



Getting NDIS Ready: Literature Review

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Table of Contents

1	FIGURES & TABLES	6
2	INTRODUCTION	7
2.1	AIMS OF THE PROJECT	7
3	DEFINITIONS & BACKGROUND	8
3.1	ABBREVIATIONS	8
3.2	DISABILITY	8
3.2.1	INTERNATIONAL: ICF	8
3.2.2	INTERNATIONAL: UNCRPD	8
3.2.3	THE AUSTRALIAN DISABILITY SERVICES ACT (1993)	10
3.2.4	NDIS ACT (2013) AND “ELIGIBILITY CRITERIA”	10
3.3	PRIMARY HEALTH DEFINITIONS AND BEST PRACTICE	13
3.3.1	INTERNATIONAL: WHO ALMA-ATA DECLARATION (1978)	13
3.3.2	INTERNATIONAL: PHCPI CONCEPTUAL FRAMEWORK	13
3.3.3	INTERNATIONAL: PHCPI KEY INDICATORS FOR PRIMARY HEALTH CARE	16
3.3.4	AUSTRALIAN PRIMARY HEALTH CARE:	16
3.3.5	ROLE OF PRIMARY HEALTH NETWORKS	16
3.3.6	INTERACTION BETWEEN THE HEALTH SYSTEM AND THE NDIS	17
3.4	DISABILITY SUPPORT	18
4	THE NATIONAL DISABILITY INSURANCE SCHEME	20
4.1	NDIS BACKGROUND	20
4.2	WHAT NDIS FUNDS	20
4.1.1	THE “REASONABLE AND NECESSARY” LEGISLATION	20
4.1.2	THE NDIS RULES “REASONABLE AND NECESSARY” SUPPORT	21
4.3	NDIS AND HEALTH FUNDING RESPONSIBILITIES	22
5	RESEARCH SCOPE	25
6	DELIMITERS: WHAT IS ‘IN SCOPE’ OR ‘OUT OF SCOPE’?	26
6.1	OUT: RURAL AREAS	26
6.2	OUT: AGEING AND DISABILITY	26
6.3	UNCLEAR: SECONDARY AND TERTIARY LEVEL HEALTH SERVICES	26
6.4	UNCLEAR: AUSTRALIAN IMMIGRANTS	26
6.5	EXISTING RESOURCES: INTEGRATED ATLAS OF MENTAL HEALTH	27
6.6	IN: CAREGIVERS AND FAMILY	28
6.7	IN: RESTRICTIONS ON ACCESS TO SERVICES AND ADVOCACY	28
7	DEMOGRAPHIC INFORMATION	29
7.1	GENERAL POPULATION INFORMATION FOR CESP HN REGION	29
7.2	ESTIMATES RELATING TO PEOPLE WITH A DISABILITY WITHIN THE CESP HN REGION	30
7.3	ESTIMATES OF PEOPLE IN THE CESP HN REGION LIKELY TO BE ELIGIBLE FOR NDIS	32
8	PEER-REVIEWED LITERATURE: METHOD	34
8.1	SEARCH METHODS FOR IDENTIFICATION OF STUDIES	34
8.2	INCLUSIONS	34
8.3	EXCLUSIONS	34
8.4	ELECTRONIC DATABASE SEARCHES	35

8.5	SELECTION OF RELEVANT DATABASE RECORDS	35
8.6	SEARCHING OTHER SOURCES	35
8.7	SYNTHESIS OF RECORDS RETRIEVED	36
8.8	SEARCH RESULTS	36
9	<u>LITERATURE REVIEW: THE FINDINGS</u>	<u>38</u>
9.1	THE HEALTH AND DISABILITY INTERFACE	38
9.2	PHILOSOPHICAL UNDERPINNINGS OF INDIVIDUAL FUNDING	39
9.3	SELF-DIRECTION AND DECISION-MAKING	40
9.4	INFORMATION AND RESOURCES	41
9.5	PROFESSIONAL DEVELOPMENT AND SUPPORT	44
10	<u>RECOMMENDATIONS</u>	<u>46</u>
	<u>LITERATURE: KEY REFERENCES</u>	<u>49</u>
	<u>APPENDIX 1 - DATABASE SEARCH STRATEGY</u>	<u>52</u>

EXECUTIVE SUMMARY

The disability sector in Australia is undergoing a major reform, with the NDIS gradually rolling out across the country. The NDIS will start in the CESP HN region in July 2017. This reflects a wider international paradigm shift regarding attitudes towards persons with disabilities that is now becoming entrenched in international health. In 2006 the UN adopted the ‘Convention on the rights of Persons with Disabilities.’ A person-centred approach stresses that persons with disabilities are not only the objects of medical treatment, but subjects capable of claiming their rights and making decisions for their lives based on their free and informed consent. The Australian government ratified the UNCPD, and the National Disability Insurance Scheme legislation was drawn in 2013 and passed Treasury in 2016. However, the relationship between the NDIS and health services is still as yet undetermined.

The aim of this project was to explore the interface between the NDIS and health, as it relates to the Central and Eastern Sydney primary health network (CESPHN). In Chapter 3, the report outlines key definitions that arise from the various legislative acts and their implementations. In particular it identifies restrictions upon the NDIS in the form of the eligibility criteria, and the funding related to disability supports. Chapter 4 reports the changes to funding structures through individualised packages that are attached to the person. This climate results in a somewhat complex interaction of funding and responsibilities for primary health care.

Chapter 5 and 6 discuss the delimiters of this “desktop research”, required in order to meet a relatively short time frame. It provides discussion on the “grey areas,” and why rural CESP HN areas and aging population were deemed to be outside the scope of this research project. It discusses a lack of clarity between primary health versus primary health networks, and areas in which CESP HN can anticipate some ongoing lack of clarity. It advises on existing resources related to disability and mental health. It notes the importance of caregivers and family, as well as recognizing that there are specific and as yet unforeseen needs of CaLD (culturally and linguistically diverse) peoples moving to the NDIS.

The demographic information in Chapter 7 outlines the people in the CESP HN area expected to move over to the NDIS in 2017. Estimates indicate that **14,700 participants in the CESP HN region will enter the NDIS by June 2018**, with this number anticipated to increase to 18,100 by June 2019 (NDIA 2016). This section

outlines their key demographics. Chapter 8 outlines a list of important services that could be constructed within the later phases of this research.

Chapter 9 outlines peer-reviewed literature related to the NDIS and primary health, drawing upon international and Australian journals. Chapter 10 announces its findings around the health and disability interface. Although not all systems and procedures will change, it acknowledges that the person-centered philosophy upon which the legislation is built is changing the way that health is provided. This has broader implications than individualised packages alone. Importantly, in regards to the NDIS, the report identifies that the central lynchpin around which the entire climate will now move is advocacy. This makes the distribution of information and resources invaluable, and also means that professional development will be very helpful in assisting people with disabilities (particularly intellectual disabilities) in a successful transition.

The first recommendation of this report is that CESP HN develop resources for people with disabilities customised for the area, in culturally appropriate versions for various ages. It encloses a framework recommended as a checklist for these resources. The second recommendation is that CESP HN promote education and advocacy in its region. The third is that CESP HN promote professional development to assist people with disability in relevant skills in the NDIS climate - goal setting, problem solving etc. The fourth is that the lived experience of the people with disability (such as gathered in the workshops) guide CESP HN's approach to disability. Of particular importance is hearing from those on individualized packages. The fifth is identifying risks and setting protocols in place to prevent hospitalisation, with some suggestions given related to aspiration, poly-pharmacy, seizures, and behaviours of concern.

1 FIGURES & TABLES

Figure 1 – PHCPI Conceptual Framework

Figure 2 – NDIS health factsheet

Figure 3 - Proportion of people with a disability & NDIS eligible in CESP HN region (est)

Figure 4 – NDIS participants across all trial sites by primary diagnosis

Figure 5 - Results from database and grey literature searches

Figure 6 - Framework for information provision for individualised funding

Table 1 - Age breakdown of general CESP HN population

Table 2 - Age breakdown of people with a disability in CESP HN region

Table 3 - Main diagnosis/condition as a percentage of people with disability

Table 4 - NDIS participant estimates

Table 5 - Estimated workforce engaged in providing disability support

Table 6 - Strategies for information provision

2 INTRODUCTION

2.1 Aims of the project

The primary questions that structured this research were:

- How do disability services, particularly relating to the NDIS and the primary health sector interact in the CESP HN region?
- How can CESP HN anticipate the changes ahead in regards to the NDIS and individualised funding packages?

In recognition of the impending transition towards individualised funding packages, a desire to understand the possible future interaction between disability services and the primary health sector framed this research, and for particular attention to be given to how services in the CESP HN region were perceived by people with disability (service consumers) and health professionals (service providers), this research was broken into a number of different parts:

- Reviewing available peer-reviewed literature on possible intersections between the primary health sector and the NDIS legislation.
- Examining available grey literature regarding the NDIS transition.
- Identifying how the underpinning philosophy of the NDIS may change the delivery of primary health care (particularly within the CESP HN region).
- Seeking relevant international examples that may provide helpful information to guide a best practice approach for the new climate.
- Attempting to identify the demographic information of people within the CESP HN area that may roll over to the NDIS
- Investigating the lived experience of people with disability (service consumers) within this region
- Engaging health professionals (service providers) to ascertain their working knowledge of the needs of people with disabilities and potential areas of improvement

Many of the above aims were addressed in the form of workshops facilitated by Mark Bagshaw, and Innov8 Consulting Group.

3 DEFINITIONS & BACKGROUND

3.1 Abbreviations

AHP – Allied Health Professional

CESPHN – Central and Eastern Sydney Primary Health Network

NDIS – National Disability Insurance Scheme

NDIA – National Disability Insurance Agency

GP – General Practitioner

PWD – Persons with Disability

3.2 Disability

There are various definitions and terminologies relating to “disability”. This section outlines some of these challenges, as well as explaining the chosen definition for this research.

3.2.1 International: ICF

The International Classification of Functioning, Disability and Health (ICF) is the WHO framework for measuring health and disability at both individual and population levels. It is a classification of health and health-related domains that uses the term disability as an umbrella term for impairments, activity limitations and participation restrictions. The ICF provides both standard language and a conceptual basis for the definition and measurement of health and disability. Within it, “disability” is seen as the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and social or environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limitations on supports).

3.2.2 International: UNCRPD

The United Nations Convention on the Rights of Persons with a Disability (UNCRPD, Article 1, p3) is an international treaty that seeks to promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities. Within this document, Article 2 presents key international definitions. Within the context of the UNCRPD, “persons with disabilities” is applied to all persons

with disabilities including those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various attitudinal and environmental barriers, hinder their full and effective participation in society on an equal basis with others. The UNCRPD is based on a number of general principles:

- respect for dignity;
- non-discrimination;
- participation and inclusion;
- respect for difference;
- equality of opportunity;
- accessibility;
- equality between men and women; and
- respect for children.

There are a number of references to primary health found within this document. For example Article 16 relates to health services specifically for those who have been exploited or abused; Article 26 relates to timely and appropriate access to habilitation and rehabilitation. However, Article 25 has the most relevance to the primary health system, and is listed below.

Article 25:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Source: UNCRPD, Article 25

The treaty has been ratified by 172 nation states to date, with 92 also ratifying its optional protocol.

3.2.3 The Australian Disability Services Act (1993)

In Australia, The Disability Services Act (1993) defines “disability” as an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of those impairments. It adds a number of clarifications, including:

- which is permanent or likely to be permanent
- which may or may not be of a chronic or episodic nature
- which results in substantially reduced capacity of the person for communication, social interaction, learning or mobility and a need for continuing support services.

Definitions regarding disability in the international and national setting are highly relevant, as *not all Australians with disability are eligible for the NDIS*. Therefore, as the primary focus of this study was structured around the interface between CESPAN and the NDIS, the definition of disability as in the 1993 Act above was not used, but instead parameters set by the NDIS have been used.

3.2.4 NDIS Act (2013) and “Eligibility Criteria”

The NDIS Act (2013) does draw upon the Disability Service Act (1993) definition to develop its eligibility criteria. The NDIS does not so much provide a definition of disability, but rather, details eligibility criteria for funding. This criterion was used to

create search terms for the literature review in order to refine the project's scope, and to ensure clarity and quality. This is the definition of disability used in this report.

GENERAL ELIGIBILITY

The eligibility criteria set out in the NDIS Act (2013) states that in order to be eligible as a NDIS participant, you must be aged less than 65, live in the appropriate areas on a specified date, and be an Australian citizen or hold a permanent visa or a Protected Special Category visa (Appendix 1 - *Accessing the NDIS – Factsheet*). In addition to this the following criteria must be fulfilled. It states that you may meet the disability requirements if:

- *You have an impairment or condition that is likely to be permanent (i.e. it is likely to be life long) and*
 - *Your impairment substantially reduces your ability to participate effectively in activities, or perform tasks or actions unless you have:*
 - *assistance from other people or*
 - *you have assistive technology or equipment (other than common items such as glasses) or*
 - *you can't participate effectively even with assistance or aides and equipment and*
 - *your impairment affects your capacity for social and economic participation and*
 - *you are likely to require support under the NDIS for your lifetime.*
- An impairment that varies in intensity e.g. because the impairment is of a chronic episodic nature may still be permanent, and you may require support under the NDIS for your lifetime, despite the variation.*

Source: NDIS Act (Treasury 2013)

In addition, there are early intervention requirements outlined by the NDIS.

EARLY INTERVENTION REQUIREMENTS

The term early intervention in the NDIS Act (2013; Treasury 2016) refers to receiving supports early on in the course of a condition. This can include early intervention in childhood but also includes early intervention for adults with conditions such as Multiple Sclerosis or Motor Neurone Disease. The NDIS Act (2013) states that:

People with disability may meet the early intervention requirements:

- *If you have an impairment or condition that is likely to be permanent and*
 - *There is evidence that getting supports now (early interventions) will help you by:*
 - *reducing how much help you will need to do things because of your impairment in the future and*
 - *improving or reducing deterioration of your functional capacity or*
 - *helping your family and carers to keep helping you and*
 - *those supports are most appropriately funded through the NDIS, and not through another service system.*
- OR*
- *you are a child aged under 6 years of age with developmental delay which results in:*
 - *substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development and*
 - *results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; and*
 - *those supports are most appropriately funded through the NDIS, and not through another service system.*

Source: *NDIS Act (2013)*

3.3 Primary Health definitions and best practice

Within the available literature (both informal and peer-reviewed) there is relative confusion around the term “primary health”, which is commonly referred to as ‘the black box of health.’ There are a range of primary care, primary health and primary health care definitions. In pursuit of a best practice framework for disability, this section outlines the chosen definition for this report, which was drawn from the available literature in Australia but also internationally, and the researchers’ perceptions of the CESPAN network and its activities.

3.3.1 International: WHO Alma-Ata Declaration (1978)

The World Health Organization (WHO) describes ideal primary health care for the international community within its Alma-Ata declaration of 1978. Rather than clinical care, which was once the prime focus of GPs, this declaration describes health as a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity:

Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.

Source: WHO (“Declaration Of Alma-Ata International Conference On Primary Health Care” 1978)

3.3.2 International: PHCPI Conceptual Framework

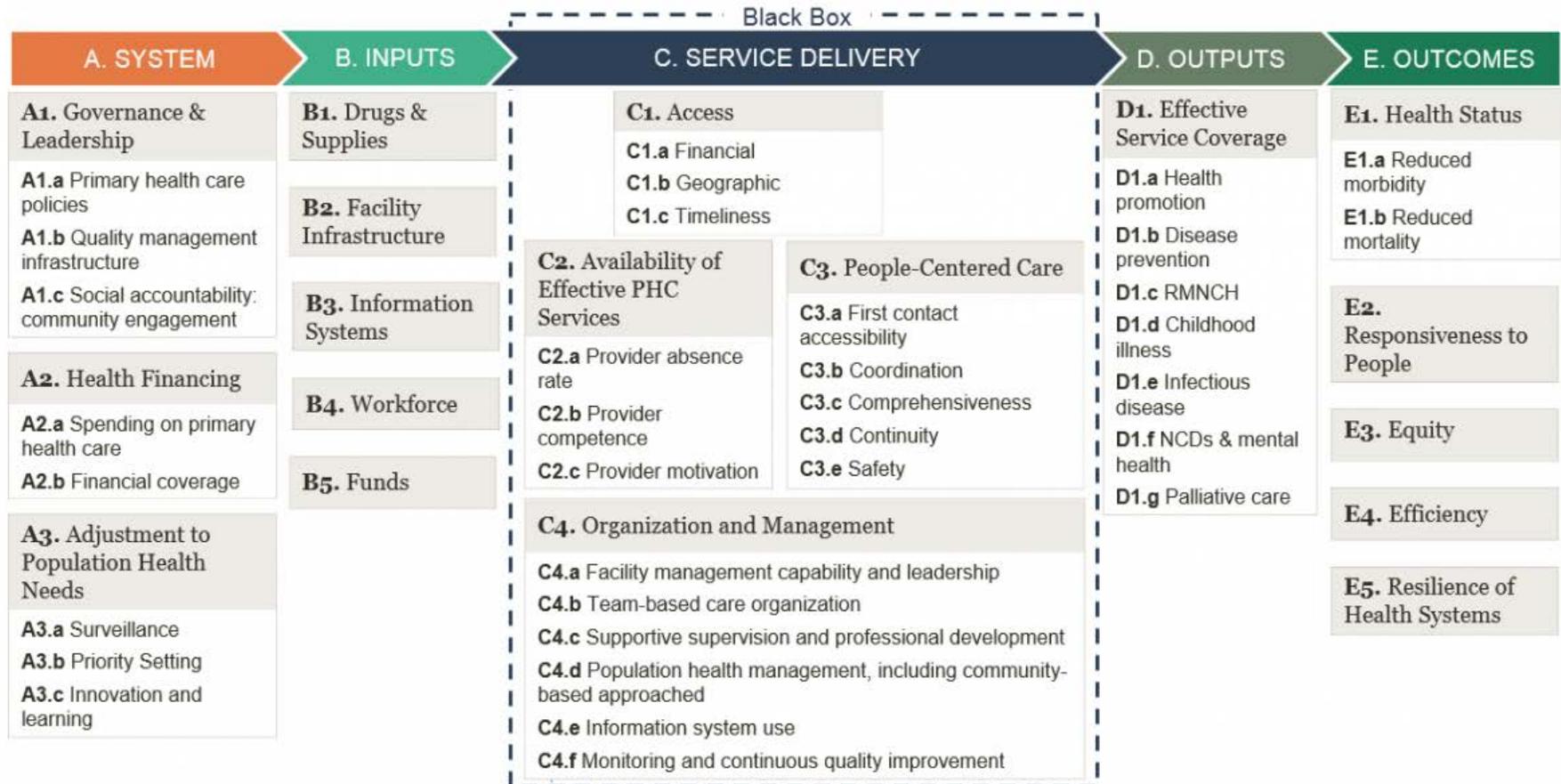
Despite the apparent lack of clarity about primary health care, there is consensus within the literature that strong primary health care promotes resilience, efficiency and equitability for all, including persons with disability. As the foundation of any national health system, primary health care connects all people and families with trusted health workers and supportive systems throughout their lives and provides access to services

ranging from family planning and routine immunizations to treatment of illness and management of chronic conditions.

In recognition of the universal importance of primary health care, in 2015 the Bill & Melinda Gates Foundation, World Bank Group and World Health Organization together launched a partnership to support best practice primary health care. They recognize that while many primary health systems internationally record various data inputs (number of health workers, medicines, supplies etc.), there is a global lack of measurement regarding the effectiveness of these systems. Their **Primary Health Care Performance Initiative (PHCPI) Conceptual Framework** (See Figure 1 next page) defines what the group considers important to measure in regards to primary health. In particular, this includes monitoring processes and recognizing the importance of the experience of those who receive care. The organization has launched an evidence-based database specifically for primary health care (<https://hse.phcperformanceinitiative.org/>) that includes ratings for reliability.

The PHCPI aims to address knowledge gaps by developing new indicators and data collection tools that can be useful for countries trying to improve the performance of their PHC system. These are relevant in regards to measuring the effectiveness of primary health within the CESP HN region, but also reflect the person-centred philosophy that underpins the NDIS.

Figure 1: PHCPI Conceptual Framework¹



¹ <http://phcperformanceinitiative.org/about-us/measuring-phc>

3.3.3 International: PHCPI Key Indicators for Primary Health Care

The key indicators used by the PHCPI include:

- **Access:** Do patients have affordable, timely access to PHC that is geographically convenient?
- **Availability of effective PHC services:** Are PHC facilities functioning, with workers who are motivated, competent, and equipped to provide PHC services?
- **People-centered care:** Does the system offer the well-established key functions of PHC including, first contact accessibility (from the user perspective), coordination, comprehensiveness, continuity, and safety?
- **Organization and Management:** Does the system appropriately organize and manage important elements of PHC delivery, including team-based care, supportive supervision, population health management, and use of information systems that aid in monitoring services and continually improve quality?

3.3.4 Australian Primary Health Care:

The Australian Primary Health Care Research Institute sets the definition of primary health care. This definition emphasises “first level care”.

...socially appropriate, universally accessible, scientifically sound first level care provided by health services and systems with a suitably trained workforce comprised of multi-disciplinary teams supported by integrated referral systems in a way that: gives priority to those most in need and addresses health inequalities; maximises community and individual self-reliance, participation and control; and involves collaboration and partnership with other sectors to promote public health. Comprehensive primary health care includes health promotion, illness prevention, treatment and care of the sick, community development, and advocacy and rehabilitation.

Source: Primary Health Care Research & Information Service (PHCRIS) Fact sheet (www.phcris.org.au)

3.3.5 Role of Primary Health Networks

In line with international developments, the Australian Government established Primary Health Networks (PHNs) on 1 July 2015. The Primary health networks play a particular role according to Michael W. Moore (in Booth et al, 2016) who states:

The PHNs are tasked with resolving service provision gaps in a cost-efficient manner. In many cases, these gaps, once revealed, can be filled by negotiation with existing providers. In some cases, PHNs may choose to step into the gap, funding new services through their small, discretionary, Commonwealth-provided, flexible funding budget. Frontline services funded by PHNs will be commissioned through external providers. In contrast to Medicare Locals, PHNs have greater economies of scale. They already commission a wide range of mental health-related services, with further commissioning roles being developed to address identified gaps in local service provision.

Source: (Booth et al, 2016)

This research was commissioned due to the lack of clarity of how PHNs may “step into the gap” to redress inequalities or lack of accessibility for those with disability, but in particular, regarding new gaps that may occur with the NDIS roll out in 2017.

3.3.6 Interaction between the health system and the NDIS

As outlined more fully in Section 4.1.1. principles were developed in April 2013 by the Council of Australian Governments (COAG) to address the division of responsibilities between the NDIS and other service systems, and in particular the interaction between the NDIS and health and hospital services. Thus, the NDS Background Paper commissioned in 2014 entitled *People with Disability and Hospitalisation: Challenges and Opportunities in NSW* states the following:

The [Commonwealth, State and Territory] health system will remain responsible for the diagnosis and clinical treatment of health conditions, including ongoing or chronic health conditions, and other activities that aim to improve the health status of Australians, including general practitioner services, medical specialist services, dental care, nursing, allied health services (including acute/post-acute), preventive health, care in public and private hospitals, pharmaceuticals, and other universal health entitlements.

The health system will also be responsible for funding time limited, goal-oriented services and therapies where the predominant purpose is treatment directly related to the person’s health status or after a recent medical or surgical event, with the aim of improving the person’s functional status including rehabilitation, palliative care, or post-acute care.

The NDIS will be responsible for supports related to a person's ongoing functional impairment and that enable the person to undertake activities of daily living, including "maintenance" supports delivered or supervised by clinically trained or qualified health practitioners where this is directly related to a functional impairment and integrally linked to the care and support a person requires to live in the community and participate in education and employment.

Source: NDS Background Paper (2014)

In many cases, a GP would work with the service provider or hospital to predict the needs of a person once they are discharged from hospital into the community. They may draw up a summary of current health, current medications plus support needs - particularly related to communication, eating requirements, and behaviours of concern. This may include listing the trigger points for these behaviours, and possible ways the hospital staff might adjust their interaction and environment to prevent or modify some of these behaviours –e.g. for people with autism/anxiety this may be having a quiet space, not giving too many verbal commands, and preventing over crowding in the room.

On discharge, the GP may also need to identify additional supports the person may require to minimise post-discharge adverse events. A person with functional limitations may be further compromised in regards to showering or the changes of dressings.

3.4 Disability Support

Within this research design, the term “disability support” was generally used to indicate the provision of supports and services to people with disability potentially available via individualised funding packages. Specifically, there are three areas of relevant support, with varying degrees of interaction with the NDIS:

- **NDIS funded supports and services** that relate **directly** to the provision of primary health (allied health professionals who may be NDIS funded to provide services)
- **NDIS funded supports and services** that relate **indirectly** to the provision of primary health (this includes transport, accommodation, care, and day programs)

- **Non NDIS-funded supports and services** which may benefit from adopting the philosophy and framework that NDIS is built upon (any GP or doctor's visits).

This will now be outlined with the rules for eligibility under the NDIS legislation.

4 THE NATIONAL DISABILITY INSURANCE SCHEME

4.1 NDIS background

The National Disability Insurance Scheme (NDIS) provides supports and services to people with a disability who are eligible for this scheme. It is based on the NDIS Act (2013), which is the legislation that underpins the scheme. The National Disability Insurance Agency (NDIA) is an independent commonwealth statutory agency that oversees and implements the NDIS. This reform involves a shift from block funding to individual funding. This means that although service providers/organisations have previously received government money to provide services to a set number of people, the money is now directed towards the individual with a disability.

The NDIS is being progressively rolled out across Australia. The NDIS areas that fall within the CESPHN boundaries are due to start rolling out in **July 2017**.

4.2 What NDIS funds

The NDIS will fund 'reasonable and necessary supports and services'. This is a term that is often used descriptively, however it is important to note that reasonable and necessary supports are a legislative requirement covered in Section 34 NDIS Act, (2103) and also detailed in the NDIS Rules.

4.1.1 The "Reasonable and necessary" legislation

National Disability Insurance Scheme Act (2013)

Section 34

Reasonable and necessary supports

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.

Source: The NDIS Act (2013)

4.1.2 The NDIS Rules “Reasonable and necessary” support

Schedule 1 Considerations relating to whether supports are most appropriately funded through the NDIS

7.1 The Act limits the supports that can be provided or funded under the NDIS to supports that are not more appropriately funded or provided through other service systems, for example as part of a universal services obligation or in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

7.2 The considerations set out in this Schedule must be taken into account by the CEO in deciding whether a support is more appropriately provided or funded by the NDIS or another service system.

7.3 For the avoidance of doubt, while this Schedule sets out considerations relevant to whether a support should be considered to be more appropriately provided or funded through another service system, it does not purport to impose any obligations on another service system to fund or provide particular supports.

Note: The considerations set out in this Schedule are derived from the Principles to determine the responsibilities of the NDIS and other service

systems, agreed to by the Council of Australian Governments, and dated Friday 19 April 2013. That document also includes principles relating to aged care. They are not relevant to this Schedule, but are given effect to in section 19 of the Act, and the National Disability Insurance Scheme (Becoming a Participant) Rules 2013.

Health (excluding mental health)

7.4 The NDIS will be responsible for supports related to a person's ongoing functional impairment and that enable the person to undertake activities of daily living, including maintenance supports delivered or supervised by clinically trained or qualified health practitioners where these are directly related to a functional impairment and integrally linked to the care and support a person requires to live in the community and participate in education and employment.

7.5 The NDIS will not be responsible for:

(a) the diagnosis and clinical treatment of health conditions, including ongoing or chronic health conditions; or

(b) other activities that aim to improve the health status of Australians, including general practitioner services, medical specialist services, dental care, nursing, allied health services (including acute and post-acute services), preventive health, care in public and private hospitals and pharmaceuticals or other universal entitlements; or

(c) funding time-limited, goal-oriented services and therapies:

(i) where the predominant purpose is treatment directly related to the person's health status; or

(ii) provided after a recent medical or surgical event, with the aim of improving the person's functional status, including rehabilitation or post-acute care; or

(d) palliative care.

Source: NDIS Rules (2013)

4.3 NDIS and health funding responsibilities

The interface between different funding sectors and the NDIS is complex, and health is no exception. Within the state and federal government bilateral agreements ("National Disability Insurance Scheme (NDIS) - Bilateral Agreement between Commonwealth and NSW - 16 September 2015 | Council of Australian Governments (COAG)" 2016), the responsibilities of health and NDIS were addressed. The NDIS has produced fact sheets outlining general guidelines regarding funding responsibilities. See Figure 2 below.

Figure 2 – NDIS Health Factsheet

The Scheme will fund supports that assist a participant to undertake activities of daily living required due to the person's disability. This includes:

- *aids and equipment such as wheelchairs, hearing aids and adjustable beds*
- *items such as prosthetics and artificial limbs (surgery remains the responsibility of the health system)*
- *home modifications, personal care and domestic assistance. This will assist participants exiting the health system to live independently in the community or move back into their own home*
- *allied health and other therapy where this is required as a result of the participant's impairment, including physiotherapy, speech therapy or occupational therapy. The health system is responsible for these supports if they are required as part of rehabilitation from an accident or injury or as part of treatment for medical conditions (see below).*

Supports funded by the health system

The health system has responsibility for assisting participants with clinical and medical treatment. This includes:

- *the diagnosis and assessment of health conditions clinical services and treatment of health conditions – including all medical services such as general practitioners, care while admitted in hospital, surgery, the cost of medical specialists and so on*
- *medications and pharmaceuticals*
- *sub-acute care such as palliative care, geriatric and psychogeriatric care*
- *post-acute care, including nursing care for treating health conditions and wound management*
- *dental care and all dental treatments.*

Which system assists with rehabilitation?

The Scheme and the health system will work closely together where a person needs rehabilitation following an accident or injury.

Where the initial rehabilitation is needed following injury, accident or other medical event, the support is the responsibility of the health system. This means that any surgery or treatment following an injury, accident or other medical event is not funded by the Scheme.

The health system would provide supports that enable a person to regain their maximum achievable level of functioning. This could include, for example, care in a

rehabilitation unit after a spinal cord injury.

The Scheme assists the participant once the health system has provided these rehabilitation services. The supports offered by the Scheme may include:

- *home modifications, aids and equipment*
- *personal care and domestic assistance to enable the participant to live independently in the community*
- *on-going allied health or other therapies to enable the participant to maintain their level of functioning.*

Which system assists with early intervention?

The Scheme will fund early intervention treatments for participants, which increase their functional capacity. This includes supports such as a speech therapy and occupational therapy. However, if the support is provided after a recent medical or surgical event, with the aim of improving the person's functional status, this support is the responsibility of the health system. This includes rehabilitation or post-acute care.

What happens if the health system doesn't fund the supports I need?

If the health system is responsible for a support, the Scheme cannot fund that support, even if the health system does not provide it.

However, the Scheme may still be able to provide assistance to participants, for example, a Local Area Coordinator can assist the participant to make contact and discuss their needs with appropriate healthcare providers.

Source: NDIS Factsheet – health and the NDIS

5 RESEARCH SCOPE

This document serves as a summary of the “desktop research” in regards to the literature that was reviewed, and the process by which the review was undertaken. This task was primarily intended as a precursor to the workshops and in order to identify pre-existing knowledge that may prepare CESP HN for the transition over to the NDIS.

During this stage CDS researchers conducted an intentional review of:

- grey literature (reports and documentation on NDIS available largely online)
- peer-reviewed published literature
- basic demographic information

The research also drew upon the expertise of the CDS staff and their knowledge about the NDIS, and what information was and was not accessible to the general public. All of the above formed the basis for recommendations to CESP HN.

6 Delimiters: What is ‘In Scope’ or ‘Out of Scope’?

Due to pragmatic constraints, there were a number of areas that were designated out of scope for the purposes of the peer-reviewed literature review. Others were unclear, and these areas are outlined below.

6.1 Out: Rural Areas

The vast majority of the CESP HN area is in the city. However, it is important to note that the CESP HN area does include Norfolk Island (pop 2210) and Lord Howe Island (pop 347), which are also covered in the NDIS. These areas will need further consideration.

6.2 Out: Ageing and Disability

The researchers note a clear correlation between disability and increasing age. That said however, the NDIS is currently only for people under the age of 65 (please see eligibility criteria). Considering that the focus of this project was to prepare CESP HN for the NDIS, our desktop research and literature review were both limited to people with disabilities under the age of 65.

6.3 Unclear: Secondary and Tertiary Level Health Services

There was a particularly grey area related to differing levels of the health services, the interaction with disability, and the NDIS. The chosen definition of “primary health care” determined that secondary and tertiary level health services were excluded from the search of the peer-reviewed literature. However, some findings are reviewed here.

6.4 Unclear: Australian Immigrants

Within the international literature, there is recognition that Culturally and Linguistically Diverse or CALD peoples with disability are particularly vulnerable.

The eligibility rules govern whether an immigrant is able to receive the NDIS.

Section 23

(1) A person meets the residence requirements if the person:

(a) resides in Australia; and

(b) is one of the following:

- (i) an Australian citizen;*
- (ii) the holder of a permanent visa;*
- (iii) a special category visa holder who is a protected SCV holder; and*
- (c) satisfies the other requirements in relation to residence that are prescribed by the National Disability Insurance Scheme rules.*
- (2) In deciding whether or not a person resides in Australia, regard must be had to:*
- (a) the nature of the accommodation used by the person in Australia; and*
- (b) the nature and extent of the family relationships the person has in Australia; and*
- (c) the nature and extent of the person's employment, business or financial ties with Australia; and*
- (d) the nature and extent of the person's assets located in Australia; and*
- (e) the frequency and duration of the person's travel outside Australia; and*
- (f) any other matter relevant to determining whether the person intends to remain permanently in Australia.*

Source: The NDIS Act (2013)

This suggests that there will be families on permanent resident visas that will be covered by the NDIS. Their specific needs in regards to primary health are not yet anticipated in the literature.

6.5 Existing Resources: Integrated Atlas of Mental Health

People with mental health conditions are eligible for NDIS funding (if they meet the criteria). Therefore this area was not excluded from the literature review. However, a comprehensive report on this topic was conducted for CESPHE by a range of organizations (See Integrated Atlas of Mental Health in Appendix). The Chief Investigator on this project was Luis Salvador-Carulla, Professor of Disability and

Mental Health at the Faculty of Health Sciences (University of Sydney). His field of interest is support decision systems and policy in long-term care, disability and mental health, and Intellectual Developmental Disorders.

The Integrated Atlas of Mental Health allows policy planners and decision makers to build bridges between the different sectors and to better allocate services. It includes the anticipated changes under the NDIS (p15) based on impacts to mental health services within other nations with individualised packages (p127). It outlines a range of available services within the CESPHE area such as non-acute in-patient and residential services (p54, 73), general support services (81) and employment services (p79).

Importantly, this document calibrates terminology of programs/services across local health areas and mental health networks. The Department of Health defines “Mental health services” as any services in which the primary function is specifically to provide people affected by mental illness or psychiatric disability, and/or their families and carers clinical treatment, rehabilitation or community support.

6.6 In: Caregivers and Family

Within this report, caregivers and family were included along with people with disabilities as the consumers of services and supports. We recognize, that carers play an integral role in the care of people with disabilities.

6.7 In: Restrictions on Access to Services and Advocacy

From the desktop research it became clear that advocacy for people with disabilities is increasingly important in regard to any person with disability gaining access to NDIS funding and ascertaining the best supports and services. Health professionals can assist individuals in contacting their peak advocacy body. We acknowledge that this is a critical area that requires greater attention, and perhaps future research.

7 DEMOGRAPHIC INFORMATION

Introduction

The following figures are estimates calculated from publically accessible sources (listed below), as very little data was available for the CESP HN region specifically. Data used to calculate the estimates below included:

- National Disability Insurance Agency. Market Position Statement, New South Wales. March 2016.
- Australian Bureau of Statistics. Survey of Disability, Ageing and Carers, Australia: 2015.
- Central and Eastern Sydney PHN Annual Report 2016.
- National Disability Insurance Scheme. Annual Report 2014-2015.

7.1 General population information for CESP HN region

- Population in CESP HN region as of 2016 = 1,497,186
- Expected population in 2031 = 1,851,500
- 49.8% men
- 50.2% women
- 35% born outside Australia (compared to 26% in all NSW)
- 35.2% speak a language other than English at home (compared to 22% in NSW)
- 0.8% Aboriginal (compared to 2.5% in all NSW)

Table 1 – Age breakdown of general CESP HN population

Age	Percentage of total CESP HN population
0-14 years old	15.7%
15-64 years old	70.9%
64+ years old	13.4%

Source: Central and Eastern Sydney PHN Annual Report 2016. The original source of the figures quoted in the CESP HN Annual Report are not cited. It appears however, that they are based on ABS data, and are therefore estimates derived from population figures.

7.2 Estimates relating to people with a disability within the CESPHN region

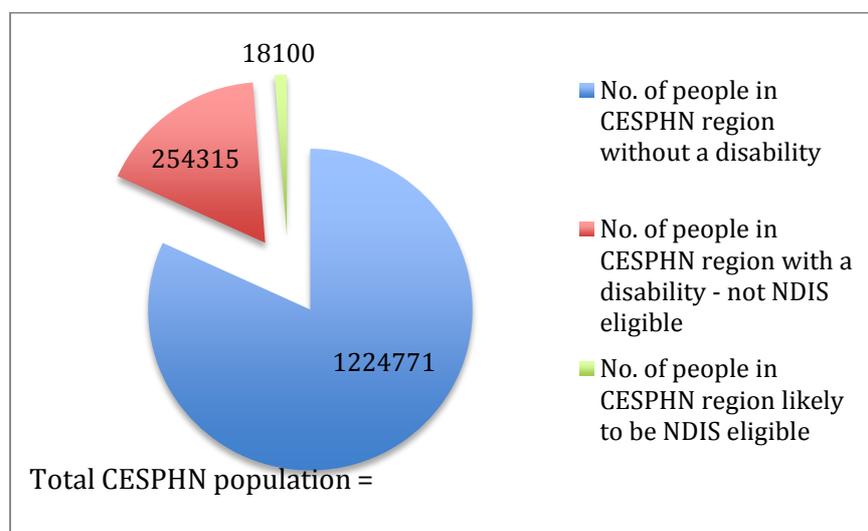
- Total number of people in the CESPHN region with a disability = 272,415
- Of this group, 44% are aged over 65 years (Table 2). People over the age of 65 years are not eligible for NDIS funding.
- Approximately 18,100 people are estimated to be eligible for NDIS funding (Figure 3 & Table 4)

Table 2 Age breakdown of people with a disability in CESPHN region

Age	Number of people with a disability in CESPHN region by age group
0-14 years old	20,672 (7% of all people with disability)
15-64 years old	132,894 (49% of all people with disability)
65+ years old	118,849 (44% of all people with disability)
Total people with a disability in CESPHN	272,415

Source: Estimates based on Australian Bureau of Statistics. Survey of Disability, Ageing and Carers, Australia: 2015. NSW level data.

Figure 3 - Proportion of people with a disability & NDIS eligible in CESPHN region (est)



- Number of people with a severe or profound disability in CESP HN region = 86,837
- This equates to 5.8% of the total population in the CESP HN region

Table 3 – Main diagnosis/condition as a percentage of people with disability

Main condition (Estimate based on ABS (NSW) data 2015)	%
<i>Physical conditions</i>	
Cancer, lymphomas and leukaemias	1.5%
Endocrine, nutritional and metabolic disorders	0.0%
Diabetes	2.5%
Disorders of the thyroid gland	0.5%
Other	0.3%
Diseases of the nervous system	6.3%
Diseases of the eye and adnexa	2.4%
Diseases of the ear and mastoid process	7.6%
Diseases of the circulatory system	0.0%
Heart disease	2.9%
Stroke	1.4%
Hypertension	1.5%
Other	0.8%
Diseases of the respiratory system	0.0%
Asthma	2.4%
Other	1.9%
Diseases of the digestive system	1.9%
Diseases of the musculo-skeletal system and connective tissue	0.0%
Arthritis and related disorders	14.3%
Back problems	13.2%
Other	4.9%
Congenital and perinatal disorders	0.6%
Injury, poisoning and other external causes	0.0%
Head injury and acquired brain injury	0.7%
Other	6.2%
Other physical conditions	6.2%
<i>Mental and behavioural disorders</i>	
Psychoses and mood affective disorders	0.0%
Dementia and Alzheimer's	2.7%
Depression and mood affective disorders	3.6%

Other	1.2%
Neurotic, stress-related and somatoform disorders	0.0%
Nervous tension and stress	1.6%
Other	3.0%
Intellectual and developmental disorders	5.9%
Other mental and behavioural disorders	2.5%
Total of all people with a disability in the CESP HN region (est)	100.0%

Source: Australian Bureau of Statistics. Survey of Disability, Ageing and Carers, Australia: 2015. NSW level data.

7.3 Estimates of people in the CESP HN region likely to be eligible for NDIS

Bilateral agreements between the Commonwealth NSW Governments (Council of Australian Governments (COAG) 2016) have resulted in actuarial estimates regarding the number of participants who will receive NDIS funding within each local health district. These estimates indicate that:

- 14,700 participants in the CESP HN region will enter the NDIS by June 2018, with this number anticipated to increase to 18,100 by June 2019 (Table 4)
- The total number (2019) equates to 1.2% of the overall CESP HN region population

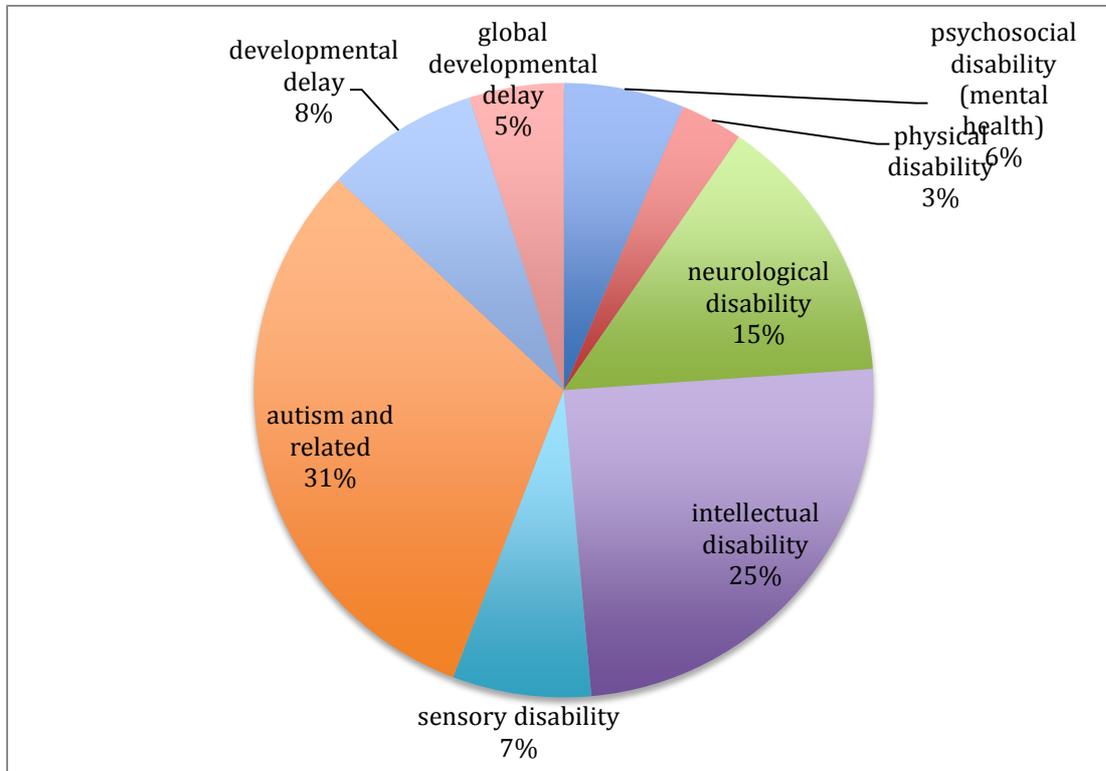
Table 4 NDIS participant estimates

Local Health District (LHD)	June 2018	June 2019	Participants per 100km²
South Eastern Sydney LHD	7700	9500	1967 participants
Sydney LHD	7000	8600	6930 participants
Total for CESP HN	14,700	18,100	8,897 participants

Source: NSW Market Position Statement, National Disability Insurance Scheme. March 2016¹

The estimated breakdown of people with a disability who are eligible for NDIS funding according to their primary diagnosis is displayed in the Figure below. These numbers are taken from national NDIA data to date.

Figure 4 – NDIS participants across all trial sites by primary diagnosis



Source: NDIS Annual Report 2014-2015 (National Disability Insurance Agency)

Estimated workforce engaged in providing disability support

The workforce engaged in providing disability supports within the region will need to increase to meet increased demand.

Table 5 Estimated disability workforce requirements

Local Health District (LHD)	Current workforce FTE	Estimated workforce FTE
South Eastern Sydney LHD	1600-2000	3150-3850
Sydney LHD	1450-1750	3150-3850
Total for CESP HN	3050-3750	6300-7700

Source: NSW Market Position Statement, National Disability Insurance Scheme. March 2016¹

PEER-REVIEWED LITERATURE: METHOD

Three researchers (Patricia O'Brien, Tanya Riches & Lanie Campbell) were involved in the production of this report. The purpose of this review was to identify any peer-reviewed literature that would assist CESP HN to prepare for the roll out of the NDIS. It was anticipated that there would be published papers that explored the interface between the primary health sector and NDIS, which could prove useful for CESP HN's planning. With this in mind, the researchers developed keywords that reflected the delimiters. This process was iterative, with modification of keywords and exclusion criteria along the way due to the open nature of this project. The methods and search strategies were documented at each stage to ensure transparency and rigour in line with an academic literature review.

7.4 Search methods for identification of studies

To be included in this review, records needed to be relevant to the interface between NDIS, disability and the primary health. Keywords were developed for each database by both researchers. The steps involved in the literature review are detailed below and displayed in Figure 5. Records were included if they related to the interface between NDIS and primary health.

7.5 Inclusions

- Records published between Jan 2011 – current were included. The year 2011 was chosen as the NDIS Act was introduced in 2013, and the aim of the project was to capture current literature around the interface between NDIS and primary health.

7.6 Exclusions

- Records relating to mental health were excluded as the Mental Health Atlas (a comprehensive report covering mental health) was completed for CESP HN recently.
- Records detailing specific health conditions and GPs role were excluded. If a health condition was discussed in relation to disability, the record was included.
- Records relating to school and education were excluded as this was outside the scope of this literature review.

7.7 Electronic database searches

The following databases were searched for English language records published between January 2011 and November 2016 (current). Ovid MEDLINE

- PsycINFO
- CINAHL (Cumulative Index to Nursing and Allied Health Literature).
- PubMed
- speechBITE
- OT seeker
- PEDro
- Google Scholar

7.8 Selection of relevant database records

Search terms were selected and adapted for each database after consultation between 2 review authors (LC and TR). LC performed the searches (Appendix 1). All records generated through the database searches were imported into Zotero reference manager. The same 2 reviewers then independently screened records for inclusion by title and abstract. The same reviewers compared records and any discrepancies between included records were discussed and inclusion/exclusion criteria re-examined. This process resulted in 100% agreement between the 2 reviewers. Duplicates were removed and the remaining full articles were retrieved.

7.9 Searching other sources

In addition to the database searches, a number of other searches were performed.

- Citation search in Google Scholar for each of the full articles retrieved
- Keyword search in speechBITE, OTseeker and PEDro
- Cochrane Database of Systematic reviews
- Keyword search in Primary Health Care Research & Information Service
- Google search with a range of keyword combinations
- Key journal keyword searches (e.g. Australian Health Review, Australian Journal of Public Administration)
- Keyword searches on a range of target websites (e.g. other CESP HN sites, Royal College for General Practitioners, Speech Pathology Australia)

7.10 Synthesis of records retrieved

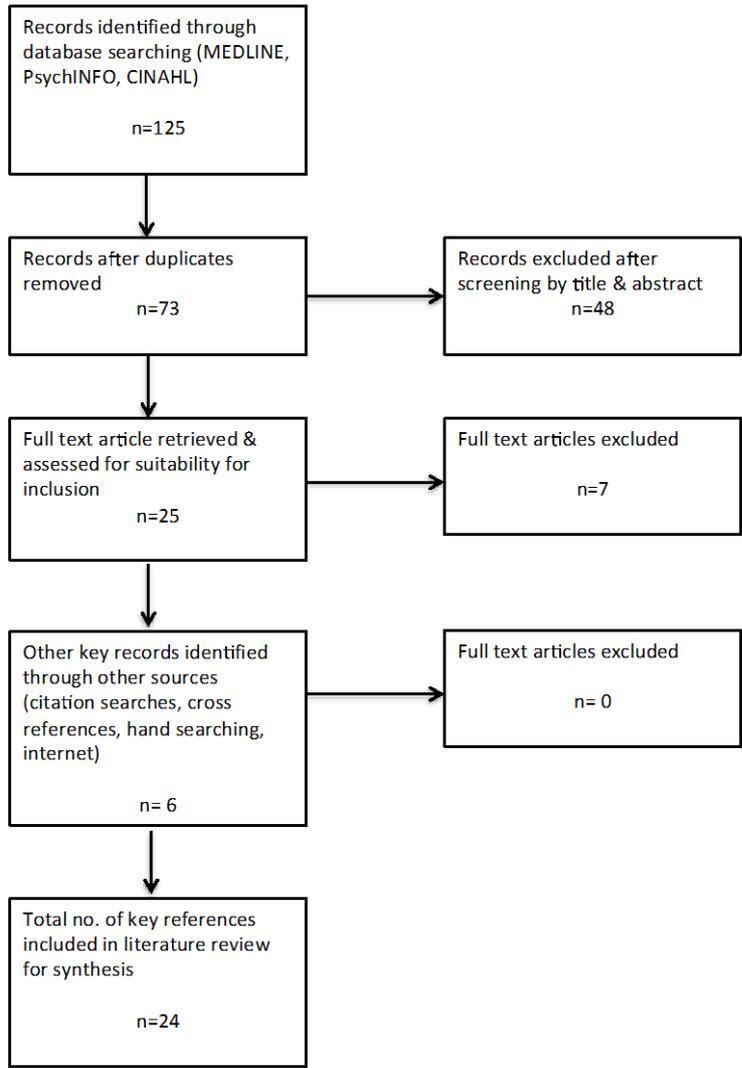
An evidence table was created to synthesise the information in the information from the records retrieved. Tags/topics were assigned and a brief summary of each record.

Tags/topics were then organised into themes and the findings organised according to these themes are reported in Section 6.3.

7.11 Search results

Figure 5 details the number of records retrieved through database and grey literature searching. Twenty-four key articles were targeted to synthesise for this project. Many other articles were also read and served to assist in background information. These references are listed at the end of this document also.

Figure 5 – Results from database literature search



8 Literature Review: The Findings

The next section reflects themes from the peer-reviewed literature, which was sorted into 5 areas:

- The interface of health and disability
- Philosophical underpinnings of individual funding
- Self direction and decision-making
- Information and resources
- Professional development and support

8.1 The Health and disability interface

As outlined in earlier sections, there is a complex interconnected relationship between a person's disability and their health, and it although it is not ideal to separate health and disability services, these funding streams are indeed separate in Australia (Gordon et al. 2012). This presents a special challenge for primary health professionals, as they are often working across both funding streams. Considering this from a person-centred approach, a person with disability may have a number of people in their support team including:

- Informal supports (family, friends, other community members),
- General practitioner and other medical specialists
- Allied health professionals
- Paid workers – care, transport, employment
- Education professionals
- Advocates or case managers

Each of these people may be funded from different sources, and be located in different places. The interaction and cohesion of this support team is of great importance to ensure quality health and disability service provision (Gordon et al. 2012; Collings, Dew, and Dowse 2016; Callaway et al. 2015). In some areas, such as social work (Bigby 2013), it is unclear how these professions can best function for people with disabilities under NDIS funding.

There are a number of ways that the academic literature recommends that the interface between the primary health sector and disability sector can be as seamless as possible.

This is particularly important in Australia at the moment, given the transition of the disability sector to individual funding. Primary health professionals can play a significant role in early detection, preventing hospitalisation and facilitating social and economic participation (Callaway et al. 2015). It notes that primary health professionals are often in a pivotal role to provide information, referrals and link people to their future support team (Beaumont 2016; Laragy et al. 2015). This does however mean that further professional development and education of primary health professionals is warranted.

People with disabilities often have different health issues from the greater population, some of which are related to their disability (Gordon et al. 2012). Many of these medical issues can take someone away from their usual roles in life, having a significant impact on what the NDIS terms “living an ordinary life.” Some health conditions such as pressure sores, spasms, and pain are more common amongst certain groups, e.g. people who have had a spinal cord injury or have cerebral palsy (Callaway et al. 2015).

8.2 Philosophical underpinnings of individual funding

The NDIS legislation’s underpinning philosophy is consistent with the international bio-psycho-social model of health. The social model of healthcare is considered good practice in primary health. It results in comprehensive collaboration that comes from the philosophical position that economic, political, environmental and economic factors need to be considered as co-determiners of health. It is envisioned that CESPAN and NDIS will be strong collaborators to help improve the outcomes for people with disabilities (Tracy and McDonald 2015).

There is also an international trend towards individual funding with the majority of countries in Western Europe and North America using individual funding in some form. Individual funding is not new to Australia, as it has been used at state levels previously. This, however, is the first national level scheme revolving around a piece of legislation and individual funding (Purcal, Fisher, and Laragy 2014) Individual funding has various permutations and labels in different countries including the terms self-managed care, consumer directed care, individual budgets and personalisation. Two major social changes have led to the push towards funding models that centre around the individual.

First, increasing competition and consumerism in the wider economy is seen mirrored within these government-funding models. Second is the increasing awareness and focus on human rights resulting in a push for people with a disability to have more control over the services they access.

However, individual funding policies do not automatically lead to greater choice and opportunities (Laragy et al. 2015), as the best ways to effectively implement them is still being developed. That said, evaluation of individual funding programs has been positive enough to expand them (Fisher KR, Gleeson R, Edwards R, et al. 2010). The authors Purcal, Fisher, and Laragy (2014) suggest that 3 elements need to be in place, in order for individual funding to be equitable.

- (1) Quality supports and services need to be available in the market
- (2) Supports for decision-making are also needed, especially for people who have an intellectual disability and/or have limited informal support networks
- (3) The rights of a person with disability, their informal support network and their paid workers need to be protected.

It is therefore important to consider the areas that this peer-reviewed literature suggests may increase the chance of success for people with disabilities. CESP HN may have a role to play in each of these three components, but particularly in supporting people with disability to make decisions in regards to health.

8.3 Self-direction and decision-making

Unsurprisingly, the literature suggests people with disabilities have a desire to be the primary person involved in decisions surrounding their own health and disability (Bellon, M., Pfeiffer, W., and Maurici, V. 2014; Fryer 2016). In fact, the concept of self-direction is central to the way the NDIS legislation and scheme has been designed. (Crozier and Muenchberger 2013) identified 4 key components of self-direction. These are:

- (1) participant control;
- (2) participant responsibility;
- (3) participant choice; and

(4) avoidance of conflict of interest.

In considering these components, it is clear that some people who will be eligible for the NDIS will need support and advocacy to ensure that their needs and life goals are well represented and supported (Collings, Dew, and Dowse 2016; Laragy et al. 2015). This is particularly the case for people with severe disabilities, as they face more barriers in accessing disability supports (Collings, Dew, and Dowse 2016; Laragy et al. 2015).

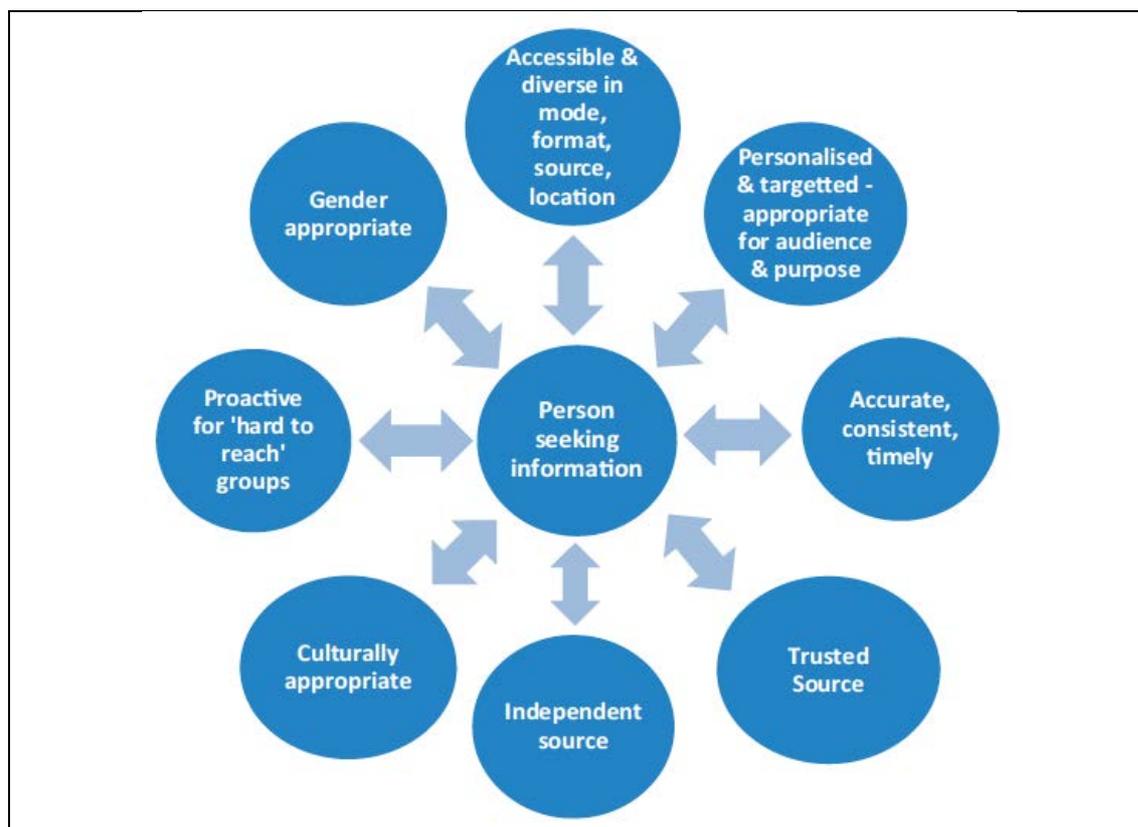
Collings, Dew, and Dowse (2016) suggest that a key litmus test of the NDIS will be how people with severe disability are enabled to make decisions and engage in their own plans. They define people with severe disabilities as people who have complex support needs, such as a combination of physical, communication and cognitive issues. People with severe disabilities have specific challenges in the NDIS planning process. The impact of impairment in communication and cognition, along with the fact that previous systems have often not encouraged involvement in decisions, often means that people with severe disabilities are not highly skilled in this area (Collings et al, 2016).

Two practical strategies that CESP HN may consider emerge from the literature. First, ensuring that primary health professionals have quality information for themselves as well as for the people with their disabilities and their support teams. Second, that primary health professionals receive quality ongoing professional development and support for working with PWD.

8.4 Information and resources

One of the cornerstones for individual funding to ensure that PWD have greater choice is increasing access to reliable, relevant information to aid decision making (Purcal, Fisher, and Laragy 2014). For this to occur, quality information is essential. Laragy, David, and Moran (2016) performed a rigorous analysis based on existing literature along with data from Australian studies of individualised funding programs. From their analysis, they have proposed a framework to help create resources that support PWD make informed decisions. Figure 6 illustrates the main components, and Table 5 details the information strategies that can be employed.

Figure 6 - Framework for information provision for individualised funding



Source: (Laragy et al. 2016)

In particular, the literature suggests that primary health professionals can play a leading role in helping people with disabilities to learn about the NDIS. Previous research suggests that customising information is important as different generations learn differently. Beaumont suggests that younger generations used social media and peer networking for their information, whereas older generations preferred face-to-face mode (Beaumont 2016). As NDIS participants are all under 65, this may skew the best mode of communication towards electronic.

Table 6 - Strategies for information provision. Relevant items selected from Laragy, David, and Moran (2016) Table 2, pg203-204

Principle	Information Strategies
Accessible and diverse in mode, format, Source and location	<ul style="list-style-type: none"> • easy to find, accessible and in plain language • both general and local information are made available

	<ul style="list-style-type: none"> • diverse formats and modes including face to face, telephone and IT
Personalised, targeted, appropriate for audience and purpose	<ul style="list-style-type: none"> • Professionals learn about people's needs • Information is appropriate to impairment, age, cultural background, stage in the funding and service pathway • Front line workers and family carers are trained and supported to provide information to person needing supports
Accurate, consistent and timely	<ul style="list-style-type: none"> • Professionals and service providers seek regular update and disseminate to services and staff through professional development and training programmes • Information feedback loops created between service user and professionals/service providers to adjust services as required
Trusted source	<ul style="list-style-type: none"> • Information comes from trusted source • Accurate appropriate information is provided • Continuity of trusted professional relationships is encouraged where appropriate
Independent source	<ul style="list-style-type: none"> • Information available independent of service providers • Advocacy groups and informal peer networks fostered to provide independent information
Culturally appropriate	<ul style="list-style-type: none"> • Professionals and front line workers have relevant cultural competence considering impairment, age, gender and community. This requires professional development and supervision. • Access ethnic groups through appropriate points of access

	<p>where culturally necessary or appropriate e.g. Elders and community leaders</p> <ul style="list-style-type: none"> • Provide written and verbal information in person's language where possible and provide interpreters as required
Proactive strategies for hard to reach groups	<ul style="list-style-type: none"> • Proactive steps taken to reach people who do not regularly access mainstream courses appropriate to their needs. E.g. disability impairment, Aboriginal and Torres Strait Islander, CALD backgrounds and socially and economically disadvantages • Information informed by differing cultural conceptions of disability
Gender appropriate	<ul style="list-style-type: none"> • Professionals and front line workers exercise relevant gender awareness • Consider gender-related barriers to sourcing information such as time, carer duties and accessibility

8.5 Professional development and support

Disability specific professional development for primary health professionals is critical for optimal health and disability service provision. People with disabilities often have a more complex interplay between their various life components (RESEARCH ROUNDup 2016; Sullivan et al. 2011) and therefore need a health practitioner to liaise closely with the patient's family and support network. They also often need longer consultation times also due to communication, cognitive and physical complexities. This may have systemic and practical implications along with primary health professionals needing special skills and extra supports for this to become a reality (Tracy and McDonald 2015). It was not until 2011 that the Royal College of General Practitioners included a chapter on disability in their curriculum (Practitioners 2016). The need for professional development, skill building and support for primary health professionals is echoed widely in the academic literature (Collings, Dew, and Dowse 2016; Bigby 2013; Davis et

al. 2015; Gordon et al. 2012; Laragy, David, and Moran 2016; Laragy et al. 2015; Beaumont 2016; Tracy and McDonald 2015).

Ideally, disability specific education would begin at an undergraduate level (Tracy and McDonald 2015), as there is consensus that universities are not adequately preparing students for their work with PWD (“World Health Organisation Report on Disability” 2016). Best practice at both undergraduate and postgraduate level education would include PWD to be involved in delivering the training (Tracy and Iacono 2008).

Professional development and resource development is warranted to ensure that primary health professionals have a way to stay abreast of the current evidence-base that informs their practice. Some recommended best practice examples in the literature, included mounting evidence to support regular health checks for people with intellectual disability (Robertson et al. 2014; Gordon et al. 2012) and skill training to help PWD to self-manage their care. Fryer’s (2016) high quality systematic literature review suggests that specific skills training (e.g. for goal setting and problem solving) improve PWD’s quality of life and feelings of self-efficacy. Although this systematic review involved people who had a stroke, it is likely that other populations would benefit from this approach also. Health professionals are potentially in a prime position to provide these types of supports, which although outside of their usual core supports, could be integrated and have considerable wide ranging benefits.

9 RECOMMENDATIONS

CESPHN can play an important part in ensuring that primary health professionals are delivering quality supports.

(1) Development of New Resources: It is recommended that resources are developed for PWD according to the framework outlined in Section 6.3.4 within a variety of formats so that primary health professionals are able to direct PWD to customised, culturally and age appropriate information. This framework could be easily adapted as a checklist.

(2) Promoting Education and Advocacy: It is recommended that primary health professionals are educated to ensure that they are aware of general referral sources for additional support, advocacy, and case management to help PWD access and negotiate NDIS funding. CESPHN may choose to develop these resources for distribution.

(3) Promoting Professional Development: Consider creating quality professional development for primary health professionals regarding specific skills training to help PWD and their informal support networks with goal setting, problem solving, coping and financial management would also be recommended. CESPHN may play a key role in supporting and providing professional development within their region, including NDIS service providers and their wider membership. The aim of this support and professional development is to ensure that members are embracing best practice prevention and management of secondary health conditions that are commonly related to certain disability diagnoses (Callaway et al. 2015).

(4) Workshop Specific Recommendations: The workshops that are being conducted in addition to this literature review should provide specific recommendations in the areas covered here.

(5) Preventing Hospitalisation: Primary health aims to identify risks and to set protocols in place to prevent or to treat early complications. Given the literature review, the following section outlines the role primary health may play in preventing the hospitalisation of a person with disability covered by the NDIS. These recommendations

were written in collaboration with Dr Seeta Durvasula from the Centre for Disability Studies.

GPs need to be proactive in checking conditions the person may be at risk of. To enable the optimal health, wellbeing and functioning of a person with disability four key trigger points are addressed below.

Trigger Point 1: Aspiration

People with severe physical and intellectual disabilities and dysphagia (difficulty swallowing) are at risk of aspiration (Therapeutic Guidelines Ltd 2012). To prevent people suffering from aspiration:

- Regular health reviews are recommended
- Ensure immunization is up to date and address issues early
- The GP would need to coordinate a multidisciplinary team to ensure that a persons' food and drink is modified to allow them to swallow safely. People with intellectual disability may not be able to report symptoms because of limited communication and this would include a speech pathologist, dietician to ensure that they are having nutritious food in purees and may recommend additional caloric supplements if they are underweight OTs may be required to make sure that the person has the right equipment for eating (modified spoons, aids to sit up straight).
- Prophylactic antibiotics through the Winter months

Trigger Point 2: Polypharmacy

Many people with intellectual disability are on multiple medications and are therefore at risk of adverse drug events due to polypharmacy. A regular medication review is recommended, with a rationalization of medications where possible.

Trigger Point 3: Epilepsy seizures

Between 25-30% of people with intellectual disability have epilepsy, compared to 1% of the general population (McGrother et al 2006). Optimal seizure

management is important to prevent hospitalisation. Strategies include the identification of triggers for seizures, regular review of anticonvulsants and their doses by a neurologist, and development of an epilepsy management plan with the family and the support organisations. The epilepsy management plan should be reviewed and kept up to date. Appropriate training of support staff is crucial.

Trigger Point 4: Behaviours of Concern (Challenging Behaviours)

Behaviours of Concern occur frequently with people with intellectual disability and are usually a reflection of underlying conditions such as physical pain or discomfort; mental health conditions such as anxiety and depression; or environmental factors. These behaviours may include aggression, self-injury or property destruction. In some circumstances people with extreme levels of aggression may be admitted to psychiatric facilities. The GP has a role in working with allied health professionals such as psychologists and speech pathologists to identify the underlying cause for the behaviour, and attempt to address it. The GP would need to consider common sources of pain such as dental abscess, constipation, gastro-oesophageal reflux. The psychologist or behaviour support professional would conduct a behaviour analysis to identify triggers, and the speech pathologist would do a communication assessment and develop communication strategies for the person so they can effectively communicate their pain or distress. By treating the physical causes and/or developing an effective behaviour support plan that includes response to acute situations this may prevent some hospital admissions.

This project's focus groups may provide more localised and specific information regarding mapping the professional development needs of service providers in the CESPAN area.

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Appendix 1 - Database search strategy

Ovid MEDLINE

Database: Ovid MEDLINE(R) <1946 to October Week 4 2016>

Search Strategy:

-
- 1 National disability insurance scheme.mp. (16)
 - 2 from 1 keep 2-3,5,8-9,13-14,16 (8)
 - 3 Community Health Centers/ or Adult/ or Primary Health Care/ or primary health.mp. (4428227)
 - 4 general practice.mp. or Family Practice/ or General Practice/ (85522)
 - 5 Allied Health Personnel/ or allied health.mp. (14839)
 - 6 NDIS.mp. (63)
 - 7 national disability insurance scheme.mp. (16)
 - 8 South Australia/ or australia.mp. or Australia/ or Western Australia/ (119839)
 - 9 3 or 4 or 5 (4499459)
 - 10 6 or 7 (75)
 - 11 8 and 9 and 10 (5)
 - 12 National disability insurance scheme.mp. (16)
 - 13 Community Health Centers/ or Adult/ or Primary Health Care/ or primary health.mp. (4428227)
 - 14 general practice.mp. or Family Practice/ or General Practice/ (85522)
 - 15 Allied Health Personnel/ or allied health.mp. (14839)
 - 16 NDIS.mp. (63)
 - 17 national disability insurance scheme.mp. (16)
 - 18 South Australia/ or australia.mp. or Australia/ or Western Australia/ (119839)
 - 19 13 or 14 or 15 (4499459)
 - 20 16 or 17 (75)
 - 21 18 and 19 and 20 (5)
 - 22 National disability insurance scheme.mp. (16)
 - 23 primary health.mp. (72681)

- 24 disability.mp. (167670)
- 25 limit 24 to yr=2011 -Current (45844)
- 26 23 and 24 and 25 (463)
- 27 26 and 18 (17)
- 28 Community Health Centers/ or Adult/ or Primary Health Care/ or primary health.mp. (4428227)
- 29 general practice.mp. or Family Practice/ or General Practice/ (85522)
- 30 Allied Health Personnel/ or allied health.mp. (14839)
- 31 NDIS.mp. (63)
- 32 national disability insurance scheme.mp. (16)
- 33 South Australia/ or australia.mp. or Australia/ or Western Australia/ (119839)
- 34 28 or 29 or 30 (4499459)
- 35 31 or 32 (75)
- 36 33 and 34 and 35 (5)

PsychINFO

Database: PsycINFO <1806 to October Week 5 2016>

Search Strategy:

- 1 primary health.mp. (16881)
- 2 general practice.mp. (4427)
- 3 allied health.mp. (2510)
- 4 exp Evidence Based Practice/ or exp Speech Therapy/ or exp Speech Language Pathology/ or exp Speech Development/ or exp Communication Disorders/ or speech pathology.mp. (68810)
- 5 occupational therapy.mp. or exp Occupational Therapy/ (7842)
- 6 physiotherapy.mp. or exp Physical Therapy/ (3298)
- 7 disability.mp. or exp DEVELOPMENTAL DISABILITIES/ or exp MULTIPLE DISABILITIES/ or exp ACCOMMODATION (DISABILITIES)/ or exp LEARNING DISABILITIES/ or exp SENSORY DISABILITIES (ATTITUDES TOWARD)/ or exp DISABILITIES/ or exp PHYSICAL DISABILITIES (ATTITUDES TOWARD)/ (108310)

- 8 national disability insurance scheme.mp. (26)
- 9 1 or 2 or 3 or 4 or 5 or 6 (101076)
- 10 7 or 8 (108310)
- 11 9 and 10 (13547)
- 12 limit 11 to yr=2011 (671)
- 13 limit 12 to (english language and (100 childhood <birth to age 12 yrs> or 120 neonatal <birth to age 1 mo> or 140 infancy <2 to 23 mo> or 160 preschool age <age 2 to 5 yrs> or 180 school age <age 6 to 12 yrs> or 200 adolescence <age 13 to 17 yrs> or 300 adulthood <age 18 yrs and older> or 320 young adulthood <age 18 to 29 yrs> or 340 thirties <age 30 to 39 yrs> or 360 middle age <age 40 to 64 yrs>) and english and human) (477)
- 14 Australia.mp. (27420)
- 15 12 and 13 and 14 (3)

CINAHL EBSCO

Keyword search “national disability insurance” (24)

Google Scholar

Advanced search 1: primary health National Disability Insurance Scheme (754)

Advanced search 2: general practitioner National Disability Insurance Scheme (1002)

First 50 returns were reviewed (title and abstract)