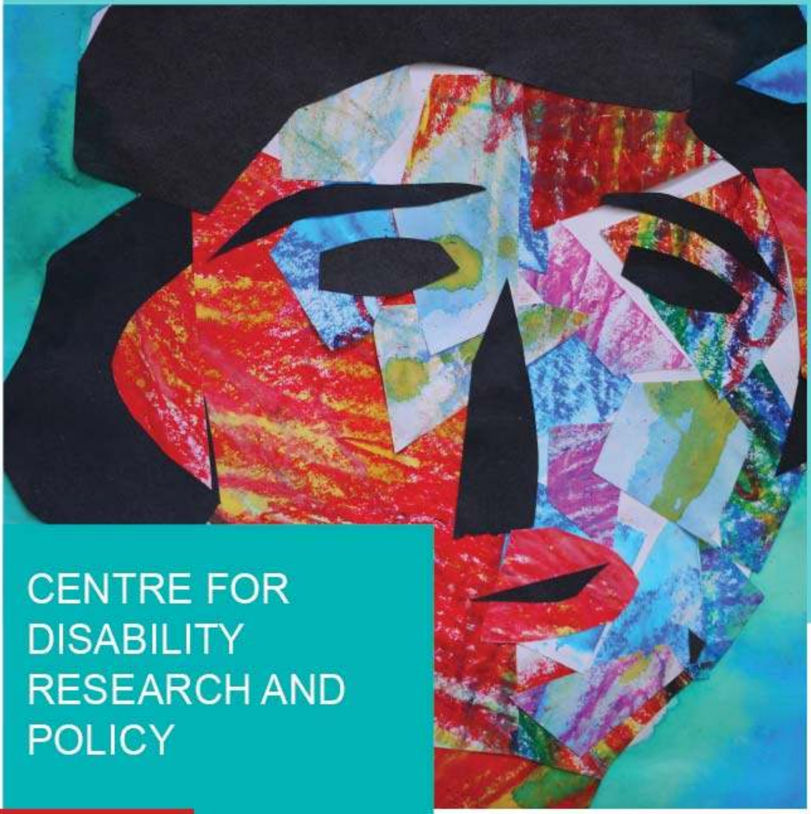
Report of Audit of Disability Research in Australia



CENTRE FOR
DISABILITY
RESEARCH AND
POLICY

THE UNIVERSITY OF
SYDNEY

Report of Audit of Disability Research in Australia

Centre for Disability Research and Policy
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Executive Summary

Introduction

In June 2012, the former Disability Policy and Research Working Group, representing inter-governmental disability officials, offered a tender for an *Audit of Disability Research in Australia*. This report details the findings of and process for conducting this Audit. The Audit was undertaken over a 14 month period to the end April 2014 by the Centre for Disability Research and Policy, University of Sydney with team members from People with Disabilities Australia (PWDA), National Disability Strategy (NDS) and University of Melbourne. The Audit team was supported by an Advisory Committee representing NGOs in the sector, DPOs and the DPRWG.

The main aim of the Audit of Disability Research was to produce a report that provides a comprehensive picture of the current state of disability research in Australia. It was expected that the Audit of Disability Research would explore and determine the gaps in disability research evidence so that areas that have not been well resourced previously or where there has been little research to date can be targeted (Audit of Disability Research Tender Specification, June 2012).

The process of conducting the Audit covered three inter-related components.

The first component entailed developing a conceptual framework based on the human rights and social equity approaches embedded in national legislative, governance and policy documents. These approaches promote the social and economic participation of people with disabilities, their health and wellbeing.

The second component involved reviewing the scientific and grey literature from 2000 to 2013 to produce a descriptive map of disability research in Australia in this time period. This stage provided a broad analysis based on title and abstract of all research meeting the criteria determined for the purpose of the Audit. The analysis focused on identifying gaps in disability research and ascertaining research challenges to develop recommendations for improvement or addressing gaps.

The third component involved a review of evaluation of evidence frameworks used most typically in health, social services and policy research. This review provided the foundation for developing a ‘fit for purpose’ hierarchy of evidence framework that could be used to guide disability research in the future.

The report is presented in two documents. The first document contains the Executive Summary and the main body of the report in four Sections.

Executive Summary

Section 1: Background and Method for Conducting the Audit of Disability Research in Australia

Section 2: Scope of Disability Research in Australia, 2000-2013

Section 3: Evaluation of Evidence Framework, Research Gaps and Recommendations

Section 4: References for Sections 1 to 3.

The second document contains five Attachments.

Attachment 1. Conceptual Framework for Audit of Disability Research in Australia

Attachment 2. Search Strategies and Results

Attachment 3. Coding Processes

Attachment 4: Narrative Analysis

Attachment 5: Literature Database

Summary of findings

Finding 1.

In the time period 2000-2013 the quantum of disability research in Australia meeting the criteria for the Audit amounted to 2011 research documents. Of these, 1658 came from the scientific literature and 353 sourced from the grey literature.

It is not possible to know whether this is a good, satisfactory or poor result. Research is not usually scoped according to country of origin. There are however good reasons for doing so and particularly in a time of significant disability reform.

The Audit's main finding is that the current disability research base is not 'fit for purpose' to the reform agenda and is fragmented and diversified across topics and study designs. There is not a critical mass of research on topics of priority to the National Disability Strategy, the National Disability Research and Development Agenda and the National Disability Insurance Scheme.

Significant strategic and systematic investment in Australian disability research relevant to the national policy context is urgently needed to advance research informed policy in Australia.

Finding 2.

There are particular challenges in accessing disability research in Australia. Disability research is not easily accessible or widely available for example in open-access publications or easy to negotiate websites.

Ideally, people with disability, family and carers, policy makers, government and non-government service providers, practitioners, peak and advocacy organisations and members of the public – in other words, everyone - could readily access evidence on topics of priority in the disability reform agenda. This is not currently the case. There is major under-utilisation of open access journals by researchers due to the costs involved. Websites in the public domain may be difficult to navigate; websites hosted by professional or service organisations may restrict access to members only or charge for purchasing a research report.

This 'invisibility' and lack of free access to disability research in Australia severely limits the reach and impact of this research in meeting the desired outcomes of the National Disability Strategy. Targeted strategies are needed to support open access and wide dissemination in multiple formats through diverse distribution channels.

Finding 3.

A sustainable and mature research base requires focus, depth, quality and coherence. On these criteria, disability research is at an early stage of development in Australia. The overall impression arising from the Audit is of primarily stand-alone, one-off studies in topics of researcher or organizational interest. (There are exceptions to this however these are rather rare).

There is a greater concentration of disability research in Australia where there are established funding bases as in the health sector and to a lesser extent in education. Important though both areas are, they are only two of the six outcome areas in the National Disability Strategy. There is significantly less research in the Strategy's other four Strategy outcome areas: inclusive and accessible communities, rights protection, justice and legislation, economic security, and personal and community support. This augurs poorly for evidence informed policy initiatives relevant to the Australian context in these critical life areas.

Building a mature and sustainable disability research base requires ongoing investment to educate, support, attract and retain researchers in universities, institutes, and government and non-government organisations. Without such investment, individual researchers and organisations remain reliant on whatever sources of funding they can access.

Successful disability research funding models in other countries involve investment in strategic and priority areas. The focus is on research production and research training to build capacity now and for the future. Funding is programmatic allowing the building of a substantive base of knowledge over time and supplemented by targeted calls for research when new priorities arise. Funding is delivered through a network of disability training and research centres, each focusing on particular agreed strategic areas. There is much less reliance (as is the case in Australia) on distributing the research dollar broadly across a multitude of funding schemes and thinly spread across individual researchers.

Finding 4.

The disability reform agenda leans heavily on human rights and social equity principles. The values base is about choice and control, empowerment, and person-centred support. This requires that people with disability have every opportunity to engage in and drive all decisions which affect their lives. Concepts such as choice, empowerment, and person-centred support are noticeable by their relative absence from the current disability research base. A concentrated effort is required to stimulate research which addresses the concepts that are explicit in the disability reform agenda.

Research which involves consumers in all stages of design, planning, implementation and dissemination is gaining currency internationally. However, co-produced research is mostly missing from the disability research base in Australia identified in the Audit. (There are rare exceptions). In keeping with the values base of the disability reform agenda, there is an urgent need to stimulate research which is co-produced with people with disability and their representative organisations and to develop guidelines for the ethical conduct of such research.

Finding 5.

By far the greatest proportion of the research identified in the Audit *does not address* the profile, experience or issues affecting the four diverse and/ or disadvantaged groups of people with disability nominated in the National Disability Research and Development Agenda. These are Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds, women with disability, and people in regional, rural and remote areas. The neglect of the particular experiences and needs of these groups of people with disability is a major oversight which needs to be addressed.

Finding 6.

Study design is a crucial factor in the type of knowledge that can be generated in research studies. Types of knowledge vary across disciplines with study designs being selected according to the type of knowledge being sought. Overall, the Audit found a higher proportion of study designs which explore or investigate attitudes, knowledge or perspectives. These studies essentially describe the ‘problem’. While an important contribution, descriptive research cannot produce evidence based solutions (although it may propose solutions to be tested in the future).

There was much less research utilising study designs which test interventions or solutions or evaluate policy initiatives. In other words study designs that allow us to know what works, and ideally, for whom and under what conditions. Research that can determine what works and in which settings is urgently needed. For example, the disability reform agenda aims to ensure people with disability can access and use mainstream activities and services to participate fully in all aspects of society. Research on how to achieve accessible and participatory mainstream services, and at scale and across all sectors is currently missing from the disability research base in Australia.

There are encouraging signs of uptake of study designs using secondary analysis of population data and administrative datasets. These studies examine larger samples which are more likely to be representative and permit comparison of the circumstances of people with disability with those of their non-disabled peers. It would be misleading to only focus on the situation of people with disability. Without comparison within and between groups of people we cannot know whether the policy initiatives of the disability reform agenda are working, and in the desired direction, and for whom.

Finding 7.

The following areas are significantly under-represented in the disability research base:

- Safety and security, transport and communication, housing and the built environment, social relationships and community and civic participation
- Inclusion and participation of children and young people with disability in everyday life
- Experiences of people with disability as
    - Specialist service users in relation to preference, choice, control, goals and, desired outcomes– in health, education, employment, housing, sexuality, personal relationships, marriage and family, transport, communication technologies
    - Users of mainstream services in relation to preference, choice, control, goals, and desired outcomes – in health, education, community and civic participation, transport and communication, safety and security and housing and the built environment
- Effective models of accessible and adaptable mainstream services which deliver useful outcomes for people with disability
- Longitudinal studies that follow people with disability over time to better understand the potential drivers (social, economic, cultural, impairment-related) of inequalities
- Issues specific to the Aboriginal and Torres Strait Islander people with a disability, women with disability, people with disability from culturally and linguistically diverse backgrounds and people with disability living in regional, rural and remote areas
- Co-production of research with people with disability

Finding 8.

Suggested ways forward in each of five areas based on more detailed analysis of focus, contribution, gaps and relevance to policy context are as follows.

Aboriginal and Torres Strait Islander peoples

- Funding disability research with Aboriginal and Torres Strait Islander people proportional to the multiple strategies in the current policy context focusing on reducing disadvantage.
- Funding disability researchers to develop best practice guidelines for participatory, inclusive research with Aboriginal and Torres Strait Islander people with a disability, their family and carers.
- Dedicated funding to stimulating disability research that addresses the needs and experiences of Aboriginal and Torres Strait Islander carers.

- Requiring disability researchers to address the application of their findings to practice in collaboration with the Aboriginal and Torres Strait Islander people and communities who participated in the research.

Policy analysis studies

- Dedicated funding for research focusing on multidisciplinary approaches to disability policy evaluation.
- Funding of disability research to include funds for the dissemination of research in open access journals.
- Stimulating disability research which explores the experience of policy from the perspective of consumers, carers and practitioners.
- Stimulating the development of cost-effectiveness research in disability to inform policy.
- Stimulating the alignment of fit for purpose monitoring and performance indicators with policy initiatives to allow for effective evaluation and innovation.
- Developing disability policy research which focuses on the needs and experiences of Aboriginal and Torres Strait Islander people.

Research utilising administrative datasets

- Stimulating the use by disability researchers and policy makers of registries and routine surveys and datasets.
- Extending available datasets to collection of data on children and young people with disabilities.
- Collection of more comprehensive data and investment in research on priority groups including Aboriginal and Torres Strait Islander people with disability, women with disability, culturally and linguistically diverse groups and people living in regional, rural and remote areas within currently available datasets.
- Stimulating inclusion of DPOs and other key stakeholders by requiring disability researchers to collaborate with DPOs and other key stakeholders in design, implementation and dissemination of research using administrative datasets.
- Investigating in collaboration with ABS and AIHW a common set of questions on disability in all population-based surveys and promotion of the use of these questions in all population research (along the same lines as standard demographic questions).
- Working with the AIHW as the first accredited centre for the linkage of government data to design mechanisms for accessing data about specific disabilities (e.g. intellectual disability, traumatic brain injury) for linkage to other databases and to enable the selection of participants for studies. This investment is particularly important in advancing research on the causes and consequences of disability.
- Expanding the Population Health Research Network endeavours on a national data-linkage facility to include a focus on disability such as that established in Western Australia to better address the complex intersections between multiple domains (e.g. health, employment, disability, income support, and housing assistance).
- Developing accessible processes to obtain consent from participants recruited into studies for linkage of their data to administrative data (e.g. Medicare, income support).

Research utilising population data

- Developing methods (through data linkage or the inclusion of a set of standardised questions for use in generic surveys) of identifying survey participants who are in receipt of NDIS supported services and extending the sampling frame of selected surveys to include people living in various forms of supported accommodation and nursing homes.
- Stimulating the use by disability researchers of available longitudinal datasets.
- Further development of a longitudinal disability-specific survey in Australia.

Reports from Australian Institute of Health and Welfare, Australian Bureau of Statistics and Productivity Commission

- Requiring disability researchers to become familiar with these main sources of national data on disability, and consider the value of secondary analysis of them, or of collecting data that can be related to them or the national disability data standards.
- Including (i) better data on Environmental Factors (e.g. technology, attitudes); (ii) fuller data on participation e.g. use of the national data standard on 'satisfaction' with participation, so as to indicate people's feelings of choice and control in each life area; (iii) continuing effort to improve data on Aboriginal and Torres Straits Islander peoples, in partnership with Aboriginal researchers and thinkers; and (iv) new effort in analyses of disability and service access among people of culturally and linguistically diverse background – startlingly absent from the data analyses, given the significant presence of these groups in the Australian population and the newly available data since the 2006 Census.
- Increased efforts and investment to adopt the 'standardised disability identifier', developed by AIHW, into mainstream service data systems as administrative data on access to mainstream services are largely missing.
- Investment in research which specifically addresses the distinctions between long term, permanent and lifelong disability to inform the further development of NDIS inclusion and assessment practices.

Recommendations

In the short term, that consideration is given to:

1. Commissioning secondary research (systematic reviews, secondary analysis of population and administrative data) to take advantage of this robust and cost efficient mechanism.
2. Commissioning a formal research priority setting exercise (based on the methodology developed by WHO) to identify disability research priorities in Australia as articulated by people with disabilities, family/ carers, policy makers and service providers.
3. Dedicated investment to stimulate disability research which explores the experience of policy from the perspectives of consumers, carers and practitioners.
4. Including funds within disability research to ensure wider dissemination of research. This would include open access journals and freely available, accessible reports on 'unlocked' websites with dedicated research sections and stable URLs.
5. Investment in maintenance and biennial update of the Audit of Disability Research in Australia database to provide an ongoing resource to identify research gaps, enable monitoring of disability research in Australia over time, and assist in developing research collaborations to build capacity, coherence and critical mass in disability research.

In the medium term, that consideration is given to:

6. Dedicated funding for co-production of research with people with disability and DPOs including developing guidelines on disability inclusive rights based research.
7. Collection of more comprehensive data and stimulating research on priority groups including Aboriginal and Torres Strait Islander people with disability, women with disability, culturally and linguistically diverse groups and people living in regional, rural and remote areas and children and young people.
8. Increased efforts and investment to adopt the 'standardised disability identifier', developed by AIHW, into mainstream service data systems as administrative data on access to mainstream services are largely missing.
9. Routine reporting of disability statistics, including prevalence, living circumstances and health and wellbeing, by age, sex, geography, ethnicity and Aboriginal and Torres Strait Islander peoples.
10. Programmatic funding to a network of centres with specific expertise and focus to build disability research capacity (training and research production) in agreed strategic and priority areas.

11.

Section 1: Background and Method for Conducting the Audit of Disability Research in Australia

Background

The Audit of Disability Research in Australia (the Audit) was offered for tender by the DPRWG in June 2012 against the background of the National Disability Research and Development Agenda[1], the National Disability Agreement (NDA)[2], the National Disability Strategy (NDS)[3], and the National Disability Insurance Scheme (NDIS)[4].

The broad aims of the National Disability Research and Development Agenda (hereafter referred to as the Agenda) are to 'facilitate the creation of a comprehensive evidence base and the foundations of robust research that will inform policies and practices of the disability sector, governments and the mainstream community" (p. 4).

Aim

The main aim of the Audit of Disability Research was to produce a report that provides a comprehensive picture of the current state of disability research evidence in Australia. It was expected that the Audit of Disability Research would explore and determine the gaps in disability research evidence so that areas that have not been well resourced previously or where there has been little research to date can be targeted (Audit of Disability Research Tender Specification, June 2012). Specifically the Audit report was to focus on identifying gaps in disability research and ascertaining research challenges to inform the work of intergovernmental disability committee officials.

Assumptions Underpinning the Audit of Disability Research in Australia

Disability Policy and Research Context

As set out in the Audit Tender Specifications (June 2012), the Audit aim and process was driven by consideration of the National Disability Research and Development Agenda (2011), hereafter referred to as the Agenda. The Agenda specifies five directions for National Disability Research and Development. The Directions are:

- Australian disability demographic profile and trend information, including access to social and economic inclusion data.

- Disability related social and economic inclusion research including research which focuses on human rights, participation in community life, access to mainstream activities and services, and broader systems change.
- Evaluations, reviews and research to contribute to the evidence base to improve service delivery and support options. Analysis of the factors that support sector sustainability, sector development and improved organisational capability.
- Research on the profile, experiences and issues affecting diverse and/or disadvantaged groups of people with disability, such as:
    - Aboriginal and Torres Strait Islander communities
    - People from culturally and linguistically diverse backgrounds
    - Women with disability
    - People in regional, rural and remote areas.

Development of the Agenda was informed by the National Disability Agreement (NDA, 2009)[2], the National Disability Strategy 2010-2020 (NDS, 2011)[3], the National Carer Strategy[5] (NCS, 2011), the Productivity Commission Inquiry into National Disability Long-term Care and Support Scheme (2011)[4] and subsequently the National Disability Insurance Scheme (NDIS, 2012). The Audit of relevant research on disability in Australia was conducted taking into account this disability policy and research context.

Scope of Audit

The aim of the Audit was to produce a comprehensive picture of the current state of disability research evidence in Australia. This aim is analogous to a descriptive mapping of the scope of available disability research. For clarity, it was understood that:

- *The Audit is only concerned with disability research which is readily available and accessible* in the scientific literature and the grey literature. It is not intended to be an exhaustive investigation for research which cannot be easily identified or accessed.
- *The Audit represents a scoping* of the available and accessible disability research from the scientific and grey literature. It was not intended as a systematic review or series of systematic reviews as commonly understood[6]. As befits an audit process, the approach taken was to combine traditional search and review techniques together with descriptive mapping to present a picture of the current state of disability research in Australia. However, the database compiled for the Audit presents an excellent resource for the future conduct of systematic reviews on topics of relevance to intergovernmental disability committee officials.
- *The outcomes of the Audit* will be limited inevitably by the quality of the data available. The ability to generalize from this data will be dependent on depth and/or breadth of the disability research evidence.

Time Frame for the Audit

The time frame for the searches undertaken for the Audit was from 2000 to 13th November 2013. This extended period offered greater opportunities to capture research closer to Report completion and a longer time period to enable organisations providing grey literature to undertake this resource intensive task.

Definitions of Research and Inclusion and Exclusion Criteria

Definition of Research for Purposes of the Audit

The definition of research adopted for the Audit was that of the former Australian Government Department of Innovation, Industry, Science and Research and Tertiary Education, now the Department of Industry, outlined below:

> Research is defined as the creation of new knowledge and/or the use of existing knowledge in a new and creative way so as to generate new concepts, methodologies and understandings. This could include synthesis and analysis of previous research to the extent that it leads to new and creative outcomes.

Criteria for inclusion and exclusion for the Audit

Scientific literature

Inclusion criteria

i. Published in a peer reviewed journal

ii. A paper which documents the results of an investigation and/or secondary analysis of existing data reporting the aim of the investigation, method, findings and conclusions and/or recommendations.

iii. A full paper or report that meets criteria (i) and (ii) above.

Exclusion criteria

i. An opinion piece, viewpoint, perspective or invited comment

ii. Research which is primarily medical, surgical, clinical or pharmacological

iii. Not easily accessible via the internet or electronically via library subscriptions

Grey literature

Inclusion criteria

i. That available on a website, by request, as an organizational document available from disability related networks, government documents, theses and research that is reported as underway either by website or in response to request

ii. Documents that report the result of investigating a particular topic/ topics using data either from original sources or as secondary analysis of existing data. Such documents need to include the aim of the investigation, the method used, the findings and conclusions and/or recommendations.

iii. A full paper or brief report that meets criteria (i) and (ii).

Exclusion criteria

i. Opinion piece, viewpoint, perspective or invited comment
ii. Research which is primarily medical, surgical, clinical or pharmacological
iii. A descriptive article of one case study
iv. Not accessible on a public website in a reasonable period of time using a straightforward search strategy
v. Media releases and presentations on research

In keeping with the definition of research provided above, stories of lived experience in the form of single case studies or aggregated case studies were included if consistent with all other criteria. Although the importance of capturing the lived experience of people with disability as frequently reported for example in NGO newsletters is recognised, purely descriptive stories of one case study were not considered to meet the criteria for research for the purposes of this Audit.

Method

Multi-disciplinary Research Team and Advisory Group

Research Team

The Research Team was led by Professor Gwynnyth Llewellyn, Director, Centre for Disability Research and Policy, University of Sydney. The team included Professor Eric Emerson, Dr Jennifer Smith-Merry, Dr John Gilroy, Ms. Ros Madden, Ms. Kathy Thorncraft from the University of Sydney, Professor Anne Kavanagh, University of Melbourne, Ms. Therese Sands, People with Disabilities Australia (PWDA), and Gordon Duff on behalf of Ken Baker, National Disability Services (NDS). Dr Tracy Robinson and Dr Rebecca Barton were Research Fellows for the Audit assisted by Dr Andy Schmidt in October- November 2013.

The Advisory Group

- Australian Federation of Disability Organisations: Lesley Hall (then Matthew Wright)
- Carers NSW: Elena Katrakis (then Timothy Broady)
- Children with Disability Australia: Stephanie Gottlieb
- Australian Government Department of Social Services, representing the former DPRWG: Karen Wilson
- Family Advocacy: Belinda Epstein-Frisch
- First Peoples Disability Network Australia: Damian Griffis

- National Ethnic Disability Alliance: Norhawa Bee Mohamed Ismail
- National People with Disabilities and Carers Council: Lorna Hallahan
- Siblings Australia: Kate Strohm
- Women with Disabilities Australia: Iva Strnadova

Process

The Audit progressed through the day to day work of the core research team – Llewellyn, Robinson, Barton and Thorncraft – with regular face to face or telephone team meetings of the Research Team and Advisory Group, and one on one consultation as required. The Research Team and Advisory Group were involved in design, conceptualization and implementation discussions for the project and input into and review of the Report.

The process of conducting the Audit covered three inter-related components.

The first component entailed developing a conceptual framework based on the human rights and social equity approaches embedded in the Australian legislative, governance and policy documents. The primary driver in the Australian policy context is to promote the social and economic participation of people with disabilities, their health and wellbeing. The conceptual framework is described below. .

The second component involved reviewing the scientific and grey literature from 2000 to 2013 to produce a descriptive map of disability research in Australia during this time period. Analysis of the descriptive map focused on identifying gaps in disability research and ascertaining research challenges to develop recommendations for addressing gaps in the research base. The findings on the current state of disability research in Australia are presented in Section 2 of this Report.

The third component involved a review of evaluation of evidence frameworks used most typically in health, social services and policy research. This review provided the foundation for developing a 'fit for purpose' hierarchy of evidence framework that could be used to guide disability research in the future. The proposed fit for purpose evaluation of evidence framework is explained in Section 3 of this Report along with the research gaps and the recommendations. Section 4 of the Report contains a listing of all references in the Audit database.

Conceptual Framework

A conceptual framework for the Audit was developed to:

i. Guide the search for documents in the scientific and grey literature
ii. Code documents meeting Audit criteria and
iii. Guide the analysis of all included documents.

This framework was drawn from the UN Convention on Rights of Persons with Disabilities[7] and specific Australian policy documents as follows:

i. National Disability Strategy, 2010-2020 (2011)[3]
ii. National Research and Development Agenda (2011)[1]
iii. Australian Framework for Social Inclusion (2010)[8]
iv. Australian Gender Indicators Framework (2012)[9].

The frameworks adopted in the World Report on Disability (2011)[10] and the Community–based Rehabilitation (CBR) Guidelines and Matrix (2010)[11] were also taken into account. The International Classification of Functioning, Disability and Health (ICF) [12] informed the dimensions identified in the conceptual framework. These documents enshrine human rights and social equity approaches to disability and utilise the bio psychosocial- cultural-environmental model of disability.

The conceptual framework underwent several revisions by the core research team with input gathered at face to face meetings, on line meetings, teleconferences and email exchanges with the full Research Team and the Advisory Group. The conceptual framework was finalised in July 2013 to guide the search and coding processes.

Explanation of the Conceptual Framework

At the centre of the conceptual framework is the person (child or adult) with a disability. Surrounding the person with disability are their family (including parents, siblings, extended family), carers, friends and neighbours. People with disability and their family and carers are understood to have interests in and concerns about eight domains of everyday life. In this conceptual framework these domains cover community and civic participation, economic participation and security, education, health and wellbeing, housing and the built environment, safety and security, social relationships, and transport and communication.

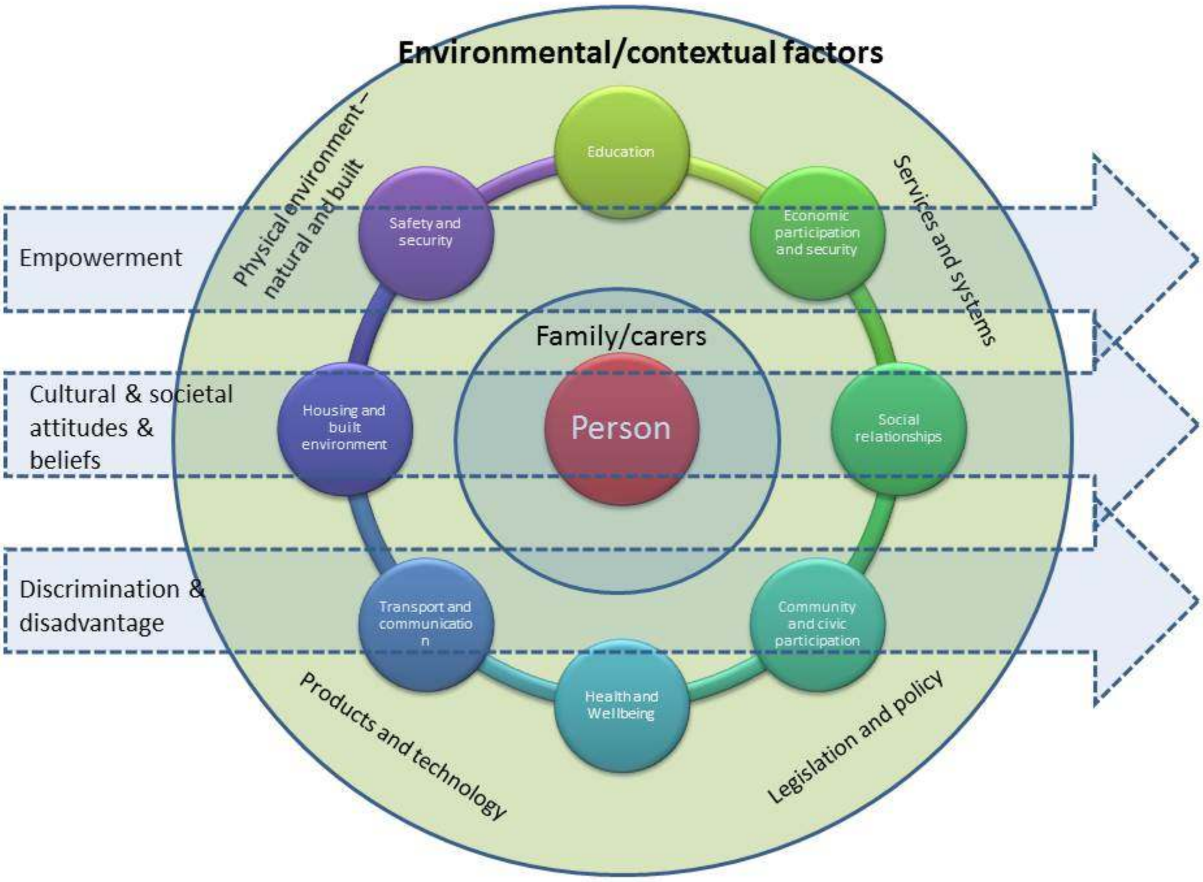
The eight domains of everyday life are illustrated in Figure 1. Importantly, domains are analogous to multi-dimensional constructs and therefore bring together many dimensions under the domain heading. A full description of the domains and associated dimensions is appended as Attachment 1.

Domains of life do not capture the multiplicity of factors which influence and impact on the lives of people with disability and their family/carers. The conceptual framework takes these influences into account in two ways. First, the framework acknowledges within four inter-linked quadrants the impact of the physical environment both natural and built, services and systems, legislation and policy, and products and technology on the lives of people with disability and their family/ carers.

Second, there are three cross-cutting issues determined as highly relevant to the everyday lives of people with disability and their family/carers, their social and economic participation and their health and wellbeing, and the exercising of their fundamental rights and freedoms as embedded in the UN Convention on the Rights of Persons with Disabilities[7]. These are:

- empowerment described here as the extent to which people with disability have control over their lives and their participation in society
- cultural and societal attitudes and beliefs
- discrimination and disadvantage with a focus on exclusion and barriers to participation broadly conceived.

Figure 1. Conceptual framework for the Audit



Search Methods

Scientific Literature

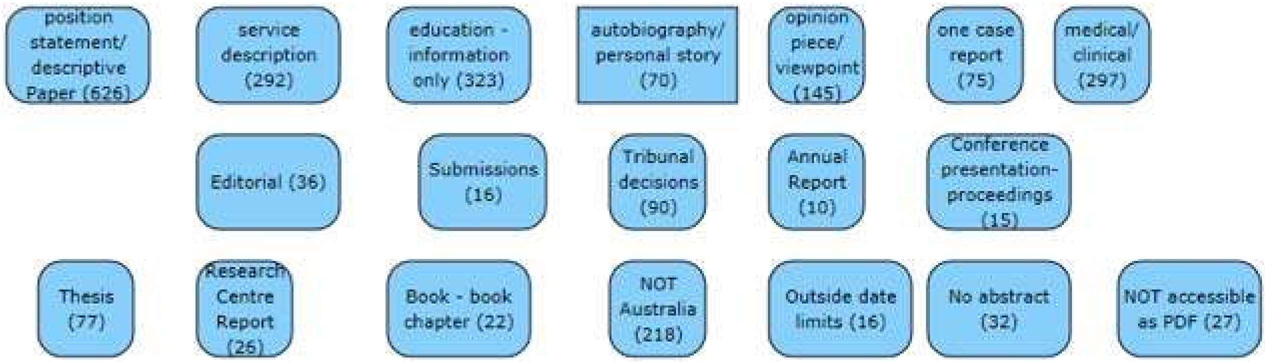
Full details of the search strategy and results for the scientific literature are included in Attachment 2.

Data bases searched were: AMED, Avery, CINAHL, Compendex, ERIC, Informit (including the following databases - A+Education, Ausport, Families & Society Collection, Humanities & Social Sciences Collection, Literature & Culture Collection, Indigenous Australia, AGIS, FAMILY, APAIS, AMI, AusSportMed, Heath & Society Collection, Health Collection, RURAL, Transport Index, ALISA, BUILD, ENGINE, ARCH), Medline, PsycINFO,Scopus, Sociological Abstracts and Web of Science.

Using this method across the multiple databases and eight single content domains of the conceptual framework – education, economic participation and security, social relationships, community and civic participation, health and wellbeing, transport and communication, housing and the built environment, and safety and security –10,432 items remained for possible inclusion after duplicates removal and initial screening. Of these, 1819 items did not have an abstract. The remaining 8491 potentially relevant documents were loaded into EPPI 4 Reviewer[1] software for further screening and analysis.

Bulk searches in EPPI 4 Reviewer removed a further 678 documents which included duplicates, those *not relevant by type of paper* (e.g. editorial, book review) and *not relevant by target group* (e.g. ADHD, frail elderly, low back pain) leaving 7813 for individual screening. The exclusion category *not relevant by target group* refers to 'conditions' not included as disabilities in ABS data definitions. Individual screening resulted in a further 3158 documents excluded as *not relevant by target group* and a further 2201 documents which, although relevant by target group, were excluded by *type of paper* (e.g. autobiography, education –information piece only, service description). All documents were reviewed to ensure that the study reported was conducted in Australia or as part of cross country study including Australia data. The number of excluded documents in each category by *type of paper* is illustrated in Figure 2. Note NOT accessible as PDF document describes documents not available electronically in any format.

Figure 2.



Grey Literature

Full details of the search strategy and results for the grey literature are appended as Attachment 3. Eight data sources were initially identified as follows: Federal, State and Territory Government Department Reports; Federal, State and Territory Agencies and Commissions Reports; Research Centre Reports; NGO Research Reports; Doctoral Theses; Books and Book Chapters; Published Abstracts/ Conference Proceedings; and Australian Standard®.

Three data sources did not reveal items suitable for inclusion. The 54 disability relevant Australian Standard® did not meet Audit research inclusion criteria. Screening of a random selection of published abstracts/ conference proceedings (initially 593 with an additional 15 identified during screening in EPPI 4 Reviewer data base) suggested that very few would meet Audit inclusion criteria, requiring intense resource effort for very little return. Of the initial 491 items books and book chapters the majority were text books or review chapters, educational manuals or practical guides none of which met the criteria for research. Consequently, Australian Standards®, Published Abstracts/ Conference Proceedings, and Books and Book Chapters were not included in the review and coding phase.

The final number of grey literature documents included in the Audit following screening was 353. Sources and frequency of research documents in the grey literature are shown in Table 1.

Table 1. Sources and frequency of research documents in the grey literature

Source	Number	Percentage %
Government reports	51	14
Statutory agency reports	21	6
AIHW/ ABS reports	115	33
Research Centre reports	65	18
Non-government organisations	63	18
Doctoral theses*	38	11
Total	353	100

**theses with no publications in scientific literature*

Analysis Methods

Descriptive Mapping

Descriptive mapping aims to identify the scope of research activity in a given field. Typically therefore it is undertaken using key wording strategies on computerized searches and the subsequent results are bulk coded under a small number of key aspects – for example population focus, study design and so on. Using reference management or systematic review software scoping a field of research endeavor by keywording is time and resource efficient and effective.

It became apparent very early that keywording as a primary strategy for the Audit project would not be adequate for the task of scoping relevant research in the disability sector. The reasons for this are as follows. First, disability is an umbrella term or multi-dimensional construct which requires specification by those responsible for classification and categorization in scientific literature databases and in the grey literature which is primarily accessed by websites. There is no one standard approach to this which created significant challenges in identifying research which is relevant to the aim of the Audit. Second, meaning and definitions given to the term disability are relative (and therefore different) to particular time periods, disciplinary fields, organizational stakeholder base and focus (e.g. NGOs or Statutory Agencies), and to classification and categorization of research documents in international scientific publications databases. Third, there is the same lack of standard definitions and meaning given to concepts/ terms which are regularly used in the disability field such as inclusion, participation, mainstream, choice, empowerment and so on. The diversity of meaning given to these concepts is exacerbated in the scientific literature where editorial policy determines which particular terms are used.

Fourth, terms used have different meanings dependent on country context. The British term learning difficulties is a case in point used in the UK to refer to people with intellectual disability. In Australia this terms refers to people (most frequently children and young people) with specific literacy and numeracy learning difficulties, not intellectual disability.

For these reasons the Audit required a much more resource intensive approach to descriptive mapping than using the keywording strategy. All potentially relevant documents required individual reading of title and abstract (and if necessary full text document) to determine whether the document met inclusion criteria. The Research Team and Advisory Group took the view that for the purposes of the Audit disability would be understood as described in Article 1 of the UN Convention on the Rights of Persons with Disabilities as follows:

> Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers

may hinder their full and effective participation in society on an equal basis with others[7] .

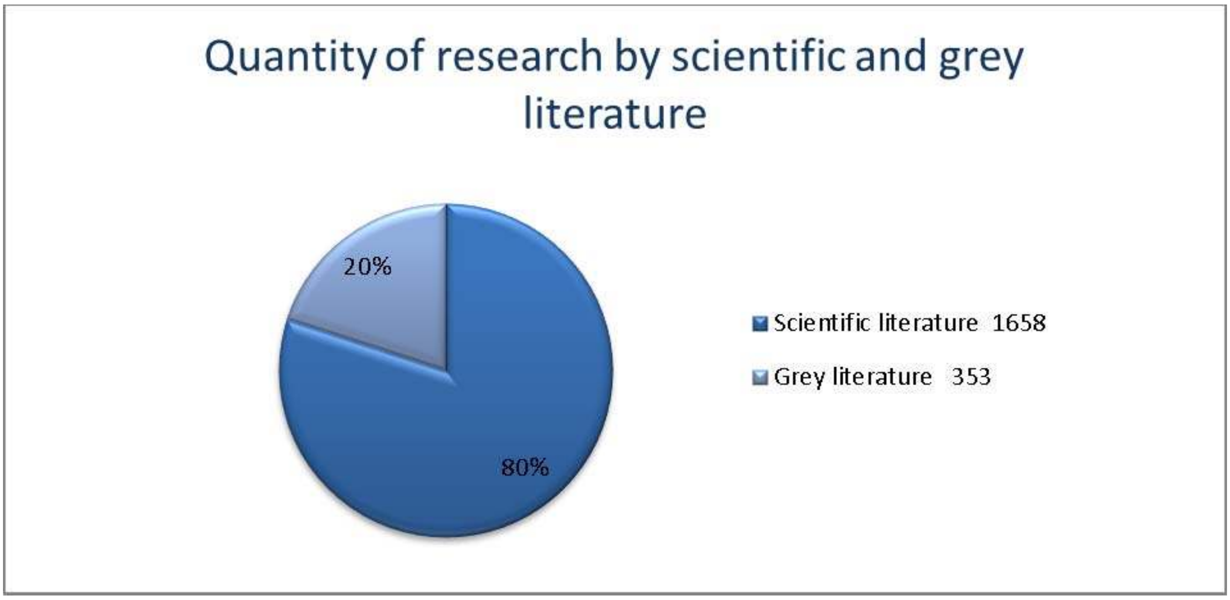
Analysis Framework

The analysis framework for the Audit comprised four components. These were:

- The conceptual framework described above and in detail in Attachment 1
- A framework to differentiate type of investigation developed for the purposes of the Audit and detailed in Attachment 3
- Keywording on concepts/ terms emphasized in the current policy context
- Narrative analysis in topic areas where it was anticipated there would be added benefit and value.

A total of 2011 documents from the scientific and grey literature met the Audit criteria (included documents) and were subsequently coded for analysis. The 1658 included documents from the scientific literature (1658) were coded in EPPI 4 Reviewer[2]. The 353 included documents from the grey literature were coded in EndNote X7. Proportion of included documents by literature type is illustrated in Figure 3.

Figure 3



Coding

The details of the coding processes undertaken are appended in Attachment 3. All documents were coded using title and abstract according to:

- The domains in the conceptual framework taking into account the dimensions under each domain

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[22] EPPI 4 Reviewer http://eppi.ioe.ac.uk/cms/Default.aspx?alias=eppi.ioe.ac.uk/cms/er4

- By family/carers or services to identify research studies which focused primarily on one or other
- By the four diverse and/or disadvantaged groups nominated in the Agenda
- By study design/ type of investigation
- By environmental/ contextual factors to align with the four factors in the conceptual framework

Coding by domain

All research documents were coded exclusively into one of 8 single domain categories or 2 multiple domain categories as follows: Community and Civic Participation; Education; Economic Participation and Security; Health and Wellbeing; Housing and the Built Environment; Safety and Security; or Transport and Communication. Studies that addressed multiple domains were coded as ‘More than One Domain but Not All’ or as ‘All Domains’.

Coding by family/carers or services

Research documents that addressed family/ carers or services were coded by these categories to differentiate these studies from those addressing people with disability.

Coding by diverse and/or disadvantaged groups

Research documents that *specifically focused* on one or more of the four Agenda nominated diverse and/or disadvantaged groups were coded as Aboriginal and Torres Strait Islander peoples; people from culturally and linguistically diverse backgrounds; women with disability; and people living in regional, rural and remote areas.

Coding by study design/ type of investigation

Determining the scope and quantity of research according to the type of investigation/ study design was undertaken by review of all titles and abstracts and where necessary review of the full text document. The framework to differentiate type of investigation framework was broadly based to include disability research from across disciplinary fields. This framework does not equate to a hierarchy in relation to quality of study design or evidence of strength of study design. There were 17 mutually exclusive categories in this framework. These are intervention studies (randomised controlled trials (hereafter RCTs), study protocol only, observational studies), secondary analysis studies (population data, administrative datasets, file audit/ document review), literature review (systematic review, narrative review), measure development studies, questionnaire studies, qualitative studies, mixed methods investigation, policy analysis, legal analysis, historical analysis, and media/creative arts/ cultural analysis.

Coding by environmental/ contextual factors

Research documents that *specifically addressed* any one or more of the following were coded accordingly as legislation and policy, physical environment, attitudes/ disability identity, and products and technology.

Keywording analysis

Using keywording as a time efficient and effective method to descriptively map was not possible due to the complexity and multi-dimensional nature of the Audit. Instead, keywording was employed on selected concepts/ terms after detailed coding on the scientific literature had taken place. The concepts/ terms used were those emphasized in the current policy context. These were: attitudes; choice; disability, discrimination and law; empowerment; family-centred; health promotion; identity; person-centred support; and quality of life.

Narrative analysis on selected topic areas

Narrative analysis of selected topic areas was employed to address focus, contribution, gaps and relevance to policy context of research in selected areas. The analysis undertaken by members of the Research Team used a guiding framework as follows: What relevant research with particular emphases or focus has been undertaken in Australia during the time period? What is the overall contribution of this body of literature to the disability sector broadly speaking? What has been the impact of this body of research broadly speaking for example for policy, governance, in service provision and/or initiatives, and in practice? What utility, applicability, value and relevance does this research have for people with disability? How well does this research meet the requirements of the current policy context? What gaps are there in this particular area because there are topics that are little researched or because the research methodologies used to date are inadequate? What additional research needs to be undertaken in this area?

Development of recommendations

Recommendations were developed throughout the Audit process, at the conclusion of all analyses, and at the drafting stage of this Report. Recommendations are presented relevant to the short term and medium term in Section 3.   Section 4 comprises the references included in Sections 1-3.

Section 2: Scope of Disability Research in Australia 2000-2013

Introduction

The material presented here derives from the scoping of disability research in the scientific and grey literature in Australia over the period 2000-2013. The references for all the documents are held in EPPI 4 Reviewer (scientific literature) and EndNote X7 (grey literature). The data for the descriptive mapping in this section comes from review of all included documents (that is, those meeting Audit criteria) of which there were 1658 in the scientific literature and 353 in the grey literature.

Descriptive Mapping and Analysis

Descriptive mapping and analysis aimed to *identify gaps in disability research and ascertain research challenges* with a view to developing recommendations for improvement or addressing gaps.

Descriptive mapping typically involves wide ranging searches to scope the literature and capturing information on a small number of key aspects of identified studies[1,2]. In this Audit, mapping comprised the scope and quantity of research according to the domains and the contextual factors in the conceptual framework; the quantity of research by people groups with attention to the four diverse and/or disadvantaged groups nominated in the Agenda; and the scope and quantity of research according to the type of investigation/study design. In addition to descriptive mapping, keywording was used to identify the frequency with which topics emphasized in the current policy context are represented in disability research over the thirteen years. The findings from and commentary on the descriptive mapping and analysis and keywording are presented in Part A of this Section 2 of the report below.

Narrative analysis was also undertaken on selected topics where it was anticipated that there would be added benefit and value from in-depth analysis and synthesis. Following this, Part B of this Section 2 of the report contains the findings on and ways forward from this narrative analysis.

Part A – Findings and Commentary on Descriptive Mapping and Analysis and Keywording

The findings from each literature are presented separately with the descriptive mapping findings from the scientific literature presented first followed by the findings from the keywording strategy. The findings from the grey literature follow; the final sub-section in Part A offers a commentary on all findings presented to date.

Across both literatures relevant research included people with disability, their families and carers, and services. The format for presentation of the descriptive mapping findings follows that of the conceptual framework with attention to the following features.

- The domains of everyday life
- By family/carers and services
- By environmental/contextual factors
- By the four diverse and/or disadvantaged groups
- By type of investigation

Domains of everyday life

The first component of the descriptive map of the scientific literature addresses the domains of everyday life and includes research about people with disability, their family/ carers and/or services.

The greatest proportion of disability research in Australia between 2000 and late 2013 reported in the scientific literature addresses the Health and Wellbeing domain (n=594: 36%). The single content domain in which there is least research in this time period is Safety and Security (n=48: 3%). The single content domains in descending order from more to less research studies were Health and Wellbeing (n=595: 36%); Education (n=314: 19%); Economic Participation and Security (n=167: 10%); Community and Civic Participation (n=117: 7%); Social Relationships (n=116: 7%); Housing and the Built Environment (n=97: 6%); Transport and Communication (n=93: 6%); and Safety and Security (n=48: 3%). The proportion of studies addressing All Domains (n=74: 4%) was nearly two thirds of the studies in the two multiple domain categories with the remaining studies addressing More than One Domain but not All (n=41: 2%) The scope of research by domain is presented in Table 2.

Table 2. Scope of research by domain in the scientific literature

Domain	No.	%
DOM_COMM	117	7
DOM_ECON	167	10
DOM_EDU	314	19
DOM_HEALTH	595	36
DOM_HOUSE	97	6
DOM_SAFE	48	3
DOM_SOC	116	7
DOM_TRANS	93	6
DOM_>1butnotALL	41	2
DOM_ALL	74	4

Family/carers and services

Not all research studies focused on people with disability. For example, of the 594 studies in the Health and Wellbeing domain, just over half (321: 54%) addressed people with disability. The remaining studies (273: 46%) were fairly evenly divided between those which addressed the health and wellbeing of family/carers (140: 51%) and those that focused on services (134: 49%).

Similarly of the 314 studies in the Education domain, just over half (162: 51%) addressed people with disability. Of the remaining 151 studies in the Education domain, 127 (84%) focused on services with only 24 (16%) focusing on family/carers. The proportion of research by focus on people with disability; family/carers; and services is illustrated in Figure 4. Table 3 presents the breakdown by domain and people groups.

Figure 4.

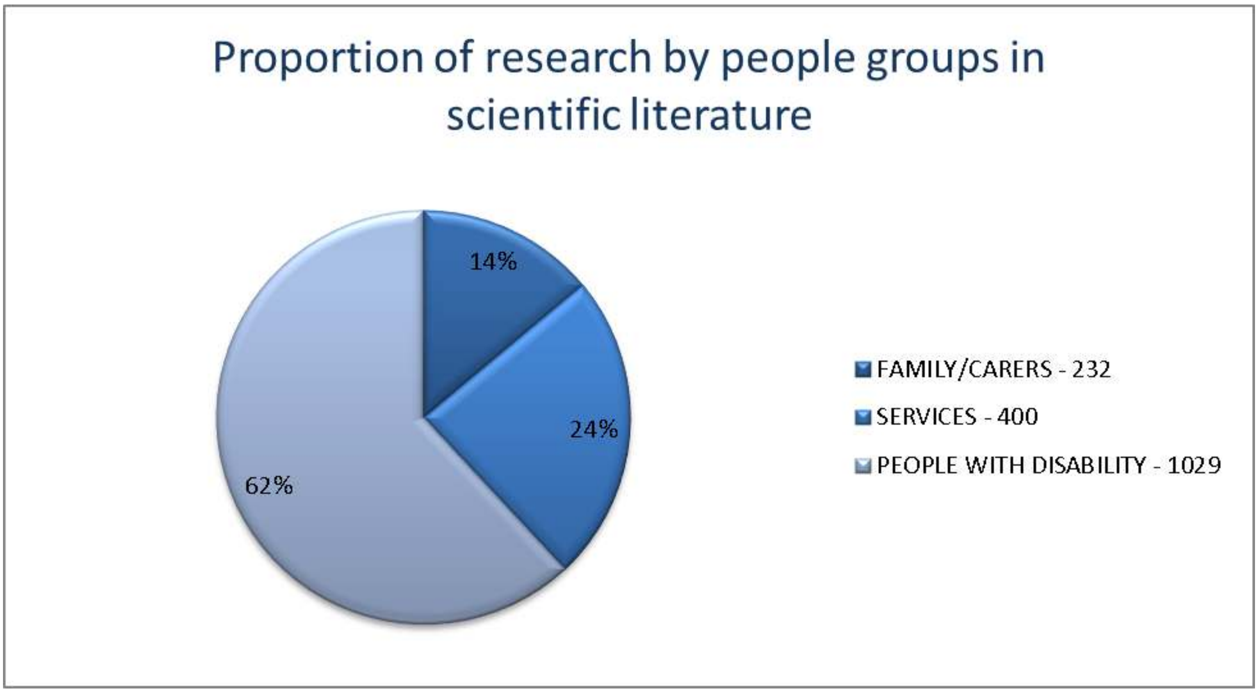


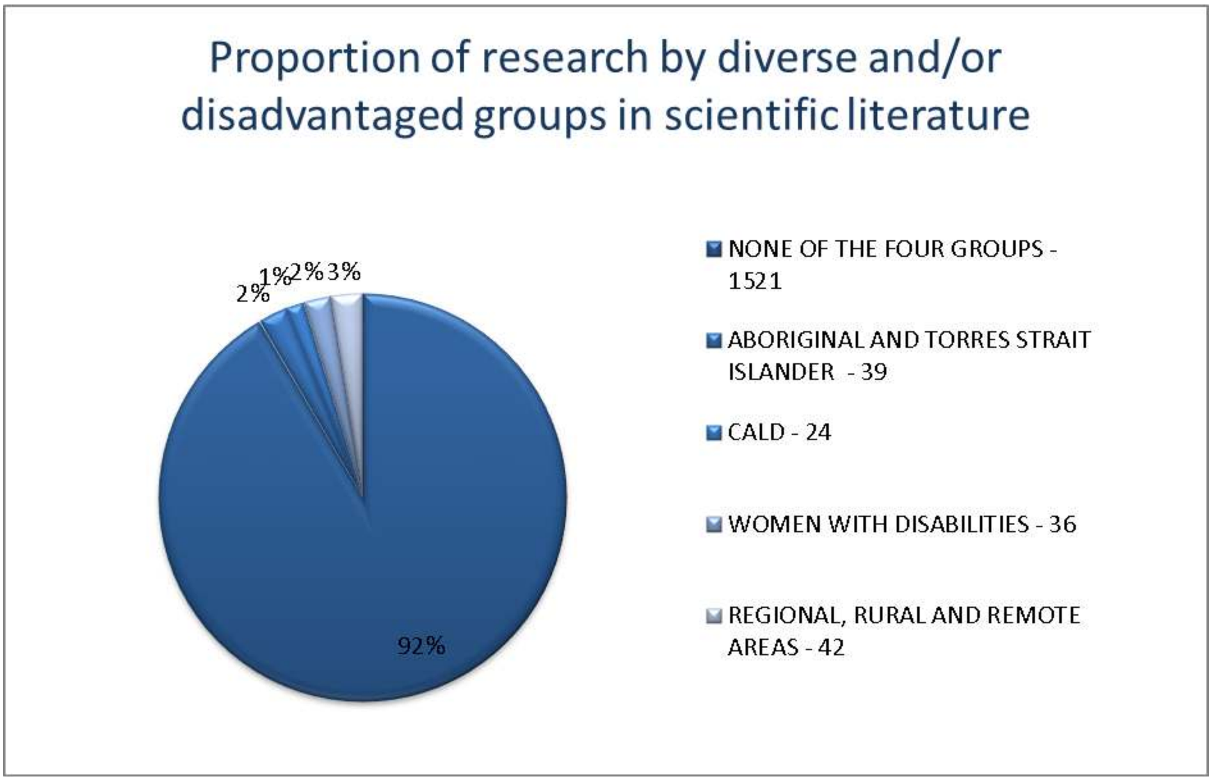
Table 3. Domains by people groups in the scientific literature

Domains	Groups			
	People with disability	Family and carers	Services	Total
Community and Civic Participation	73	6	38	117
Economic Participation and Security	133	18	16	167
Education	162	24	127	313
Health and Wellbeing	321	134	140	595
Housing and the Built Environment	50	14	33	97
Safety and Security	31	7	10	48
Social relationships	82	17	17	116
Transport and Communication	73	5	15	93
More than One Domain but Not All	32	5	4	41
All Domains	72	2	0	74
Total	1029	232	400	1661

Diverse and/or disadvantaged groups of people with disability

By far the greatest proportion of research *does not* address the Agenda nominated diverse and/or disadvantaged groups. Only 137 documents out of 1658 (8%) were concerned with issues for one or more of the four groups. Of the 137 documents there were 42 (30%) that addressed people with disability living in regional, rural and remote areas; 39 (28%) that addressed Aboriginal and Torres Strait Islander people with disability; 36 (25%) addressed women with disability; and 24 (17%) addressed people with disability from culturally and linguistically diverse backgrounds. The distribution of research across these four groups compared to not about these groups is shown in Figure 5.

Figure 5



There was a similar pattern of research by domain in relation to the four diverse and/or disadvantaged groups as in the scientific literature as a whole. By far the greatest proportion of disability research for these four groups was in the Health and Wellbeing domain (n=70: 53%) with the least research in the Housing and Built Environment domain (n=3: 2%).

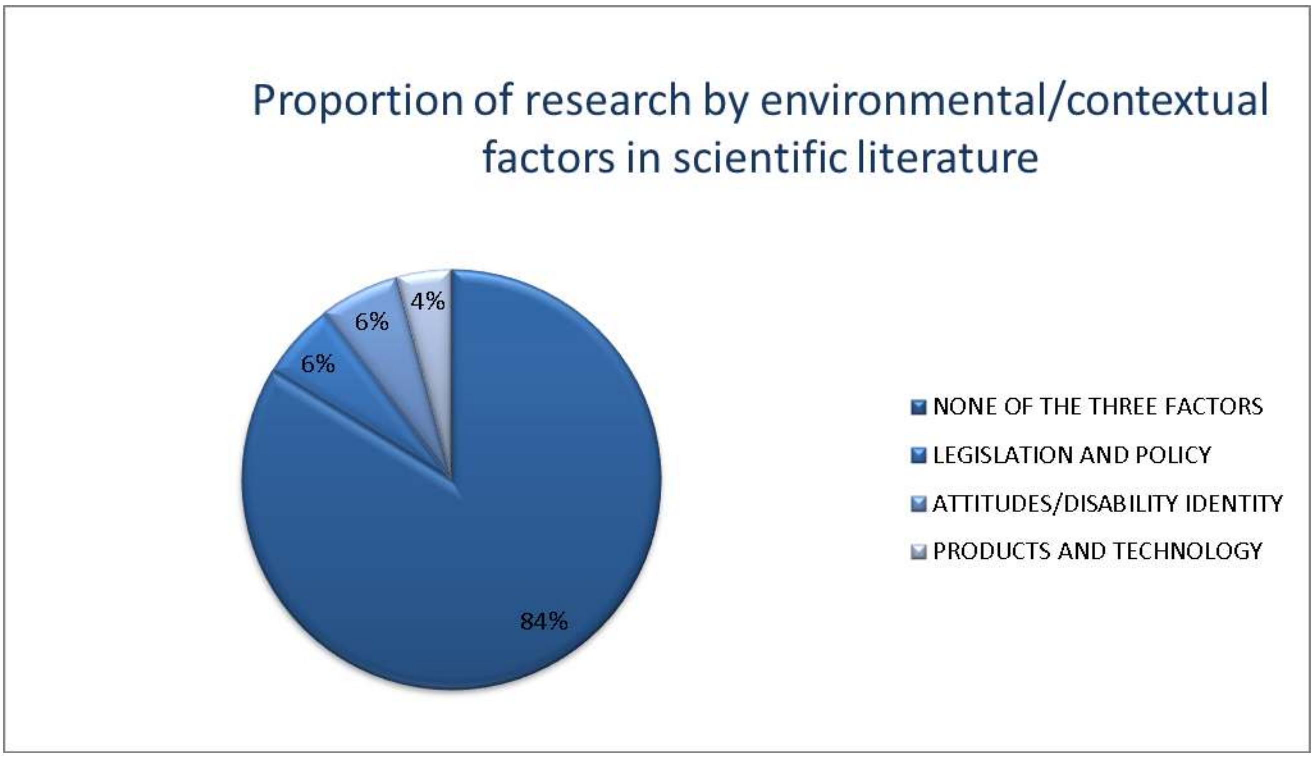
The mapping of research focus by domains as illustrated in Table 2 is instructive with the following caveats. First, the coding process required all research documents to be coded exclusively to one of 10 domain categories. There were eight single content domains and two multiple domain categories. Thus research addressing for example health and behavioral outcomes of a particular intervention would be coded as ‘More than One Domain but Not All’. Studies which addressed all the domains such as those seeking the experiences of parent-carers as they age and the ageing of their son or daughter with a disability across all life domains would be coded as ‘All Domains’. This means that when considering the relatively smaller number of studies in several domains such as Safety and Security (48) and Transport and Communication (93) and Housing and the Built Environment (97) we need to take into account that an additional 4% of studies addressed each of the single content domains (in that they addressed ‘All Domains’) plus up to 2% of other studies (coded ‘More than One Domain but Not All’).

Second, each domain is composed of multiple dimensions as described in Attachment 1. Within the confines of the Audit it was not possible to analyse in depth over 2000 studies across the scientific and grey literature to determine spread and depth of research across each dimension within each domain. To understand the relative emphasis on dimensions within each domain requires a suite of systematic reviews on chosen dimensions. This process would also include the application of a hierarchy of evidence framework to provide findings on distribution and quality of evidence on nominated dimensions. The database and processes developed during the Audit would allow researchers to undertake these reviews.

Environmental and contextual factors

Four environmental and contextual factors were included in the conceptual framework as described in Attachment 1. It was apparent during the coding process that no documents in the scientific literature specifically focused on the items included under the physical environment (natural and built). Only 264 (16%) of the 1658 documents addressed the remaining three environmental and contextual factors – legislation and policy (n=99: 36%), attitudes/ disability identity (n=102: 38%), and products and technology (n=70: 26%). A small number of studies (n=7) addressed more than one domain. The proportion of research addressing each of the remaining three factors is illustrated in Figure 6.

Figure 6



Study design/type of investigation

The findings reported above do not take into account the study designs of relevant disability research in Australia in the time period 2000-2013. The findings thus far provide an overall picture of the scope of disability research but do not speak to the trustworthiness (related to study design) and therefore the utility of the findings for evidence informed policy and practice.

The findings on type of study design according to the 17 types represented in the type of investigation framework for the Audit are portrayed graphically in Table 4.

Table 4. Distribution of research by type of investigation in the scientific literature

Code	Count	%
Randomised controlled trial (RCT)	22	1
Study protocol only	16	1
Observational study	330	20
Program evaluation	40	2
Secondary analysis: Population data	93	6
Secondary analysis: Administrative data set	83	5
File audit/ document review	86	5
Systematic review	19	1
Narrative review	33	2
Measures development	116	7
Questionnaire study	260	16
Qualitative	329	20
Mixed methods investigation	36	2
Policy analysis	73	4
Legal analysis	61	4
Historical analysis	19	1
Media/Creative Arts/Cultural analysis	46	3
Total	1658	100

The most frequently occurring study types were intervention observational studies (n=330: 20%) and qualitative studies (n-329: 20%) with the least frequently occurring study protocol only (n=16: 1%), systematic review (n=19: 1%), historical analysis (n=19: 1%) and RCT (n=22: 1%).

The label *descriptive* research is typically used for studies that employ a survey/questionnaire design and qualitative studies which explore, describe, or examine attitudes, knowledge, or perspectives including the lived experience of people with disability. Together questionnaire studies (n=260: 16%) and qualitative studies (n=329: 20%) comprised 36% of all the studies. In other words, over 1/3rd of all the studies were descriptive.

With regard to studies in the scientific literature which set out to measure the *outcome of an intervention*, RCTs (n=22: 1%) and observational studies (n=330: 20%) together comprised 21%, that is, just on 1/5th of all studies examined the effects of an intervention. *Systematic reviews* which typically assess the state of the evidence on particular topics using standardised processes, constituted a very small proportion 1% (n=19) of the total.

Larger scale studies using population data or data about sub-populations where there is the opportunity to examine associations between variables comprised 176 studies in total. Of these, 93 (6%) were secondary analysis studies using population data and 83 (5%) were studies employing secondary analysis of administrative datasets. Together just over 1/10th of all studies employed designs with larger samples more likely to be representative and permitting comparison of the circumstances of people with disability with those of their non-disabled peers.

Keywording findings

Keywording utilising EPPI 4 Reviewer facility 'text included in title/abstract' was undertaken on selected topics/ concepts - attitudes, choice, disability, discrimination and law, empowerment, family-centred, health promotion, identity, person-centred support, and quality of life. The frequency distribution of research on these topics/ concepts in the scientific literature is illustrated in Table 5.

The topics chosen for keywording reflect topics/ concepts that are emphasized in the current policy context. Many of these concepts/ terms have entered the disability sector discourse over the past decade. Choice, empowerment and person-centred support for people with disability are standout features of the NDS, the Agenda and the NDIS. The NDA speaks to attitudes within the policy area of inclusive and accessible communities, and to disability, discrimination and the law within the policy area of rights protection, justice and legislation. Health promotion for people with disability and promoting preventive health action are also addressed in the health and wellbeing policy area as is wellbeing and enjoyment of life which is broadly analogous to quality of life.

Table 5. Distribution of keywords by topics/ concepts in the scientific literature

Keywords	Count	% rounded
Attitudes	92	11
Choice	54	6
Disability, discrimination and law	103	12
Empowerment	16	2
Family-centred	318	38
Health promotion	23	3
Identity	27	3
Person-centred support	71	9
Quality of life	128	16
Total count of keywords	832*	100
No. Documents with keywords	678	41
No. Documents with no keywords	980	59
Total documents	1658	100

**Total count exceeds documents as some title/abstract contain more than one keyword*

People with disability developing a sense of identity is a topic frequently encountered in disability studies, cultural studies and media studies literature. These literatures are often overlooked in scoping and/or narrative and/or systematic reviews. This is a significant problem in the disability field which benefits from a multi-disciplinary focus. Initiatives to forge models for robust systematic reviews across disciplinary boundaries are warmly welcomed as are systematic reviews grounded in real-world problems such as those being developed by Oliver and colleagues[2] at the Centre for Evidence-Informed Policy and Practice in Education EPPI Centre[3] and Pawson and colleagues[4] at the Social Care Institute for Excellence (SCIE)[5]. The substantive data base developed for this Audit will allow researchers in collaboration with people with disability and policy makers to design innovative, real-world problem based systematic reviews to inform the policy context and future directions in disability research in Australia.

Findings from the grey literature

The grey literature includes documents from Federal, State and Territory government departments, federal, state and territory statutory agencies and commissions, research centre reports, non-government organization reports, and doctoral theses. The grey literature presented significant challenges in collection, collation, reviewing, coding and analysis. This section therefore begins with a commentary to place the subsequent findings in context.

1. Grey literature as a construct

The grey literature represents a construct with poorly defined parameters. The grey literature is variously described as that which is informally published written material (such as reports) that may be difficult to trace via conventional channels such as published journals and monographs. Grey literature is frequently defined by its exclusion from the scientific literature. It is literature which is not published commercially or is not widely accessible and is of particular importance in the area of public policy.Grey Literature Strategies - http://greylitstrategies.info/ - is an ARC Linkage project that aims to provide best practice guidelines for producing and managing grey literature. The project is a partnership between Swinburne University of Technology, Victoria University, the National Library of Australia, the National and State Libraries Australasia, the Australian Council for Educational Research and the Eidos Institute. The findings from the Grey Literature Strategies project are eagerly awaited to assist with overcoming the challenges experienced in the Audit in accessing and scoping the grey literature. The findings should also provide direction to those who produce grey literature so that their reports and findings can be readily identified, easily located, accessible and more widely available.

2. Sources of and drivers for producing grey literature

Potentially relevant sources of grey literature were identified in the Audit Tender Specifications (June 2012) and by the Research Team and Advisory Committee. Documents produced by the various sources differ by driver of research activity, stakeholder input and control, resources available for conduct of the research, and audience and mechanism/s for dissemination of findings/ report.

This diversity requires resource intensive processes to determine inclusion and exclusion criteria, identify and subsequently locating documents that meet inclusion criteria, screen the documentation available (abstracts are not frequently found/ executive summaries may exist of varying length and quality), and code included documents prior to review and undertaking analysis.

3. Restricted parameters scoping the grey literature

Scoping the grey literature was restricted to that manageable within the time and resources available to the Audit team. It was beyond scope to search the websites of all potentially relevant non-government organisations in Australia and an alternative strategy was employed as discussed in Attachment 2. Searching all potentially relevant research centre websites in Australia also proved to be elusive for several reasons. There is not a national mechanism such as a network of research centres and/ or researchers undertaking disability research or one agency responsible for funding centres to undertake disability and rehabilitation research and training as there is in the United States (National Institute of Disability and Rehabilitation Research - http://www2.ed.gov/about/offices/list/osers/nidrr/index.html). There is also disability relevant research being undertaken by researchers in universities and institutes who are not associated with a formally recognised research centres or without identifiable websites where their research is located. Their research is inaccessible using cost effective strategies. This also applies to the research being undertaken on broadly based social and cultural topics that may include people with disability, their family or carers, or service providers.

Research from Research Centres may be published as one or more individual journal articles as well as documented on websites as technical reports/ policy briefs/ working papers. Checking whether for example a report in the grey literature was also represented by publications in the scientific literature would be a very large task indeed and accuracy would be difficult to guarantee. In contrast, the task of checking doctoral theses with regard to publications from the thesis is made somewhat easier by unique identifier of thesis author.

4. Lack of a standard approach to developing and disseminating research

There is no one standard approach to undertaking or disseminating research findings in the grey literature. The laudable aim of the Audit to comprehensively include research from the grey literature in reality required resources disproportional to the benefits gained. The application of inclusion/exclusion criteria created some concern (and confusion) for representatives of the source agencies. Undertaking research is not the primary business of most grey literature source agencies with the exception of research centres and doctoral candidates. Therefore it is not surprising that identifying potentially relevant documents was a very difficult and resource intensive task. Concerns were also expressed from the non-government organisations that their productive work in undertaking consultation and developing detailed submissions to government enquiries was ‘discounted’ by the inclusion criteria for the Audit.

The following caveats apply to the findings in the grey literature by domain, by people groups, by environmental and contextual factors and by type of investigation. First, screening of documents had to be undertaken on whatever materials where to hand on the website or provided by the source agency, either as abstract, executive summary or brief report. Second, in a number of instances it was not possible to apply mutually exclusive domain codes (as was done in the scientific literature). Third, an additional code of ‘not specified’ was needed to manage those documents where there was a lack of specificity or clarity of focus or design. In contrast, peer review and a (somewhat) more standard approach to reporting in the scientific literature permitted the application of a more reliable, mutually exclusive categorization schema for domains, type of investigation and environmental and contextual factors.

Findings by domain

The scope of research by domain and people groups is illustrated in Table 6. The grey literature, as noted, is an amalgam of materials produced for a variety of reasons by quite disparate organisations (non-government, statutory agencies, research centres) or individuals as is the case for doctoral theses. The documents therefore tended to be quite broadly based and not as directed/ focused on particular topics/ domains as the research in the scientific literature. The domain codes were expanded to include Domain Not Specified. Note in Table 6 that over one quarter (26%) of the total number of documents (n=353) were coded as either More than One Domain but Not All or All Domains or Domain Not Specified. This means that when considering the relatively smaller number of studies in several domains such as Social Relationships (4), Safety and Security (10) and Transport and Communication (12) we need to take into account that an additional 10% of studies addressed each domain (in that they addressed 'All Domains') plus up to 9% of other studies (coded 'More than One Domain but Not All) and another 4% of other studies (coded as Domain Not Specified).

Table 6. Scope of research by domain in the grey literature

Code	No.	%
DOM_COMM	27	7
DOM_ECON	22	5
DOM_EDU	39	9
DOM_HEALTH	52	12
DOM_HOUSE	24	6
DOM_SAFE	10	2
DOM_SOC	4	1
DOM_TRANS	12	3
DOM_>1butnotALL	38	9
DOM_ALL	41	10
DOM_NOTSPEC	14	4
EPPI_DOUBLEFOCUS	12	3
EPPI_FAMILY/CARERS	26	6
EPPI_SERVICES	96	23
Total	417**	100

**93 of 353 documents coded as More than One domain but Not All, All domains, or Domain Not Specified*

***65 of 353 documents coded for either double focus, family/carers or services AND one Domain field*

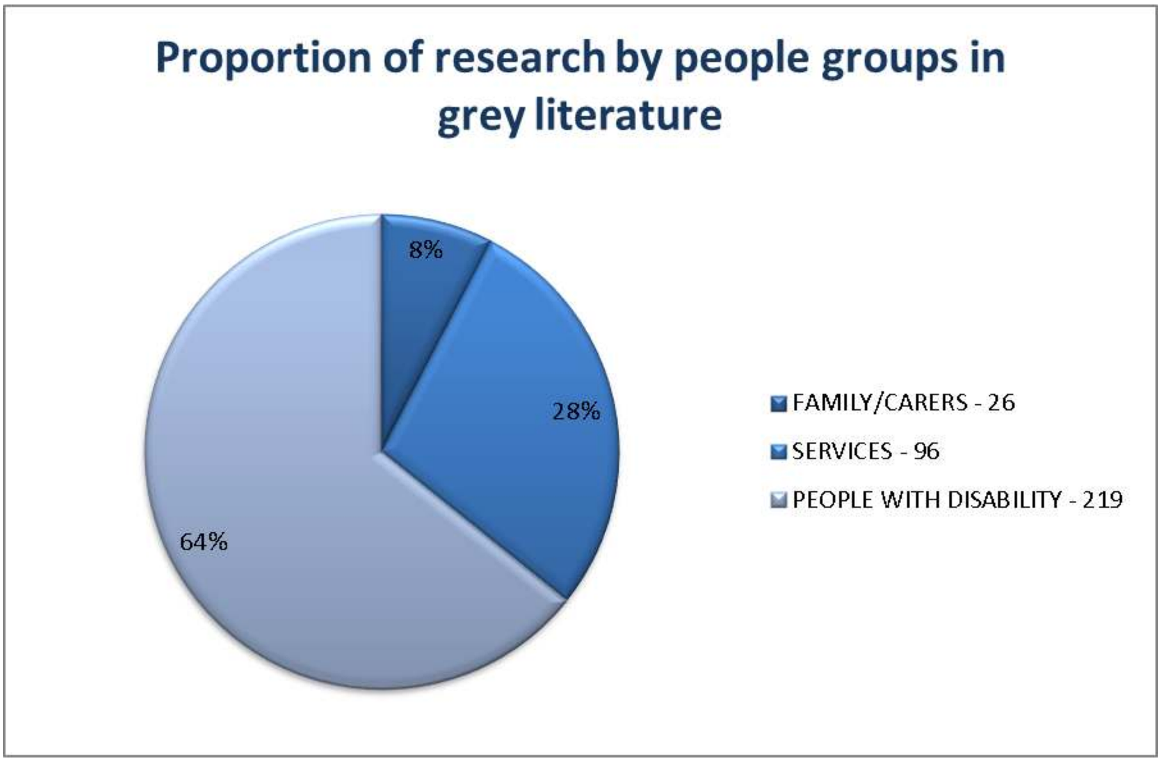
That said the largest number of documents was coded with the single domain Health and Wellbeing as was the case in the scientific literature. The single content domain in which there is least research in the grey literature is Social Relationships (n=4: 1%). The single content domains in descending order from more to less research studies in the grey literature were Health and Wellbeing (n=52: 12%); Education (n=39: 9%); Community and Civic Participation (n=27: 7%); Housing and the Built Environment (n=24; 6%);

Economic Participation and Security (n=22; 5%); Transport and Communication (n=12; 3%; Safety and Security (n=10: 2%) and Social Relationships (n=4: 1%). The number of studies addressing All Domains were 41 (10%), More than One Domain but not All (n=38: 9%) with a further 14 studies (4%) where the domain was not clearly specified.

Family/carers and services

Not all research in the grey literature focused on people with disability. In contrast to the relatively straightforward task of allocating a mutually exclusive code to family/ carers and services this proved elusive in the scientific literature with many documents addressing more than one grouping. The codes were expanded to include double focus (family/carers and /or services and/or people with disability). Of the 353 documents in the grey literature, not quite two thirds (n=219: 62%) addressed people with disability, a higher proportion than that found in the scientific literature. Of the remaining studies 134 (38%) by far the larger proportion focused on services (n=96: 71%) with 26 studies (29%) focused on families. However another 12 studies focused on both family/carers and people with disability, services and people with disability, or family/ carers and services. The breakdown of research in the grey literature by people groups is illustrated in Figure 7.

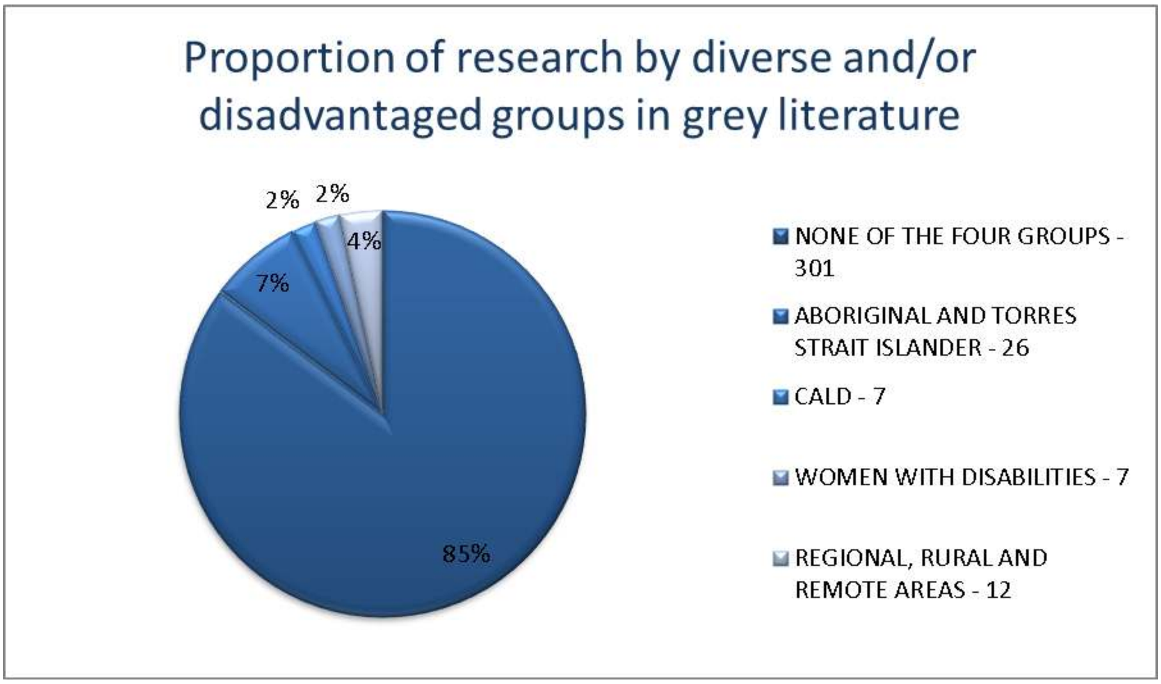
Figure 7



Diverse and/or disadvantaged groups of people with disability

By far the greatest proportion of research in the grey literature *does not* address the Agenda nominated diverse and/or disadvantaged groups, a similar finding to that in the scientific literature. Only 52 documents out of 353 (15%) were concerned with issues for one or more of the four groups. Of these 52 documents, 26, 50% addressed Aboriginal and Torres Strait Islander people with disability; another nearly one-quarter (24%) addressed people with disability living in regional, rural and remote areas; and the remaining just over one –quarter (26%) were evenly divided between women with disability (n=7: 13%) and people with disability from culturally and linguistically diverse backgrounds (n=7: 13%). The distribution of research across these four groups compared to not about these groups is shown in Figure 8.

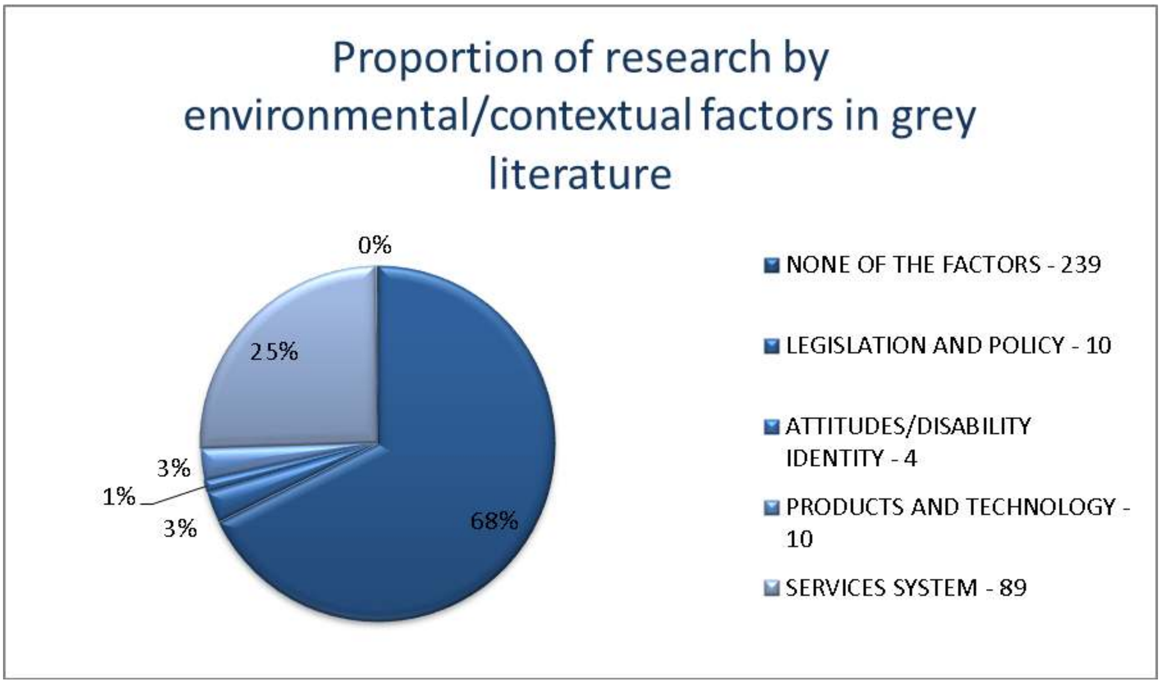
Figure 8



Environmental and contextual factors

Four environmental and contextual factors were included in the conceptual framework as described in Attachment 1. In the grey literature in contrast to the scientific literature one study specifically addressed the physical environment (natural and built). It was decided to also code the services and systems as an environmental and contextual factor of considerable focus in the grey literature. Of the 353 documents in the grey literature, around one third (n=114: 32%) were coded by an environmental/ contextual factor. Of these, the great majority (n=89: 78%) addressed services and systems. Of the remaining 25 documents, 10 documents focused on legislation and policy, 10 on products and technology, 4 on attitudes/ disability identity with the remaining one addressing the built environment. The proportion of research by environmental and contextual factors including the services system is illustrated in Figure 9.

Figure 9



Findings by type of investigation

The findings by type of investigation in the grey literature should be treated with caution. The sources of grey literature are quite diverse. Research from the Australian Bureau of Statistics and the Australian Institute of Health and Welfare was included creating the secondary analysis of population data as the most frequently occurring study type accounting for 36% (n=127) of the grey literature. Mixed methods investigations were the next most frequently occurring, accounting for 20% (n= 71 studies). Again, this is not so surprising given the high proportion of studies addressing the service system and where the studies typically involved a survey, interviews and focus groups across more than one stakeholder group. The next most frequently occurring study type was qualitative studies (n=39: 11%), followed by program evaluation (n= 27; 8%), questionnaire study (n=21: 6%), and file audit/document review (n=16: 5%) with a small number of studies or none at all in the remaining categories. The distribution of research by type of investigation is illustrated in Table 7.

Taking into account the findings from both literatures it is heartening to see that half of all studies employed a secondary analysis design using existing large (and in some instances population) data samples. This is encouraging given larger samples are more likely to be representative and permit comparison (depending on sample selection and item specificity) of the circumstances of people with disability with those of their non-disabled peers. These types of studies are particularly important to understanding disability demographic and trend information and status information on the social and economic inclusion of people with disability both of which are key directions of the Agenda.

Table 7. Distribution of research by type of investigation

Code	Count	%
RCT	1	0.3
Study protocol only	0	0
Observational study	8	2
Program evaluation	27	8
Secondary analysis: Population data	127*	36
Secondary analysis: Administrative data set	11	3
File audit/ document review	16	5
Systematic review	1	0.3
Narrative review	8	2
Measures development	10	3
Questionnaire study	21	6
Qualitative	39	11
Mixed methods investigation	71	20
Policy analysis	2	0.4
Legal analysis	0	0
Historical analysis	0	0
Media/Creative Arts/Cultural analysis	0	0
Not specified	11	3
Total	353	100

**Includes AIHW& ABS*

Further commentary is presented on three sources of the grey literature. These offer a useful scoping of grey literature material and some promising directions for the future. These three sources are non-government organisations, research centre reports, and doctoral theses.

Non-government organisations research

A total of 63 documents were identified from non-government organisations using the processes described in Attachment 2. The focus of research from non-government organisations inevitably followed the mission of the organization. The primary focus was on service systems related to the consistent work that has been done over the past few years by peak organisations such as NDS (National Disability Services). This research primarily paid attention to composition of the workforce and need for training; and, skill shortages and need for workforce planning.

A secondary focus was on families and carers and their experiences of and aspirations for service delivery. Frequently this type of research was undertaken by way of carer needs and service satisfaction surveys. Much of the research addressed barriers and challenges associated with service delivery from the family/carer perspective. There was also a focus on particular policy or practice initiatives such as family-centred models of service delivery.

A more recent focus of non-government organization research was that which addresses matters of governance, productivity and effectiveness. There was however little research that addresses effective access to and utilization of mainstream health, education, and employment services by people with disability, their family and carers. Under-researched areas by non-government organisations include the four diverse and/or disadvantaged groups of people with disability nominated in the Agenda.

Typically NGO through their mission statements and website documentation indicate strong commitment to social equity and human rights approaches to disability. As in the scientific literature however research by non-government organisations in the areas of community and civic participation, and economic participation and security for people with disability is in its infancy compared to for example the research on service delivery and service systems, particularly in the specialist disability sector.

Research Centre research reports

A total of 65 documents were located from Research Centres in the grey literature. The primary foci of these studies were in the domains of Economic Participation and Security (n=13), Education (n=11), and Community and Civic Participation (n=11), followed closely by Health (n=8), Housing and the Built Environment (n=7) and addressing Family/carers (n=7). There were only three studies focusing on the domain of Transport and Communication, one of which was related to access to information technology for people with disability. The remaining two studies explored issues in the Safety and Security domain.

Almost one third (n=19) of the research focused on issues related to service provision. Of these, seven addressed workforce issues, funding of services, access equity, and reporting and evaluation; the remaining related to services issues broadly across the following domains: Housing and the Built Environment, Community and Civic Participation, Education, Health and Economic Participation and Security.

Study design/type of investigation was fairly evenly spread across three primary methods: qualitative studies (n=13), secondary analysis of population data or administrative datasets (n=14), and mixed methods investigations (n=16). There were also seven program evaluations and seven questionnaire studies. The remaining research consisted of a mix of file audit/document review, and literature reviews, measures development, and other methods.

Diverse and/or disadvantaged groups as nominated by the Agenda were under-researched. Four studies addressed Aboriginal and Torres Strait Islander people with disability [1-4], four addressed women with disability [5-8], two address regional, rural and remote areas [9, 10], and one addressed people with disability from culturally and linguistically diverse backgrounds (and living in rural and remote areas of Western Australia) [11].

There were 14 studies reporting on secondary analysis of data from population data or administrative datasets and these are over and above those published in the scientific literature. The findings from these contribute to the robust description from secondary analysis of the living circumstances and disadvantage of people with disability and their family/carers in Australia.

A standout contribution to disability research occurs where there is an ongoing program of research and/or a substantive focus followed by a research centre. This is the case here where the majority of the secondary analysis research undertaken by research centres came from the National Centre for Vocational and Educational Research (NCVER) addressing economic participation and access to vocational education and training [e.g. [12, 13, 14]]. More widely distributed across several centres, there were a number of studies that focused on the economic, health and wellbeing outcomes for carers of people with disability [e.g. [15, 16, 17]].

Secondary analysis studies are not designed to explicitly capture the perspectives, preferences and lived experiences of these individuals (as population surveys and administrative data rarely capture qualitative data). This however is a contribution of the research from several research centres which utilised qualitative methods to explore the perspectives of people with disability and their representatives (n=11; this includes 5 qualitative studies addressing perspectives of person with disability and service providers) or included these perspectives within mixed methods investigations or program evaluations.

The greatest gap is in collaborative, participatory and inclusive research with people with disability or their representative organisations. Of the research centre studies only five [2,6,11] were conducted in partnership with, or were commissioned by, peak disability/advocacy organisations. The remainder of the studies were commissioned by government departments or driven by independent or university-based research centres.

Doctoral theses

As described in Attachment 2, there were 214 disability relevant theses located. Of these, 85 had one or more publications directly attributed to the thesis in the scientific literature and were considered in the analysis of that literature. A further 91 did not contain an abstract that met inclusion criteria, leaving 38 for the analysis described here.

The majority of these theses were undertaken were in the field of education of this the majority focused on inclusive education in primary and high school. The remaining domains were represented by four studies addressing community participation, four on communication, two on social relationships, and one each addressing economic participation, housing and health. The theses represent diverse disciplinary fields with scholars in arts and the humanities, social sciences, health sciences, social work, business and economics and so on.

Consistent with the scientific literature and the analysis of the grey literature issues affecting people with disability from the four diverse and/or disadvantaged groups were under-researched. Two studies explored experiences of Aboriginal and Torres Strait Islander People, two focused on culturally diverse populations and two specifically explored rural settings.

The study design for the 38 theses considered here largely consisted of qualitative approaches (n=16) and mixed methods (n=12). The remainder involved secondary data analysis, observational studies, questionnaire studies, measures development, program evaluation, and other designs.

It is worth noting again that this analysis refers only to those doctoral theses without at least one publication in the scientific literature in the time period. There may be several reasons why there were no publications from these theses. The first is that thesis material may be distributed in various ways depending on discipline requirements including via a book or series of book chapters, published monographs, and in the case of the creative arts via an appropriate medium such as a theatre production script, video or short film. Second, although in some disciplines there is encouragement to publish at different stages of thesis production, in others publication is not expected until after examination and final award. The database and processes developed during the Audit would allow researchers to undertake further analyses of disability doctoral research being produced in Australia, an undertaking critical to building capacity in disability research through the next generation of disability researchers in Australia.

Commentary

1. Health and Wellbeing focus

Health and Wellbeing was the stand out domain represented in the scientific literature with almost twice the amount of disability research compared to the next most populated (Education) and 12 times the research in the domain with the least number of studies (Safety and Security). Similarly in the scientific literature, the Health and Wellbeing and Education domains dominated (22% and 29% respectively with studies coded All Domains included). There are several possible explanations for the high proportion of disability research in the Health and Wellbeing domain.

Firstly, the domain was quite broadly conceived with a diversity of dimensions relating to health and wellbeing. Medical research was excluded from the search strategies with additional exclusions during screening of primarily surgical, pharmacological, or clinical research. That said there remains a strong focus in disability research on health and wellbeing of people with disability by researchers particularly those publishing in the scientific literature. This may be attributed partly to the earlier predominance of the individual (medical) model of disability, due to researcher interest in health and behavioral outcomes associated with particular impairments.

Secondly, in the scientific literature within this domain there were many studies conducted by health professionals/health researchers that focused on developmental progress and/or fine motor, communication, mobility and language outcomes for children with developmental disability. Thirdly, studies on quality of life, subjective wellbeing and indicators of health status for adults with disability were dominant within this domain. Quality of life was frequently brought into play as an outcome measure in observational intervention and questionnaire studies. A focus on causes of disability and studies of maternal health and childhood disability and also indicators of health status were more likely to be found in secondary analysis research utilizing population data such as the ABS Survey of Disability, Ageing and Carers (SDAC) and also administrative datasets such as Transport Accident Commission data from Victoria.

2. Relative lack of attention to other domains of life

Australian policy and strategy documents in disability are premised on the person-environmental interaction perspective embedded in the UN Convention on the Rights of Persons with Disabilities. This takes into account that persons with impairments are often prevented from exercising their human rights and fundamental freedoms by attitudinal and environmental barriers which results in their being disabled.

This perspective is most clearly seen in the six outcomes which structure the National Disability Strategy of which health and wellbeing is only one. The other five are inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; and learning and skills. These were represented by considerably less research in both the scientific and grey literature in the period 2000-2013. One explanation for this in the scientific literature is its ‘lag’ nature in the time taken between a research study commencing and the publication of results. If this is the case it could be expected that over the coming decade the relative proportion of research across the domains will alter as the literature ‘catches up’ with the policy context.

The regular reporting mechanism to the COAG Reform Council on the National Disability Agreement offers one opportunity for determining progress on selected indicators of economic participation and social inclusion, choice, wellbeing and independent living, and support for carers and families. A considerable database has been generated in this Audit. Investment in maintenance and update of this database would provide an ongoing resource to continue to identify research gaps in relation to new policy initiatives; enable monitoring of focus and robustness of disability research in Australia over time; and assist in developing research collaborations within the disability sector and with other sectors and disciplines to build capacity, coherence and critical mass in disability research. The processes and strategies developed in the Audit mean that this can be done cost-effectively on a biennial basis by the experienced Research Team. This would contribute significantly to achieving a prominent aim of the Agenda which is to 'facilitate the creation of a comprehensive evidence base and the foundations of robust research that will inform the policies and practices of the disability sector, governments and the mainstream community" (Agenda, 2001, p.4).

3. Proportion of research studies addressing family/carers and services

A reasonably high proportion of studies in the Health and Wellbeing and Education domains (just under half in the scientific literature and around one third in the grey literature) addressed individuals other than people with disability. The proportionally higher focus on services in these two domains may reflect the more formal organization and professionalization of services within those domains compared to the remaining 6 domains. Studies in the Health and Wellbeing and Education domains in the scientific literature address well-known issues of the domain - relevant professionals. For example, there were many studies in the Education domain on pre-service and practicing teacher attitudes towards inclusion of students with disabilities at all levels of the education system from pre-school through to university and vocational education. Studies in the Health and Wellbeing domain were similarly system oriented addressing 'hot' topic areas such as models of early intervention, therapy services, and home and community care services. A not surprising finding was the proliferation of studies in the Health and Wellbeing domain addressing family perspectives on caring as well as their associated health and wellbeing outcomes.

4. Utility and relevance of research for people with disability

Consultation undertaken by the National People with Disabilities and Carers Council for the report *Shut Out: The experience of people with disabilities and their families in Australia* (2009)[6] detailed issues of concern and particular interest to people with disability and their families. These included exclusion and discrimination, employment, negotiating the built environment, education, the social experience of disability, the experience of disadvantaged groups and the particular difficulties faced with the service system. This is the 'closest' national perspective available on issues of concern and particular interest to people with disability, their family and carers. It could be assumed that research on topics included in the *Shut Out* report would be relevant and useful to people with disability. The consultations however were undertaken in a previous policy context prior to the conceptualization and implementation of the NDIS and research topics or endeavours were not specifically addressed.

It is not possible therefore to comment on whether the disability research identified in this Audit is useful for or relevant to people with disability. As yet there has not been a concerted or systematic effort to identify the research *priorities* of people with disability at the national level (beyond the high level approach in the Agenda). Some peak organisations and disability specific organisations have begun setting their own research agendas such as that developed by the Cerebral Palsy Alliance, ASPECT, and NDS. These however are developed with a specific focus and may not necessarily speak to all people with disability, their family and carers or to policy makers or disability researchers more broadly. There is an opportunity for Australia to identify the research priorities of different stakeholders – people with disability, families and carers, policy makers and disability researchers. There are published models of research priority setting exercises in disability for example by WHO and colleagues addressing research priorities in mental health and for people with intellectual disability and autism[7-8]. To establish the utility and relevance of research requires the commissioning of a formal research priority setting exercise (based on the methodology developed by WHO) to identify disability research priorities in Australia as articulated by people with disability, family/carers, policy makers and service providers.

5. Range of study designs

The framework to differentiate type of investigation was designed to be as inclusive as possible of disability research emanating from different disciplines. Just over 10% (n=199: 12%) of the study designs were those that are typically left out of scoping reviews. These are policy, legal, historical and media/creative arts/cultural analysis studies. The first two – policy and legal analysis – present excellent opportunities to understand the governance context which heavily influences the day to day lives of people with disability, their family and carers and disability and service providers. Historical analysis and media/creative arts/cultural analysis provide insights into the social and cultural understandings and representation of people with disability. This knowledge is needed to inform the policy directions of the National Disability Strategy. In particular to increase awareness and acceptance of the rights of people with disability, remove societal barriers preventing people with disability from participating as equal citizens, and ensure that people with disability are safe from violence, exploitation and neglect.

6. Frequency of study designs

There was a higher proportion of intervention study designs than is usually the case in scoping studies in the social care/social welfare sector. This is possibly due to a large number of studies falling in the health and wellbeing domain. In the health sector there is a greater emphasis on and investment in intervention, effect and outcome studies. This is not the case in the disability sector where interventions are usually multi-dimensional, and influences other than the target intervention can be difficult to regulate or control. Systematic reviews are required to examine the evidence produced by the intervention studies identified in this Audit. These reviews would provide robust evidence of what works, and if the data is available, for whom and under what circumstances in the topic areas of the research investigations.

7. Co-production and dissemination of research with people with disability

There appears to be little focus on the co-production of research with people with disability. The involvement of people with disability in the design, implementation and dissemination of research is needed to fulfil the principles of the UN Convention and the commitment in the NDS and the Agenda to inclusive and rights based research. It is encouraging to see a reasonable proportion of qualitative studies and mixed methods investigations which explore the perspectives of people with disability. This however is not the same as co-production. As yet there are few model approaches for researchers committed to working collaboratively with people with disability. Australia could take a lead in developing guidelines for co-produced research building on the work done in the NHMRC guidelines and accompanying documents for conduct of research with Aboriginal and Torres Strait Islander peoples[8].

Findings - Part B Narrative Analysis and Way Forward

Narrative analysis was undertaken on selected topic areas utilizing the included documents from the scientific literature. The topics in order of reporting are:

Aboriginal and Torres Strait Islander peoples (Gilroy)
Policy analysis studies (Smith-Merry)
Studies utilising administrative datasets (Kavanagh)
Studies utilising population surveys (Emerson)
Reports from Australian Institute of Health and Welfare, Australian Bureau of Statistics and Productivity Commission (Madden)

The major findings in relation to each topic area are summarized here followed by suggested ways forward to address the gaps identified in each analysis. The full findings are appended in Attachment 4.

Aboriginal and Torres Strait Islander people with a disability

There is a rather small body of research about Aboriginal and Torres Strait Islander people with disability, with 39 papers in the scientific literature and 30 in the grey literature. Most frequently, the studies addressed intellectual disability, cognitive disability and developmental disability; hearing impairment in children; and identifying barriers and solutions to accessing services. There is also a body of research utilizing existing datasets such as NATSISS.

There are encouraging signs of qualitative researchers working collaboratively with Aboriginal and Torres Strait Islander peoples by recruiting Aboriginal people or Aboriginal controlled community organisations to facilitate interviews and focus groups. There is also a recent emphasis on developing cultural appropriate assessment practices and diagnostic tools.

The size of the body of research is disproportionately small compared to the multiple strategies in Australian policy documents to redress the disadvantage of Aboriginal and Torres Strait Islander people with a disability. Although guidelines exist for ethical conduct of research with Aboriginal and Torres Strait Islander people, best practice approaches to participatory inclusive research are needed. There is also a significant gap is research attention to the needs and experiences of Aboriginal and Torres Strait Islander carers.

Way forward

- Funding disability research with Aboriginal and Torres Strait Islander people proportional to the multiple strategies in the current policy context focusing on reducing disadvantage.
- Funding disability researchers to develop best practice guidelines for participatory, inclusive research with Aboriginal and Torres Strait Islander people with a disability, their family and carers.
- Dedicated funding to stimulating disability research that addresses the needs and experiences of Aboriginal and Torres Strait Islander carers.
- Requiring disability researchers to address the application of their findings to practice in collaboration with the Aboriginal and Torres Strait Islander people and communities who participated in the research.

Policy analysis research

There is a small body of policy analysis research comprising 73 papers (4% of the scientific literature). This literature includes papers making policy recommendations, critiquing current policy, theoretical work on policy and that which comparatively critiques policy approaches used in Australia and other countries. Much of this is quite dated and does not necessarily reflect the current policy context due to the lag experienced in traditional avenues of scientific publication. There is no clear evidence in this small body of studies that have been purposefully constructed purposefully to be useful to policy makers. For example, examining data, making recommendations that can be drawn on and illustrative examples of effective outcomes from case studies or service implementation.

There is a lack of research in this body of papers utilizing the experiences of people with disability and/ or their family and carers to influence policy development. The topics covered broadly reflect academic interests in social policy coming from disciplines or research centres whose primary interest is not disability. An obvious gap to be filled therefore is research that draws on the knowledge held by services and practitioners in particular policy environments to identify areas of innovation or barriers to effective implementation.

Way forward

- Dedicated funding for research focusing on multidisciplinary approaches to disability policy evaluation.
- Funding of disability research to include funds for the dissemination of research in open access journals.
- Stimulating the disability research which explores the experience of policy from the perspective of consumers, carers and practitioners.
- Stimulating the development of cost-effectiveness research in disability to inform policy.
- Stimulating the alignment of fit for purpose monitoring and performance indicators with policy initiatives to allow for effective evaluation and innovation.
- Developing disability policy research which focuses on the needs and experiences of Aboriginal and Torres Strait Islander people.

Studies utilizing secondary analysis of administrative datasets

The 83 (5%) studies in this body of literature utilise secondary analysis of existing administrative datasets. This type of analysis may be particularly useful for providing detailed information and comparisons of people with and without disability; however this relies on data on disability using agreed definitions and being collected according to standard rules and forms for data collection. The primary datasets used come from the health and disability sector. The largest contribution comes from researchers taking advantage of the most advanced linkage of datasets in the country from the well-established Western Australia Data Linkage Unit. An additional contribution of this Unit is the breadth of linked datasets including but not limited to those from the health, disability, family support and care and protection, housing, police, justice, and education sectors, all of which are relevant to people with disability.

The contribution of research employing secondary analysis of administrative datasets is not yet fully realized in Australia. The recommendations from this analysis speak to mechanisms to ensure accessibility and utility of existing datasets and to expand opportunities through focus on those areas currently under-represented in this body of literature.

Way forward

- Stimulating the use by disability researchers and policy makers of registries and routine surveys and datasets.
- Extending available datasets to collection of data on children and young people with disabilities.
- Collection of more comprehensive data and investment in research on priority groups including Aboriginal and Torres Strait Islander people with disability, women with disability, culturally and linguistically diverse groups and people living in regional, rural and remote areas within currently available datasets.

- Stimulating inclusion of DPOs and other key stakeholders by requiring disability researchers to collaborate with DPOs and other key stakeholders in design, implementation and dissemination of research using administrative datasets.
- Investigating in collaboration with ABS and AIHW a common set of questions on disability in all population-based surveys and promotion of the use of these questions in all population research (along the same lines as standard demographic questions).
- Working with the AIHW as the first accredited centre for the linkage of government data to design mechanisms for accessing data about specific disabilities (e.g. intellectual disability, traumatic brain injury) for linkage to other databases and to enable the selection of participants for studies. This investment is particularly important in advancing research on the causes and consequences of disability.
- Expanding the Population Health Research Network endeavours on a national data-linkage facility to include a focus on disability such as that established in Western Australia to better address the complex intersections between multiple domains (e.g. health, employment, disability, income support, housing assistance).
- Developing processes to obtain consent from participants recruited into studies for linkage of their data to administrative data (e.g. Medicare, income support).

Studies utilising secondary analysis of population data

In this body of literature comprising 93 papers (6%), the majority of research used data from just four datasets: SDAC, the National Survey of Mental Health and Wellbeing, the Longitudinal Study of Australian Children, and the annual Household Income and Labour Dynamics in Australia Survey. The topics covered were extremely diverse with substantive focus on overall prevalence of disability and prevalence among sub-groups of particular interest including the four diverse and/ or disadvantaged groups nominated in the Agenda.

Information on the prevalence of disability can be used to evaluate the ‘reach’ of disability services and can be used to track changes in the nature and patterning of ‘need’ within the Australian population. Information on changes in the social context experienced by people with disability in Australia can be used to monitor progress and provides valuable information on the broader social context within which disability policies are implemented. There are however limitations which need to be taken into account particularly in relation to the representativeness of the population of people with disability included, the cross sectional nature of the datasets, and that the datasets were not designed specifically for topics of policy relevance in the disability sector (with the exception of SDAC) and may not reflect the disability reform agenda. The following ways forward would address some of the current gaps.

Way forward

- Developing methods (through data linkage or the inclusion of a set of standardised questions for use in generic surveys) of identifying survey participants who are in receipt of NDIS supported services and second, extending the sampling frame of selected surveys to include people living in various forms of supported accommodation and nursing homes.
- Stimulating the use by disability researchers of available longitudinal datasets.
- Further development of a longitudinal disability-specific survey in Australia.

Reports from Australian Institute of Health and Welfare, Australian Bureau of Statistics and Productivity Commission

This body of literature comprised 115 papers accessed via grey literature processes. These publications primarily address population data on disability and national data on services sourced from official statistics under the remit of the relevant statutory agencies. Accordingly these provide statistical information and commentary on statistical interpretation and technical information. There are many analyses focused entirely on disability and the disability experience; there are others which are focused on 'population health' and often include disability briefly as just an indicator of a 'health outcome' or 'health status'. The scope of the reports is broad covering (but not limited to) prevalence of disability, participation by people with disability, disability services data, informal care, and expenditure on disability, all regularly reported some annually or biennially. The power of such information to inform innovation and policy has been realised recently in Australia through the statistical information available to the Productivity Commission Inquiry leading to the formulation of the NDIS.

To capture the capacity of national statistics and research emanating from the official publications requires familiarity with and understanding of these datasets by disability researchers. It also requires ongoing review of accessibility and relevance to inform policy makers and the disability sector more broadly as information needs change or expand. The following ways forward address areas where there is room for improvement in the available national data and analyses.

Way forward

- Requiring disability researchers to become familiar with these main sources of national data on disability, and consider the value of secondary analysis of them, or of collecting data that can be related to them or the national disability data standards.
- Including (i) better data on Environmental Factors (e.g. technology, attitudes); (ii) fuller data on participation e.g. use of the national data standard on 'satisfaction' with participation, so as to indicate people's feelings of choice and control in each life area; (iii) continuing effort to improve data on Aboriginal and Torres Straits Islander peoples, in partnership with Aboriginal researchers and thinkers; and (iv) new effort in analyses of disability and service access among people of culturally and linguistically diverse background – startlingly absent from the data analyses, given the significant presence of these groups in the Australian population and the newly available data since the 2006 Census.

- Increased efforts and investment to adopt the ‘standardised disability identifier’, developed by AIHW, into mainstream service data systems as administrative data on access to mainstream services are largely missing.
- Investment in research which specifically addresses the distinctions between long term, permanent and lifelong disability to inform the further development of NDIS inclusion and assessment practices.

Section 3: Evaluation of Evidence Framework, Research Gaps and Recommendations

Introduction

The Audit aimed to provide as comprehensive a picture as possible of the scope, quantity, focus areas, and types of investigation in disability research in Australia in the time period 2000-2013. In line with the specifications of the Audit to identify gaps in disability research and ascertain research challenges this equates more closely to a helicopter view than a fine grained appraisal of individual research studies. By necessity given the challenges in identifying and locating relevant disability research as described in Attachment 2, the findings of the Audit are predicated on descriptive mapping, keywording and narrative analysis by title and abstract.

The approach taken to considering the weight of evidence was internally consistent with the conceptual framework and the broad based type of investigation framework. Both frameworks were specifically designed and contextualized within the Australian legislative, strategy and policy environment. In weighing the evidence, consideration was given to the social equity and human rights principles which underpin the NDS, the Agenda, and the NDIS and to the desired outcomes of these policy approaches. This led to a fit for purpose perspective on appraising evidence in contrast to delineating a standard hierarchy for application to disability research already conducted or research proposals. Prior to describing this, there is a brief commentary on traditional approaches to appraising evidence.

Appraising evidence

Appraisal of evidence is undertaken for many purposes including for example to understand the 'state of knowledge' in relation to a particular topic, to identify processes or practices that are evidence informed, and to assist with decision making.

Frameworks to critically appraise evidence are most highly developed in the health care sector. In this sector the concept of evidence based health care has become entrenched over the past three decades. Evidence based medicine developed from concern about the efficacy and effectiveness of clinical interventions. It is not surprising therefore that randomized controlled trials have become known as the gold standard of evidence with other intervention designs regarded as lower levels of evidence. Not surprisingly the power of this idea spread to other fields including social services, social policy and education. In these fields it is frequently lamented that it is difficult or impossible to conduct RCT's and that evidence from studies with alternative designs is regarded as of less value.

The approach taken in this Audit to searching and reviewing the literature was purposively broad based. This was in keeping with understanding of disability as resulting from person-environment interaction rather than based solely in an impairment, health condition or chronic illness, all of which may result in disability but not inevitably so. Consequently evaluating evidence based on the well- known systems designed to appraise the quality of clinical interventions would not fit the diversity of relevant disability research included in the Audit.

There is now a substantive field of endeavor devoted to developing checklists of criteria for assessing evidence. These checklists of criteria have expanded from the original focus on clinical interventions to incorporate other study designs including qualitative and mixed methods investigations.

Systematic reviews have gained wide currency as a way to appraising evidence. In some fields systematic review is now considered a research method in and of itself. This research method comprises a secondary analysis of the literature using a systematic, explicit and accountable approach to answer a specific research question. The growth and development in mechanisms to appraise evidence has led to some confusion about which is the most appropriate approach. Critically appraising the literature can involve evaluating evidence from individual studies or evaluating a body of evidence in relation to a particular research topic/question. The former rely heavily on evaluating the type of study design using specific frameworks for quantitative as well as qualitative study designs. Frameworks for appraising a body of evidence such as GRADE[1] utilize individual study evaluation and additional criteria to assign graded related to the quality of the evidence.

Critical appraisal of evidence has been driven by the research community. Not surprisingly therefore as Gough et al (2012)[2] note "there has been a focus on assessing the quality of research on the basis of the way the research has been designed and the methods used to conduct the research" (p. 156). This does not take account of relevance to the sector or to the end users of the research. Alternative frameworks which incorporate quality and relevance now exist such as TAPUPAS[3] designed in the UK for the social care sector and which has relevance for disability research. Pawson[3] and colleagues argued that appraisal of knowledge in social care needed to take into account five different sources of knowledge with different traditions, standards, and means of expression. These five sources of knowledge are: organisational knowledge gained from management and governance of social care, practitioner knowledge gained from the conduct of social care, policy community knowledge gained from the wider policy environment, research knowledge gathered systematically with predetermined design, and user knowledge gained from experience of service use and reflections there upon. From this, a generic set of questions was developed to form TAPUPAS[3]. These questions are:

- **T**ransparency – are the reasons for it clear?
- **A**ccuracy – is it honestly based on relevant evidence?

- **P**urposivity – is the method used suitable for the aims of the work?
- **U**tility – does it provide answers to the questions it sets?
- **P**ropriety – is it legal and ethical?
- **A**ccessibility – can you understand it?
- **S**pecificity – does it meet the quality standards already used for this type of knowledge?

This type of framework incorporates the focus on study design and attempts to quantify other relevant sector-driven contextual considerations. An approach such as this does not subscribe to the view that there is a hierarchy of evidence rather that evidence needs to be assessed according to criteria appropriate to the nature of the evidence as well as the context from which the evidence derives and the purpose to which that evidence will be put. This suggests that rather than a hierarchy of evidence forming the frame for evaluating individual studies or a body of evidence, a matrix approach may be of more benefit.

Developing contextually relevant critical appraisal of evidence frameworks is a developing field of endeavor. To the best of our knowledge there is currently no one framework specifically designed for assessing the weight of evidence in disability research. To this end the following section describes the components considered necessary to effectively evaluate evidence in the interests of the second broad aim of the Agenda which is to "support the continued development of a more inclusive Australia" [4] (p.9). These components are derived from the literature on critical appraisal and evaluation of evidence, the experience and expertise of the Research Team and the Advisory Group, and the conduct of this Audit. This framework builds on the work being undertaken to develop contextually relevant critical appraisal of evidence tools in the social services sector described briefly above.

Fit for purpose evaluation of evidence framework

An evaluation of evidence framework for disability research needs to be multidimensional to take into account the multi-sector nature of disability research. There are three fundamental components: design fit of purpose and executed to the highest standard; relevance and utility to the sector; and co-production. Each is briefly described with a process by which these could be implemented.

Design fit for purpose and executed to the highest standard

Utilization of relevant research design and method criteria as specified for example by Cochrane Collaboration and Campbell Collaboration dependent on field/ sector of research endeavor. The Cochrane Collaboration Handbook for Systematic Reviews of Interventions is Version 5.1.0 (March 2011) is available online at http://handbook.cochrane.org/. This Handbook covers a diverse range of health sector research including RCTs, non-randomized interventions, qualitative designs, patient reported outcomes, reviews of individual patient data, public health interventions and health promotion. The

Campbell Collaboration has a resource centre at http://www.campbellcollaboration.org/ with relevant resources such as user involvement in appraising evidence and an equity checklist for appraisal of equity/ disadvantage considerations in research studies.

Examples of design fit for purpose include well-constructed cross-sectional surveys for point prevalence, well-constructed longitudinal surveys for analyses of relationship between environmental factors that are not easily amenable to controlled change and outcomes, RCTs for analyses of association between environmental factors that are amenable to controlled change and outcomes, well-executed qualitative methods for understanding individual's experiences of policy initiatives and practice models.

A particular difficulty evident in disability research is the representativeness of the sample group in relation to the broader population. This results in multiple studies with samples or populations which are not comparable. This means that findings from these studies cannot be aggregated easily.

To gain the best evidence from this body of research requires a robust and defensible framework such as GRADE already utilized by WHO and associates in disability related research internationally for example the work by Einfeld[5] . The GRADE guidelines can be accessed at http://www.gradeworkinggroup.org/ with links to detailed discussion papers on using GRADE at http://www.gradeworkinggroup.org/publications/JCE_series.htm

Relevance and utility to the sector

The focus of the Agenda is "on research that will lead to improved outcomes for Australians with a disability"[4] (p.10). Robust research that addresses issues that are relevant to the sector is critical to developing evidence informed policy. Reviews of research using the TAPUPAS framework suggest that this is worth considering seriously to examine relevance and utility in addition to design fit for purpose and executed to a high standard (see e.g. [6, 7,8,9]).

The Agenda specified six principles to provide a 'guide to the core values for disability research and development, consistent with the National Disability Agreement objectives and outcomes" [4](NDRDA, 2011, p. 14). These principles are inclusive and rights based, responsive and diverse, practicable and outcomes orientated, collaborative and cross disciplinary, accessible and communicated, and efficient and targeted. A concerted effort is required to build a body of disability research which accords with these principles.

Co-production

There is some evidence that inclusive rights based research is gaining currency in Australia with the best known examples involving people with intellectual disability as co-researchers. Participatory research is the subject of much discussion and debate in many fields including questions such as who participates? Who is the community? What degree or level of participation is appropriate?

In the absence of a generic checklist for critically appraising co-production in disability research the description supporting the principle of Inclusive and Rights Based could initially stand in its stead as follows:

Research should be built on the premise that the lived experience of people with disability should influence the development, design, conduct, analysis, dissemination and application of research and evaluation. It should aim to include and engage people with disability at every level, including in research and policy[4] (p.11).

Consideration needs to be given to developing guidelines for inclusive rights based research for use in Australia. Over a decade ago guidelines were developed by the NHMRC for Ethical Conduct in Aboriginal and Torres Strait Islander Research. These guidelines are available at https://www.nhmrc.gov.au/guidelines/publications/e52. There is also a resource booklet available for Aboriginal and Torres Strait Islander peoples to refer to when making decisions about health research in their communities available at https://www.nhmrc.gov.au/guidelines/publications/e65 . These are valuable practical resources for Aboriginal and Torres Strait Islander communities and for researchers. Further, these guidelines provide direction for policy makers and other stakeholders to critically appraise research planned or already undertaken with Aboriginal and Torres Strait Islander peoples. These guidelines would benefit from updating to specifically include Aboriginal and Torres Strait Islander people with a disability using the questions included below, as a minimum.

There is a strong case to be made for developing guidelines and an accompanying resource booklet for conducting inclusive, rights based research with people with disability. The consultative, drafting and review approach taken in developing the NHMRC Ethical Conduct in Aboriginal and Torres Strait Islander Research approach has direct relevance to the disability sector. Utilising this approach in conjunction with the six principles in the Agenda would result in a highly desirable outcome for all people with disability and their representative organisations, for the disability sector and for policy makers seeking to critically appraise disability research proposals. Three core questions are proposed here to start discussions on developing these guidelines and in the interim as appraisal criteria for intergovernmental disability committees.

- Which people with disability or their representative organisations are involved in the planning and implementation of the research project?
- How will the findings of this project assist in achieving positive change for people with a disability?
- How accessible are the research reports and findings for people with a disability?

Research Gaps Identified in the Audit

The following areas are significantly under-represented in the disability research base:

- Safety and security, transport and communication, housing and the built environment, social relationships and community and civic participation
- Inclusion and participation of children and young people with disability in everyday life
- Experiences of people with disability as
    - Specialist service users in relation to preference, choice, control, goals and desired outcomes – in health, education, employment, housing, sexuality, personal relationships, marriage and family, transport, communication technologies
    - Users of mainstream services in in relation to preference, choice, control, goals and desired outcomes - in health, education, community and civic participation, transport and communication, safety and security and housing and the built environment
- Models for accessible and adaptable mainstream services which deliver useful outcomes for people with disability
- Longitudinal studies that follow people with disability over time to better understand the potential drivers (social, economic, cultural, impairment-related) of inequalities
- Issues specific to the Aboriginal and Torres Strait Islander people with a disability, women with disability, people with disability from culturally and linguistically diverse backgrounds and people with disability living in regional, rural and remote areas
- Co-production of research with people with disability

Recommendations

In the short term, that consideration is given to:

1. Commissioning secondary research (systematic reviews, secondary analysis of population and administrative data) to take advantage of this robust and cost efficient mechanism.
2. Commissioning a formal research priority setting exercise (based on the methodology developed by WHO) to identify disability research priorities in Australia as articulated by people with disabilities, family/ carers, policy makers and service providers.
3. Dedicated investment to stimulate disability research which explores the experience of policy from the perspectives of consumers, carers and practitioners.

4. Including funds within disability research to ensure wider dissemination of research. This would include open access journals and freely available, accessible reports on ‘unlocked’ websites with dedicated research sections and stable URLs.
5. Investment in maintenance and biennial update of the Audit of Disability Research in Australia database to provide an ongoing resource to identify research gaps, enable monitoring of disability research in Australia over time, and assist in developing research collaborations to build capacity, coherence and critical mass in disability research.

In the medium term, that consideration is given to:

6. Dedicated funding for co-production of research with people with disability and DPOs including developing guidelines on disability inclusive rights based research.
7. Collection of more comprehensive data and stimulating research on priority groups including Aboriginal and Torres Strait Islander people with disability, women with disability, culturally and linguistically diverse groups and people living in regional, rural and remote areas and children and young people.
8. Increased efforts and investment to adopt the ‘standardised disability identifier’, developed by AIHW, into mainstream service data systems as administrative data on access to mainstream services are largely missing.
9. Routine reporting of disability statistics, including prevalence, living circumstances and health and wellbeing, by age, sex, geography, ethnicity and Aboriginal and Torres Strait Islander peoples.
10. Programmatic funding to a network of centres with specific expertise and focus to build disability research capacity (training and research production) in agreed strategic and priority areas.

Section 4: References Sections 1-3

Section 1: Background and Method for Conducting the Audit of Disability Research in Australia

1. *National Disability Research and Development Agenda, 2011.* http://www.pda.org.au/uploads/documents_for_download/item_1_national_rd_agenda_web.pdf
2. *National Disability Agreement, 2009 .* http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-agreement
3. *National Disability Strategy, 2010-2020,* Commonwealth of Australia, ISBN 978-1-921647-39-0
4. *Disability Care and Support:Executive Summary*, Report no.54, Productivity Commission 2011
5. *National Carer Strategy,* Commonwealth of Australia, ISBN 978-1-921975-00-4
6. EPPI-Centre. Evidence for Policy and Practice Information and Co-ordinating Centre. *EPPI-Centre methods for conducting systematic reviews.* London: EPPI-Centre, University of London, 2010.
7. United Nations. Convention on the Rights of Persons with Disabilities New York: United Nations, 2006
8. Australian Social Inclusion Board. Social Inclusion in Australia: How Australia is faring. Canberra: Department of the Prime Minister and Cabinet, 2010.
9. ABS 4125.0 - Gender Indicators, Australia, January 2012 http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4125.0Main+Features1Jan%202012?OpenDocument
10. *World Report on Disability*, World Bank and World Health Organisation, Geneva, 2011.
11. Community-based rehabilitation: CBR guidelines. ISBN 978 92 4 154805 2 © World Health Organization 2010, http://www.who.int/disabilities/cbr/guidelines/en/
12. *International Classification of Disability, Functioning and Health*. http://www.who.int/classifications/icf/en/

Section 2: Scope of Disability Research in Australia 2000-2013

1. EPPI-Centre. Evidence for Policy and Practice Information and Co-ordinating Centre. *EPPI-Centre methods for conducting systematic reviews.* London: EPPI-Centre, University of London, 2010.
2. Gough, D., Thomas, J., & Oliver, S (2012), Clarifying differences between review designs and methods, *Systematic Reviews,* 1:28.
   http://www.systematicreviewsjournal.com/content/1/1/28
3. Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre), Institute of Education, University of London, https://eppi.ioe.ac.uk/cms/
4. Pawson, R. (2013). *The science of evaluation. A realist manifesto.* London: SAGE.
5. Social Care Institute for Excellence (SCIE), http://www.scie.org.uk/
6. *Shut Out: The experience of people with disabilities and their families in Australia.* The National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council, 2009, http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia
7. Tomlinson, M., Yasamy, M.T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (2014). Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of Intellectual Disability Research*, early online 7th January 2014, doi: 10.1111/jir.12106, http://onlinelibrary.wiley.com.ezproxy1.library.usyd.edu.au/doi/10.1111/jir.12106/abstract
8. Jordans, M. JD., Luitel, N. Pl., Tomlinson, M., & Komproe, I. H (2013). Setting priorities for mental health care in Nepal: a formative study. *BMC Psychiatry,* 13:332. http://www.biomedcentral.com/1471-244X/13/332

Documents referenced in Research Centre Reports section

1. Biddle, N., et al., *Disability*2013, Acton, ACT :: Centre for Aboriginal Economic Policy Research. 1 electronic text (ii, 16 p. : ill., maps) :.
2. Bohanna, I.K., et al., *Assessment of acquired brain injury in Aboriginal and Torres Strait Islander Australians : guidance for DisabilityCare Australia*2013. 123 pages :.
3. Helps, Y.L.M., et al., *Aboriginal people travelling well : community report*2010, Carlton South, Vic. :: The Lowitja Institute. vi, 18 p. :.
4. Yonovitz, A., et al., *Hearing loss and communication disability within the criminal justice system / by A. Yonovitz with Grant Preston, Damien Howard and Daniel Kemp.* [Darwin? : The authors], 2003. 21p. bibl, diagr, table, 2003.
5. Carnovale, A. and Women's Centre for Health Matters Inc, *It goes with the territory! : the views of ACT women with disabilities about health and wellbeing information*2011, [Pearce, A.C.T.] :: Women's Centre for Health Matters. 38 p. ;.
6. Healey, L., et al., *Building the evidence : a report on the status of policy and practice in responding to violence against women with disabilities in Victoria : a collaborative project of the Victorian Women with Disabilities Network Advocacy Information Service, Alfred Felton research program at the University of Melbourne and the Domestic Violence Resource Centre Victoria*2008, Melbourne :: Victorian Women with Disabilities Network Advocacy Information Service. 1 v.
7. Hunter, R., et al. *Women and legal aid identifying disadvantage : final report*. 2006; Available from: http://www.griffith.edu.au/centre/slrc/pdf/ reports /laq-wla- report .pdf
8. Women's Centre for Health Matters Inc, *Strong women, great city a survey for ACT's women with disabilities !*2012, [Pearce, A.C.T.] :: Women's Centre for Health Matters. [4] p.
9. Glynn, R., L. Krefting, and Center for Remote Health, *Course development process and outcomes & course evaluation : Community based rehabilitation - primary health care for people with disabilities*2006, Alice Springs :: Centre for Remote Health. 125 p. ;.
10. Misan, G., et al., *Report to the Information Economy Policy Office of the Department for Administrative and Information Services and Department of Human Services of the Government of South Australia for the SA regional IT disability project : prepared by Gary Misan...[et al]; submitted by the South Australian Centre for Rural and Remote Health (SACRRH)*2001, Whyalla Norrie, SA :: South Australian Centre for Rural and Remote Health (SACRRH). 245 p. :.
11. Ethnic Disability Advocacy Centre, et al., *Reaching out through partnerships : addressing disability advocacy needs of ethnic regional and rural Western Australians*2001, [Subiaco, W.A.] :: Ethnic Disability Advocacy Centre. 30 p. ;.
12. Cavallaro, T., et al., *People with a disability in vocational education and training: a statistical compendium*2005, Adelaide, SA: National Centre for Vocational Education Research. 51p.
13. Mavromaras, K.G., et al., *Improving the employment rates of people with disabilities through vocational education*2011, Melbourne: Melbourne: Melbourne Institute of Applied Economic and Social Research, University of Melbourne, 2011.
14. Polidano, C., et al., *Labour market impacts from disability onset*2012, [Parkville, Vic.]: Melbourne Institute of Applied Economic and Social Research, University of Melbourne. 30 p.
15. Edwards, B. and Australian Institute of Family Studies, *The nature and impact of caring for family members with a disability in Australia*2008, Melbourne, Vic. :: Australian Institute of Family Studies. xvi, 122 p. :.
16. Hill, T., et al., *Young carers their characteristics and geographical distribution*2009, [Canberra, A.C.T. :: National Youth Affairs Research Scheme. 1 electronic text (xvi, 162 p. : ill., map) :.
17. Lymer, S., et al. *Who cares? the cost of caring in Australia 2002 to 2005*. 2006; Available from: http://www.natsem.canberra.edu.au/storage/AMP_NATSEM_13.pdf
18. Intellectual Disability Rights Service Staff, Steele, L., Redfern Legal Centre. Intellectual Disability Rights Service, Coalition on Intellectual Disability and Criminal Justice, & New South Wales Council for Intellectual Disability. (2008). Enabling justice: a report on the problems and solutions in relation to diversion of alleged offenders with intellectual disability from the New South Wales local courts system. Redfern, N.S.W.: Intellectual Disability Rights Service Inc.
19. Tannous, W. K., Dadich, A., Beckett, R., Cerebral Palsy Alliance, & University of Western Sydney. Centre for Industry and Innovation Studies. (2011). Report for Cerebral Palsy Alliance: evaluation of the Ignition Mentoring Program. Penrith South, N.S.W.: Centre for Industry and Innovation Studies, University of Western Sydney.

Section 3: Evaluation of Evidence Framework, Research Gaps and Recommendations

1. Guyat, G. H., Oxman, A. D., Vist, G. E., Kunz, R., Falck-Ytter, Y., Krottneruse, G. (2011). GRADE guidelines: a new series of articles. *Journal of Clinical Epidemiology*, *64*(4), 380-382.
2. Gough, D., Oliver, S., &Thomas, J. (2012). *An introduction to systematic reviews.* London: SAGE.
3. Pawson, R., Boaz, A., Grayson, L., Long, A., & Barnes, C. (2003). *Types and quality of knowledge in social care.* London: Social Care Institute for Excellence.
4. *National Disability Research and Development Agenda, 2011.* http://www.dprwg.gov.au/research-development/publications/national-disability-research-and-development-agenda.
5. Einfeld, S., Ellis, L., Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability*, 36(2), 137-143.
6. Kneafsey, R. (2007). A systematic review of nursing contributions to mobility rehabilitation: Examining the quality and content of the evidence. *Journal of Clinical Nursing, 16*(11c), 325-340. doi: 10.1111/j.1365-2702.2007.02000.x
7. Long, A. F., Grayson, L., & Boaz, A. (2006). Assessing the quality of knowledge in social care: Exploring the potential of a set of generic standards. *British Journal of Social Work, 36*, 207-226. doi: 10.1093/bjsw/bch307
8. Newbigging, K., McKeown, M., & French, B. (2011). Mental health advocacy and African and Caribbean men: good practice principles and organisational models for delivery. *Health Expectations, 16*, 80-104. doi: 10.1111/j.1369-7625.2011.00692.x
9. Sharland, E., & Taylor, I. (2006). Social care research: A suitable case for systematic review? *Evidence & Policy, 2*(4), 503-523.

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