

NDIS Impact, Needs and Planning Project

Scoping Study Report

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

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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.

In order to ensure that the project best meets the needs of all of the stakeholders, the project commenced with a Scoping Study involving interviews with selected key stakeholders from the disability and primary health sectors.

This report summarises the findings of the Scoping Study and makes recommendations about the overall project that we believe will enhance the outcomes it will achieve.

Scoping Study Objectives

The objectives of the scoping study and the stakeholder interviews were to understand:

- the level of awareness of, and understanding of the role of the Primary Health Networks and CESPHN in particular within their organisation;
- the level of awareness of, and understanding of the National Disability Insurance Scheme;

- stakeholders’ current perspective on their place within the primary health system and/or the disability support system;
- their view on the project objectives and scope, including their perspectives on the key issues they believe need to be explored through the project;
- their expectations of what this project will deliver for all stakeholders and for them specifically;
- their level of willingness and capacity to participate in this project;
- their thoughts on the stakeholders (organisations and/or individuals) who should be involved in the project;
- their views (if any) on the potential for this project to be conducted in a partnership arrangement with other relevant bodies (e.g. other PHNs, the Department of Health, the National Disability Insurance Agency).

Stakeholder Interviewees

17 scoping interviews were conducted over a period of three weeks, each of approximately 45 minutes to one hour duration. All interviews were recorded. The stakeholders were selected to ensure an appropriate mix of sectors (primary health, disability and the community), type (key disability types, indigenous and multicultural communities) and individual role (professional/consumer).

The following table lists stakeholders consulted:

Organisation	Full Name	Position
<i>Primary and Allied Health</i>		
CESPHN	Michael Moore	CEO
CESPHN Community Council	Peter Merritt	Volunteer
CESPHN	Catherine Goodwin	Development Manager- Mental Health, Alcohol & Other Drugs
CESPHN	Sharron Fitzgerald	Clinical Pathways Manager
Central Sydney GP Network	Aline Smith	Chair
Clinical Psychology	Tony Merritt	Sydney Clinical Psychology
Child Think, Adult Think	Jenny Harasty	Speech Pathologist

Organisation	Full Name	Position
Developmental Assessment Service	Robert Leitner	Developmental Paediatrician and Senior Staff Specialist
<i>NDIS</i>		
NDIA	Vicki Rundle	General Manager Operations
NDIA	Stephanie Gunn	General Manager Community Linkages and Acting DCEO Stakeholder Relations
<i>Disability</i>		
NSW Council for Intellectual Disability	Jim Simpson	Systemic Advocacy Team
Blind citizen	Liza Hayes	
Deaf Society of NSW	Leonie Jackson	CEO
Aussie Deaf Kids	Ann Porter	CEO
Brain Injury Australia	Nick Rushworth	Executive Officer
<i>Community</i>		
First Peoples Disability Network	Damian Griffis	CEO
Ethnic Communities' Council of NSW	Terrie Leoleos	NSW Multicultural Ageing & Disability Access Project Officer

Table 1: Stakeholders consulted during Scoping Study

Learnings

The Scoping Study has proven to be a very valuable starting point for this project. It has exceeded its objectives as outlined above, and has generated a significant amount of interest and engagement from all of the interviewees and the organisations they represent. In particular:

- it quickly uncovered a significant set of gaps between the primary health system and the disability sector, including:
 - the level of communication that does/does not exist between the two systems and between individuals across both areas;
 - a low level of understanding of the roles and responsibilities of stakeholders across the stakeholder segments;
 - a recognition that this represents a significant problem and challenge, but also a strong willingness to work together to address these challenges;

- without exception all of the stakeholders interviewed recognised the importance of this project, and the reality that this project is possibly a first attempt to address these issues;
- it immediately became clear that the specific needs of people with different types of disability are not well understood within the primary health system, leading to a range of significant and diverse issues (including basic lack of access, lack of understanding of the “whole of life” challenges of different disability types, lack of resources to respond to specific disability needs, and others);
- there was a very strong view that resolving the currently unresolved questions and issues around the connection between the primary health system and the disability support system needs early attention;
- each of the stakeholders, particularly the disability groups and the NDIA, recognised that there are potentially significant opportunities for the primary health system and the disability support system to work together to provide more effective and integrated support for people with disability;
- there is little understanding of the intersection of the roles and responsibilities of the NDIA and the PHNs, particularly related to funding specific services, leading to confusion about who is responsible for what in terms of the total service envelope required by each individual with disability;
- the need for a significant shift towards early intervention was a common theme across all disability areas, but was raised particularly in the intellectual and psychiatric disability areas and in indigenous communities;
- it became increasingly clear that mental health issues are a critical challenge across the disability sector, not just for people whose primary disability is identified as mental illness – the impact on mental health of living with any type of disability was raised by each of the disability groups interviewed;
- a particular issue was identified related to pathways for people with all types of disability after discharge from hospital, with disability advocates citing many examples of GPs and other allied health professionals having little understanding of the specific post-discharge needs of people with disability;
- the lack of a robust database of disability and primary health care services, populations of people with disability, including needs assessment and assessments of the level of knowledge across sectors of disability issues, was raised as a key issue;
- evidence from NDIS Trial Sites has indicated that many people with disability want to understand the effect of health/ill-health on their capacity to manage their disabilities, but that there is a lack of clarity about where that education should come from;
- the potential benefits of the Healthcare Homes initiative to improve support particularly for people with intellectual disability was highlighted as a key opportunity for people with intellectual disability;

- a significant number of interviewees pointed to the relevance of this project across the country, and several had thoughts on what this might mean for the project, including:
 - ensuring other PHNs are kept informed;
 - that the NDIA be closely involved;
 - that this project focuses on identifying the issues, opportunities and potential solutions, leading potentially to a range of practical projects (outside the scope of this project), possibly conducted by a range of PHNs in partnership with the NDIA;
 - the potential establishment of an ongoing action-oriented project that connected with or initiated by the project itself (i.e. a “disability services laboratory”) was raised as a possibility by the NDIA.

Project Questions

As part of the consultations conducted during the Scoping Study, interviewees were asked their opinion on the key questions that need to be asked, and wherever possible, answered by this project. This proved to be a particularly valuable exercise as it helped to focus the discussions with the broad group of stakeholders consulted, and to identify the key questions each of them felt this project needs to focus on to achieve its objectives.

The questions that were identified have been grouped under four headings:

1. background and demographic questions;
2. questions relating to the culture of the primary health and disability support systems;
3. questions about the management of primary health and disability support; and
4. questions about the systems and processes that are needed to provide effective, seamless, “whole of life” support to people with disability.

Given the resources available for this project and the significant number of questions that could be asked during the consultations, we (the consultants) will agree on a final list of questions with CESP HN prior to conducting the consultations.

Background/Demographics

- What are the general population demographic characteristics of the CESP HN (age, gender, occupation, ethnicity, socio-economic status)?
- What are the disability demographic characteristics of the CESP HN (disability type, age, gender, occupation, ethnicity, socio-economic status)?
- How do people with disability compare to the general population on these demographics?
- What are the characteristics of disability services in the CESP HN (type of service, provider type, geography, size, target group(s), unmet need)?

- What are the characteristics of the primary health care services in the CESP HN?
- How do people with disability currently rate disability/primary health services in meeting their needs?
- How does the overall health of people with disability compare to the general community?
- What factors make some individuals more vulnerable than others/negatively affect individuals' health?

Culture

- How is disability perceived by the primary health system (welfare/medical/social)?
- How is the primary health system perceived by disability services?
- How is the primary health system perceived by people with disability?
- What impact is the NDIS having on these perceptions?
- What are the factors that affect and influence culture in the primary health system, the disability support system, the population of people with disability?
- How well do these cultures align with disability directions (UN Convention on the Rights of People with Disability, Australian policies, the NDIS)?
- What impact are the cultures above having on participation of people with disability?
- What changes in culture would make the most difference to the lives of people with disability?
- What role does CESP HN have in leading/influencing cultural change?

Management

- How do the disability services and primary health care services currently interact and connect?
- What are the mechanics of this interaction at a policy level?
- What are the mechanics of this interaction at a management level?
- How will the NDIS effect these mechanics?
- Who is responsible for addressing the needs of people with disability in the primary health system?
- Who is responsible for articulating the needs of people with disability to the primary health system?
- To what extent does/should the primary health system take a "whole of life" view of the total support needs of people with disability (i.e. understanding the linkages between primary health support, disability support, and generic community support)?
- How well is the primary health system supported by management information relevant to people with disability, including ensuring

accountability and measuring improvements that result from primary health system investment in people with disability?

- What role does CESP HN have in the management of primary health support for people with disability?

Systems/Processes

- What are the key systems and processes that are used to deliver primary health support in Australia?
- How well do those systems and processes meet the specific needs of people with disability?
- Are there differences in the extent to which systems/processes meet the needs of specific disability types?
- What systems/processes are in place (if any) to ensure seamless access to primary health services and disability support services for people with disability?
- What/who are the key primary health contact points for people with disability (GP, specialist, other)?
- Is the level of information about disability and the primary health needs of people with disability adequate and available to primary health practitioners?
- Is the level of information about the NDIS currently available to the primary health system adequate?
- Is the level of information about generic primary health services and disability-friendly primary health services currently available and accessible to people with disabilities adequate?
- To what extent do management information systems in the primary health system support decision-making about the services provided to people with disability?
- To what extent are/should primary health and disability support MISs connect?
- To what extent are developments related to e-Health taking into account the needs of people with disability?
- Are there best practice examples in the provision of integrated, whole of life primary health support for people with disability? What are the key factors that make them “best practice”?
- What role(s) does the primary health system have in the delivery of the NDIS?
- To what extent is the primary health system prepared to deliver those roles?
- What existing and emerging (e.g. Health Care Homes) systems and processes need to be improved to take the needs of people with disability into account?

- Are there new systems and processes that need to be developed and implemented to improve primary health support for people with disability in the NDIS environment?
- What role does CESP HN have in monitoring/improving existing systems and processes?
- What role does CESP HN have in identifying/developing/commissioning new systems and processes to improve primary health support for people with disability?

Offers of Support and Engagement

During the discussions several interviewees offered support for the project. In particular:

- The NSW Council on Intellectual Disability offered to reach out to invite participants to a possible intellectual disability-specific workshop (currently not included in the project proposal), and to host that workshop at NSW CID premises;
- The First Peoples Disability Network offered to host and co-facilitated a workshop for indigenous people with disability at the Redfern Community Centre;
- The Deaf Society of NSW offered to host a workshop for deaf people at their premises;
- The NDIA indicated a strong interest in being involved throughout the project. Stephanie Gunn (GM, Community Linkages at the NDIA) has been appointed the executive contact for this project.
- The NDIA is exploring the possibility of offering a secondee from the Agency to this project to further strengthen the connection between CESP HN and the NDIA.

Implications for the Project

The level of enthusiasm and engagement for this project demonstrated by all of the stakeholders who were interviewed has confirmed that

- a) this is a very important project,
- b) it is very timely given developments in primary health and disability support,
- c) there is a very encouraging level of engagement in the project.

In summary, the implications of the findings of the Scoping Study are:

1. a significant degree of momentum and anticipation has already developed around this project, boding well for its success;
2. making this project successful will not only be important for CESP HN, but it will potentially also contribute significantly to the further development of Australia's disability support system;

3. in order to produce a result from this project that will maximise its value across Australia, but also keep the project funding within the CESP HN Board’s original funding envelope, the project will be best considered as a significant early step, potentially leading to further work outside the scope of this project;
4. the outcomes of this project could be expanded beyond the specific deliverable of a Business Plan for CESP HN to create a business plan template that could potentially be picked up and delivered by other PHNs, without additional cost to this project;
5. there was a view that the three planned workshops (one of which combined disability types), should be considered a minimum number of workshops, and that a preferred option would be to run specific workshops for intellectual disability and indigenous groups, and possibly also for deaf people;
6. in order to keep within the original proposed budget, but also extend the number of workshops, the project plan has been reworked to reduce the number of one-on-one interviews (significant valuable information was gained from scoping study interviews already) and removing the online survey which was considered unnecessary by scoping study interviewees.

Revised Project Plan

The following is a revised project plan that takes into account all of the findings of the scoping study. The second and final stage of the project will be conducted over a period of 12 weeks from the signing of the contract for this phase of the project.

Activity	Consulting Days
Project Inception	
Finalise and sign contract	0.25
Project Inception meeting	1.50
Finalise project plan	0.50
	2.25
Stage 1: Scoping	
Determine stakeholders (max.20) for scoping discussions and agree with CESP HN	1.50
Conduct stakeholder discussions	9.00
Document discussions and create recommended project plan	1.50
Agree project plan with CESP HN	0.50
	12.50
Stage 2: Desktop Research	
<i>1. Define and frame area</i>	
Identify and acquire disability datasets (ABS, AIHW, NDIA, FaCS, CESP HN other)	1.45
Analyse/cross-reference data against CESP HN boundaries	2.50

Activity	Consulting Days
Create demographic profile	2.00
<i>2. Detailed analysis of population with disability</i>	
Analyse/cross-reference data	2.00
Produce PWD profile	1.70
<i>3. Detailed analysis of disability, community and health sectors in CESP HN</i>	
Create disability services profile	1.70
Create community services profile	1.70
Create primary health system profile	2.50
<i>4. Review of world best practice</i>	
Literature scan and review	2.00
Identify relevant learnings	1.50
<i>5. Synthesis of evidence</i>	
Develop overall profile for CESP HN region	2.50
Identify key intersection points	0.75
<i>6. Desktop research report</i>	
Write research report	4.00
	26.30
Stage 3: Consultations	
<i>1. Ethics approval</i>	3.00
<i>2. Prepare for workshops</i>	2.50
<i>3. Disability consumer/provider workshop</i>	
Organise workshop	3.00
Conduct workshop	1.50
<i>4. Indigenous workshop</i>	
Organise workshop	3.00
Conduct workshop	1.50
<i>5. Intellectual disability workshop</i>	
Organise workshop	3.00
Conduct workshop	1.50
<i>6. Primary health provider workshop</i>	
Organise workshop	3.00
Conduct workshop	1.50
<i>7. Stakeholder leadership workshop</i>	
Organise workshop	3.00
Conduct workshop	1.50
<i>8. One-on-one interviews</i>	
Develop interview script	0.50
Conduct interviews	5.00
Document interviews	1.00
	34.50
Stage 4: Analyse/Design	
<i>1. Analysis of research and team brainstorming</i>	
Individual team members review research/consultations	2.00
Team brainstorming session	3.00

Activity	Consulting Days
2. Strategic Visioning Workshop	
Agree format/attendance for Strategic Visioning Workshop with CESP HN	0.20
Conduct Strategic Visioning Workshop	8.00
Document results of workshop	1.20
3. Operational Plan	
Prepare draft operational plan	4.00
Test draft plan with selected stakeholders	2.50
	20.90
Stage 5: Document/Deliver operational plan	
Finalise documentation for operational plan and profiles	2.00
Present plan to CESP HN	2.00
	4.00
	100
Consulting Days	

Recommendations

1. That the project progress through Stages 2-5 as soon as possible;
2. That the project plan be reworked to place more emphasis on workshops and less on face-to-face interviews, and removal of the online survey;
3. CESP HN gratefully accept the support being offered as outlined above;
4. That the project outcomes be reworked to:
 - a. conduct the consultations in a manner that answers the project questions outlined above;
 - b. include production of a business plan template for PHNs;
 - c. ensure that CESP HN and the consultants work closely with the NDIA to ensure the final recommendations in the Project Report and Business Plan contain a clear pathway to further action oriented work.