackie Campisi	Sydney City Council	Social Policy Officer, Social Programs & Services
Margaret Johnston	NSW FaCS	Acting Director, Disability, Sydney District
Tony Jones	Spinal Cord Injuries Australia	Policy and Advocacy Officer
Margaret Lazar	St Vincent's Health Network Sydney	Network Director Allied Health
Nicole Marchisone	South Eastern Sydney Local Health District	NDIS Transition Manager
Janice Oliver	South Eastern Sydney Local Health District	Disability Project Officer
Rachel Presdee	Spinal Cord Injuries Australia	
Gael Prophet	NDIA	
Angelika Rotsos	NSW FaCS	Manager, Access CST

Intellectual Disability Workshop, 30 November 2016, Sydney University

Full Name	Organisation	Position
Navid Anthony	Advanced Diversity Services	Senior Manager, Aged and Disability Services
Hawanatu Bangura	Ethnic Community Services Cooperative	Advocacy Team Leader for PWD
Bruce Blackshaw		
Mark Burgess	St Vincent de Paul	
Jackie Campisi	Sydney City Council	Social Policy Officer, Social Programs & Services
Margaret Johnston	NSW FaCS	Acting Director, Disability, Sydney District
Tony Jones	Spinal Cord Injuries Australia	Policy and Advocacy Officer
Margaret Lazar	St Vincent's Health Network Sydney	Network Director Allied Health
Nicole Marchisone	South Eastern Sydney Local Health District	NDIS Transition Manager
Janice Oliver	South Eastern Sydney Local Health District	Disability Project Officer
Rachel Presdee	Spinal Cord Injuries Australia	
Gael Prophet	NDIA	
Angelika Rotsos	NSW FaCS	Manager, Access CST
+5		People with intellectual disability and families

Primary and Allied Health Professionals Workshop, 1 December 2016, CESPHN Ashfield office

Full Name	Organisation	Position
Nicky Beckett		CNC GP Co-location
Stephen Brecht	NDIA	
Toula Dellis		Clinical Nurse Consultant
Sue Doyle	NSW FaCS	Manager Policy and Practice, Service Improvement – CRO
James Everingham	Sydney Local Health District	NDIS Change Manager
Mary Foley	Headspace	
Amy Gentle		
Mary Goslett		Psychologist and psychotherapist
Deborah Hammond	LifeAbility	Director and Occupational Therapist
Helen Ho		Exercise Psychologist
Kara Holmes		Psychologist
Laura Kelly	Sydney Children's Hospitals Network	NDIS Transition Manager
Nathan Lum		General practitioner
Vicki Lunn		General practitioner
Linda Mann	Sydney Healthpathways	GP Clinical Lead
Danielle McDonald		Psychologist
Darrin Morgan	NSW FaCS	
Merryn Peachey	St Vincent's Health Network Sydney	Transition Manager, NDIS
Catherine Scardilli	CESPHN	Practice Support and Digital Health Program Officer
Susan Smith	National Disability Services	Project Manager, Disability Safe
Arahn Sont		
Natalia Yee	Campsie Medical Practice	General Practitioner
Gulian Vaccari	CESAHN	Director
Donna Weekes	NDIA	

Aboriginal Disability Workshop, 6 December 2016, Club Redfern

Organisation	Full Name	Position
Sue Doyle	NSW FaCS	Manager Policy and Practice, Service Improvement – CRO
Darrin Morgan	NSW FaCS	
Stephen Brecht	NDIA	Director of Engagement
Sharlene McKenzie	Benevolent Society	
Pauline Deweerd	St Vincent's Health Network Sydney	Director Aboriginal Health
Kerry Fielding	NSW FaCS	Manager, Boarding House Reform Team
Wendy Jopson	CESPHN	Health Planner-Monitoring and Evaluation
Lisa Merrison	CESPHN	Team Leader, Aboriginal Health
Phillip Orcher		Aboriginal Health Clinical Care Coordinator
June Riemer	First Peoples Disability Network	Executive Officer
Brenda Shayeb		Aboriginal Health Clinical Care Coordinator
Leanne Trindall	Aged & Community Services NSW & ACT	Aboriginal Sector Development Officer
Peta Turner	NDIA	Business Support Officer, Community Engagement
+12		Aboriginal people with lived experience of disability

Experts Workshop, 13 December 2016, CESP HN Ashfield office

Full Name	Position	Organisation
Sue Doyle	Manager Policy and Practice, Service Improvement – CRO	NSW FaCS
Darrin Morgan		NSW FaCS
Olive Benjamin		Advanced Diversity Services
Stephen Brecht	Director of Engagement	NDIA
David Coyne	Manager, NDIA NSW	NDIA
Kate Finch	Manager, Systemic Advocacy	People with Disability Australia
Thushara Halnethilage	Multicultural Sector Development Officer Ageing and Disability	South Eastern Sydney Local Health District
Jenny Harasty	Speech Pathologist	Child Think, Adult Think
Tony Jones	Policy and Advocacy Officer	Spinal Cord Injuries Australia
Sarah Judd	Senior Policy and Development Officer	Carers NSW
Helen-Megi Metsamagi	Senior Social Worker	Sutherland Case Management Services
Julie Millard	Member, Inclusion Advisory Panel, CESP HN Community Council, Chair, Sydney Health Community Network	Sydney City Council
Ann Penhallurick	Project Manager, Disability Support Organisation Capacity Building Project	People with Disability Australia
Nick Rushworth	Executive Officer	Brain Injury Australia
Chris Tzarimas	Director	EIS Board
Catalina Voroneanu	Inclusion Coordinator	ECIA
Kate York	Senior Policy Officer	NSW Premier's Department
Sean Lomas		NSW Department of Health
Nathan Lum	General practitioner	
Sharlene McKenzie		Benevolent Society
Lisa Quirk	Manager Community and Reform, Disability	NSW FaCS