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<td>Appendix 3</td>
<td>Campbell Collaboration</td>
<td>134</td>
</tr>
</tbody>
</table>
# List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
</tr>
<tr>
<td>AIFS</td>
<td>Australian Institute of Family Studies</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>BEACH</td>
<td>Bettering the Evaluation and Care of Health</td>
</tr>
<tr>
<td>CADR</td>
<td>Centre for Applied Disability Research</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>CDRP</td>
<td>Centre for Disability Research and Policy</td>
</tr>
<tr>
<td>CDSR</td>
<td>Cochrane Database of Systematic Reviews</td>
</tr>
<tr>
<td>CONSORT</td>
<td>Consolidated Standards of Reporting Trials</td>
</tr>
<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>DSNMDS</td>
<td>Disability Services National Minimum Data Set</td>
</tr>
<tr>
<td>DPOs</td>
<td>Disabled People’s Organisations</td>
</tr>
<tr>
<td>DS</td>
<td>Disability Support</td>
</tr>
<tr>
<td>DSP</td>
<td>Disability Support Pension</td>
</tr>
<tr>
<td>ESRC</td>
<td>Economic and Social Research Council</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GRADE</td>
<td>Grading of Recommendations, Assessment, Development and Evaluation</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
</tr>
<tr>
<td>HILDA</td>
<td>Housing Income Labour Dynamics Australia</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>IDEA</td>
<td>Intellectual Disability Exploring Answers</td>
</tr>
<tr>
<td>LSAC</td>
<td>Longitudinal Study of Australian Children</td>
</tr>
<tr>
<td>NDA</td>
<td>National Disability Agreement</td>
</tr>
<tr>
<td>NDIA</td>
<td>National Disability Insurance Agency</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NDS</td>
<td>National Disability Services</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Cooperation and Development</td>
</tr>
<tr>
<td>PC</td>
<td>Productivity Commission</td>
</tr>
<tr>
<td>SCIE</td>
<td>Social Care Institute for Excellence</td>
</tr>
<tr>
<td>SDAC</td>
<td>Survey of Disability Ageing and Carers</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>WA</td>
<td>Western Australia</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Executive Summary

The initial Audit of Disability Research in Australia was published online in July 2014, and included scientific and grey literature, government and non-government research reports. The current Audit of Disability Research in Australia Update Report 2017, hereafter referred to Audit Update 2017, was commissioned by National Disability Services (NDS), from a funding grant offered under the National Disability Research and Development Agenda, in June 2017 and undertaken by the Centre for Disability Research and Policy (CDRP) at the University of Sydney. The Audit Update 2017, used the same methods as previously, with minor modifications to align with the Centre for Applied Disability Research (CADR) Clearing House protocol. The Audit Update 2017 addressed disability research from Australia in the scientific literature between mid-2013 and mid-2017, and research reports from the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), and the Productivity Commission (PC).

The major differences in the time period between the initial 2014 Audit and the current Audit Update 2017 are as follows:

- The majority of studies are in the domain of Education rather than Health and Wellbeing as in the 2014 Audit
- The three most written about domains are Education, Economic Participation, and Social Relationships in contrast to Health and Wellbeing, Education, and Economic Participation in the 2014 Audit
- The research designs utilised in the Audit Update 2017 were markedly similar to those in the 2014 Audit. The most frequently appearing were qualitative studies and observational studies with the least frequently occurring study protocol only, historical analysis and media/ creative arts/ cultural analysis. In the 2014 Audit, most frequently occurring study designs were observational studies and qualitative studies with the least frequently occurring study protocol only, systematic review, historical analysis and randomised controlled trials (RCTs)
- There has been an increase in the number of studies employing 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, however taken together these designs only accounted for just under 1/10th of all studies.

The narrative analyses in selected topic areas offer detailed ways forward in the body of this report. In brief, the analyses found that:

- Although there are proportionally more studies addressing Aboriginal and Torres Strait Islander people, there remains a dearth of studies addressing community relevant and policy relevant topics. There remains limited input from the community into the studies undertaken with some areas of Australia such as Central Australia and the Top End not represented.
The major shift in policy research is that almost half of the policy papers addressed the National Disability Insurance Scheme (NDIS), with papers on operational issues and also more theoretical papers examining the broader social and health policy context in which the Scheme is operating. The policy topic gaps identified in the 2014 Audit remain the same: indigenous research, rural and remote research, structured policy evaluation, policy studies addressing culturally and linguistically diverse populations (CALD) with a disability, multidisciplinary approaches to policy evaluation, and research on lived experience bringing the perspectives of people with disabilities, families and carers to policy critiques.

The studies utilising administrative data are unevenly spread across the sectors with health and justice appearing more frequently, with education and employment not as prevalent and no studies on housing. Studies were also unevenly distributed across the country with administrative data studies from New South Wales (NSW) appearing most frequently. However, the identification of disability in administrative datasets remains inconsistent; thus, the recommendation from the 2014 Audit still holds, that is, the disability flag available from the AIHW is used by all jurisdictions in all administrative datasets. As mooted in the 2014 Audit, NDIS data needs to be linked with other datasets to offer a transparent, cost-effective approach to understanding relationships between disability and the living situation of people with disabilities.

Diverse topics were covered by studies utilising case registers, however due to the nature of case registers, the studies are restricted to specific health conditions or impairments associated with disability. An advantage of case register research is examining the situation of people with specific impairments at a point in time and over time, and in a cost-effective way. The way forward is to stimulate the use by disability researchers of the available case register data.

Since the 2014 Audit there has been an increase in frequency in studies that utilise secondary data analysis of existing population-based survey data. This is also a cost-effective approach to understanding the association between disability (and functioning) and living circumstances of people with disability in Australia at a particular point of time and when the studies are a repeated cross-sectional or panel design, also over time. A major advantage of population studies is identifying and quantifying the extent of exposure and impact of exposure of people with disabilities to well-established social determinants of health and wellbeing. Overall, the way forward is to support greater use by disability researchers of available cross-sectional, longitudinal population based studies including administrative data, case registers and national and sub-national surveys.

With regard to research reports published by the ABS, AIHW and the PC, the overall pattern of statistical production has not altered significantly since the 2014 Audit although the NDIS has implications for the production of disability data. The major concerns are limitations of the available data reported by the National Disability Insurance Agency (NDIA), including lack of comparability with the well-established datasets held by the ABS and AIHW. There are new analyses and new topics being covered by the ABS and AIHW for example on mental health, access and barriers to health care, health conditions and relationship to disability, housing and homelessness, and from the PC a new report on NDIS costs. Gaps identified in the 2014 Audit remain including data on the impact of environmental factors, and analyses addressing people from CALD backgrounds. A gap still remains in analyses which identify long-term trends for example in disability services, however, these require data standards to
remain stable over time. There is serious concern that the National Disability Agreement (NDA) disability services collection is at risk without the highly desirable, but not yet achieved, coordination between the NDIA and AIHW.
Section 1: Introduction

An Audit of Disability Research in Australia was published online in July 2014 (http://sydney.edu.au/health-sciences/cdrc/projects/auditresearch.shtml) and from http://www.adhc.nsw.gov.au/about_us/research/completed_research/the_national_disability_research_and_development_agenda). The main aim of this Audit, hereafter referred to as 2014 Audit, was to produce a report to provide a comprehensive picture of the current state of disability research in Australia. The 2014 Audit covered the literature (scientific and grey literature) from 2000 to September 2013 and included research reports published by government departments and non-government organisations including organisations of people with disabilities during this time period.

One of the recommendations of the 2014 Audit was that there be:

“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” (p. 12).

In June 2017, the NDS contracted the CDRP, University of Sydney to undertake an update of the 2014 Audit. The Audit Update 2017 is the subject of this report. The terms of reference for Audit Update 2017 differed somewhat from those in the 2014 Audit which was produced with a funding grant offered under the National Disability Research and Development Agenda, jointly implemented by disability representatives from Commonwealth, State and Territory governments.

The key objectives of the Audit Update 2017 were:

1. To update the Audit of Disability Research in Australia (2014) to collate the scientific literature on disability reported since September 2013

2. To provide commentary on the updated Audit results on scientific literature on disability and specifically in relation to the 'fit for purpose' of Australian disability research for the Australian disability reform agenda

3. To propose a suitable hierarchy for categorising the scientific literature on disability that is useful for research end users.
Section 2: Method

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, Associate Professor Jennifer (Jen) Smith-Merry, Dr John Gilroy, Dr Rosamond (Ros) Madden, Professor Anne Kavanagh, University of Melbourne, and Gordon Duff, NDS. The Senior Research Officer was Dr Gabrielle Hindmarsh.

Process

The Audit Update 2017 employed processes developed for the scientific literature from the 2014 Audit. Since the time of the initial 2014 Audit, NDS had developed the CADR Clearing House. This Clearing House employs essentially the same conceptual framework from the 2014 Audit with some minor changes.

Changes required for the Audit Update 2017 were discussed with NDS staff, Gordon Duff, James Bannister and Jacquelyn Johnson, and adaptations to coding scientific literature were made as required to align with CADR Clearing House data protocol. In brief, Audit Update 2017 involved two components. The first component involved update and analysis of abstracts retrieved from the scientific literature according to inclusion and exclusion criteria from mid-2013 to mid-2017. Narrative analyses were carried out (as per the 2014 Audit) on a subset of abstracts of studies addressing Aboriginal and Torres Strait Islander research; policy; administrative and population dataset utilisation; and ABS, AIHW and PC research reports. An additional narrative analysis was added to cover studies reporting on case register research. The second component involved a desk review of assessing quality and reporting frameworks for the scientific literature.

Search Methods

The 11 databases used in the 2014 Audit were searched using the eight domains of the conceptual framework reported in the 2014 Audit. These are Community and Civic Participation, Economic Participation, Education, Health and Wellbeing, Housing and the Built Environment, Safety and Security, Social Relationships, and Transport and Communication. As in the 2014 Audit, the databases 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.

After duplicate removal and initial screening using the EndNote procedures applied in the 2014 Audit, 4,573 items remained for possible inclusion. Full details of the search strategy and results for the scientific literature are included in Attachment 1.
Analysis

All documents were coded from title and abstract according to:

- The eight domains in the 2014 Audit conceptual framework noted above with the inclusion of a ninth domain present in the CADR Clearing House data protocol which is Sector Development and Sustainability
- By study design/ type of investigation based on the descriptors used in the 2014 Audit.

Coding by domain

All research documents were coded by review of title and abstract into one of the eight domain categories or, if relevant, into two domain categories as required by the CADR Clearing House data protocol as follows: Community and Civic Participation; Economic Participation; Education; Health and Wellbeing; Housing and the Built Environment; Safety and Security; Social Relationships; Transport and Communication. All documents in each domain category were then reviewed and coded if relevant into the Sector Development and Sustainability domain. The description of each domain is detailed in Attachment 2.

Coding by study design/ type of investigation

The coding framework for study design/ type of investigation designed for the 2014 Audit was applied. Each title and abstract was read to determine coding. There are 17 mutually exclusive categories in this framework. These are intervention studies (RCTs, study protocol only, observational studies), secondary analysis studies (administrative datasets, case registers, population data, file audit/ document review), literature reviews (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. The description of each study design/ type of investigation is detailed in Attachment 3.
Section 3: Findings

The first section of the findings addresses the domains of the conceptual framework. The second section addresses study design/ type of investigation. The third section addresses the narrative analyses in the specified topic areas.

Number of studies
A total of 939 documents from the scientific literature met the Audit Update 2017 criteria.

Domains
The greatest proportion of disability research in Australia between 2013 and 2017 reported in the scientific literature addresses the Education domain (n=420: 44.7%). The two content domains in which there is least research in this time period is Housing and the Built Environment (n= 10: 1.1%) and Safety and Security (n=11: 1.2%). The scope of research by domain is presented in Table 1 and 2. The content domains in descending order from more to fewer research studies are:

- Education (n=420: 44.7%)
- Economic Participation (n=208: 22.2%)
- Social Relationships (n=156: 16.6%)
- Health and Wellbeing (n=72: 7.7%)
- Community and Civic Participation (n=35: 3.7%)
- Transport and Communication (n=27: 2.9%)
- Sector Development and Sustainability (n=17: 1.8%)
- Safety and Security (n=11: 1.2%).
- Housing and the Built Environment (n= 10: 1.1%)
Table 1. Scope of research by domain in the scientific literature

<table>
<thead>
<tr>
<th>Domain</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOM_COMM</td>
<td>35</td>
<td>3.7</td>
</tr>
<tr>
<td>DOM_ECON</td>
<td>208</td>
<td>22.2</td>
</tr>
<tr>
<td>DOM_EDU</td>
<td>420</td>
<td>44.7</td>
</tr>
<tr>
<td>DOM_HEALTH</td>
<td>72</td>
<td>7.7</td>
</tr>
<tr>
<td>DOM_HOUSE</td>
<td>10</td>
<td>1.1</td>
</tr>
<tr>
<td>DOM_SAFE</td>
<td>11</td>
<td>1.2</td>
</tr>
<tr>
<td>DOM_SOC</td>
<td>156</td>
<td>16.6</td>
</tr>
<tr>
<td>DOM_TRANS</td>
<td>27</td>
<td>2.9</td>
</tr>
<tr>
<td>Total</td>
<td>939</td>
<td>~100</td>
</tr>
</tbody>
</table>

~due to rounding % does not equal 100

Coding by the Sector Development and Sustainability domain resulted in 17 documents (see Table 2).

Table 2. Studies coded by Sector Development and Sustainability

<table>
<thead>
<tr>
<th>Domain</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOM_SECTOR</td>
<td>17</td>
<td>1.8</td>
</tr>
</tbody>
</table>

Study design/ type of investigation

The findings on study design/ type of study design according to the 17 types represented in the type of investigation framework for the Audit Update 2017 are presented in Table 3. The most frequently occurring study types were qualitative studies (n=240: 25.6%) and observational studies (n=166: 17.7%) with the least frequently occurring study protocol only (n=7: 0.7%), historical analysis (n=8: 0.9%) and media/ creative arts/ cultural analysis (n=11: 1.2%).
Table 3. Distribution of research by study design/ type of investigation in the scientific literature

<table>
<thead>
<tr>
<th>Code</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Randomised controlled trial (RCTs)</td>
<td>14</td>
<td>1.5</td>
</tr>
<tr>
<td>Study protocol only</td>
<td>7</td>
<td>0.7</td>
</tr>
<tr>
<td>Observational study</td>
<td>166</td>
<td>17.7</td>
</tr>
<tr>
<td>Secondary analysis: Administrative dataset</td>
<td>14</td>
<td>1.5</td>
</tr>
<tr>
<td>Secondary analysis: Case registers</td>
<td>25</td>
<td>2.7</td>
</tr>
<tr>
<td>Secondary analysis: Population data</td>
<td>42</td>
<td>4.5</td>
</tr>
<tr>
<td>File audit/ Document review</td>
<td>26</td>
<td>2.8</td>
</tr>
<tr>
<td>Systematic review</td>
<td>26</td>
<td>2.8</td>
</tr>
<tr>
<td>Narrative review</td>
<td>46</td>
<td>4.9</td>
</tr>
<tr>
<td>Measures development</td>
<td>42</td>
<td>4.5</td>
</tr>
<tr>
<td>Questionnaire study</td>
<td>120</td>
<td>12.8</td>
</tr>
<tr>
<td>Qualitative</td>
<td>240</td>
<td>25.6</td>
</tr>
<tr>
<td>Mixed methods investigation</td>
<td>77</td>
<td>8.2</td>
</tr>
<tr>
<td>Policy analysis</td>
<td>56</td>
<td>5.9</td>
</tr>
<tr>
<td>Legal analysis</td>
<td>19</td>
<td>2.0</td>
</tr>
<tr>
<td>Historical analysis</td>
<td>8</td>
<td>0.9</td>
</tr>
<tr>
<td>Media/ Creative Arts/ Cultural analysis</td>
<td>11</td>
<td>1.2</td>
</tr>
<tr>
<td>Total</td>
<td>939</td>
<td>~100</td>
</tr>
</tbody>
</table>

~due to rounding does not equal exactly 100

Commentary

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=120: 12.8%) and qualitative studies (n=240: 25.6%) comprised 38.3% 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=14: 1.5%) and observational studies (n=166: 17.7%) together comprised 19.1%,
that is, nearly 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 2.8% (n=26) 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 81 (8.7%) studies in total. Of these, 14 (1.5%) were studies employing secondary analysis of administrative datasets, 25 (2.7%) were analysis of case registers, and 42 (4.5%) were secondary analysis studies using population data. Together just under 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.

Narrative Analysis
This section contains detailed findings from the narrative analyses undertaken by members of the Research Team on topics of particular interest. In this Audit 2017 Update there is an additional narrative analysis topic which recognises the emerging interest in utilising secondary analysis of case register data that was not presented in the initial 2014 Audit. The narrative analyses are presented in the following order:

- Aboriginal and Torres Strait Islander research
- Policy analysis research
- Research utilising secondary analysis of administrative data
- Research utilising secondary analysis of case register data
- Research utilising secondary analysis of population data
- Research from ABS, AIHW and the PC

Aboriginal and Torres Strait Islander research
This narrative analysis was undertaken by Dr John Gilroy who accessed all documents in the scientific literature sourced for the Audit Update 2017 which specifically addressed Aboriginal and Torres Strait Islander peoples. It is possible that Aboriginal and Torres Strait Islander people were also included in other studies in the Audit Update 2017 as part of study design and sampling however this cannot be determined by review of the abstracts. As noted in the 2014 Audit there is potentially more research conducted which includes Aboriginal and Torres Strait Islander peoples.

In spite of the increase in funding for research in Aboriginal and Torres Strait Islander communities under the Australian government’s disability research agenda, there is a lack of improvement in the number and diversity of Aboriginal and Torres Strait Islander disability research studies in the Audit Update 2017. There were only 28 scientific papers which specifically addressed Aboriginal and Torres Strait Islander peoples. In saying this, it is an increase in scientific output over a shorter period of

**Grouping of documents and topics investigated**

There was a strong focus on communication disability (Armstrong et al., 2015a, b; Greenstien, 2016; Hersh, 2015) and intellectual disability (Carrol, 2015; Haysom, 2014; McGaughey, 2017; Roy & Balaratnasingam, 2014). The communication literature focused strongly on acquired disability, such as stroke, and children with speech impairments.

Interestingly, there were fewer studies on sensory disability, such as visual and hearing impairments. There were only two studies (Foreman, 2017a, b). This is a substantial change from the 2014 Audit where there were eight papers.

Like the studies sourced in the 2014 Audit, there was limited focus on acquired disabilities, such as traumatic brain injury or physical disability, despite the high rates of these disability types. Only three research teams (Armstrong et al., 2015a, b; Maxwell, 2013; Stephens, 2014) completed studies in this area. Maxwell (2013) focused on the prison system, Stephens (2014) focused on the NDIS, and Armstrong et al. (2015a, b) on communication research.

**Contribution of this body of literature**

Similar to the studies sourced for the 2014 Audit, there is limited discussion in the studies in this Audit Update 2017 on how the research adopted Indigenous research methods or if the research adopted the values and principles of Aboriginal community controlled research. The fieldwork research studies often acknowledged that they got ethics approval. However, many of the papers did not adequately report on how they actively worked with Aboriginal communities before and during the research process. Armstrong et al. (2015) research protocol is one exception, where it is explained how the research team worked with local communities and recruited Aboriginal staff to the team.

There is a higher proportion of research reporting on analysis of secondary sources of data, and these papers open up some policy concerns relating to low representation in the NDIS and social justice issues (Gilroy et al., 2017; Gooding et al., 2017; McGaughey, 2017). Furthermore, these research papers are able to report on the gaps in Aboriginal and Torres Strait Islander research (Balaratnasingam, 2015; Green et al., 2014).

Similar to the studies sourced for the 2014 Audit, most studies used qualitative methods. Interviews, focus groups, and case studies were the main research approaches. Many of these studies have empowered Aboriginal and Torres Strait Islander people with a disability by allowing them to voice their experiences as a person with a disability.

The concern for investigating the cultural relevance of diagnostic screening and assessment tools research (D’Aprano et al., 2016; Foreman, 2017; Shepard, 2017) is quite useful, as there is limited research on the cultural veracity of these tools for Aboriginal and Torres Strait Islander peoples. It is widely known that many of these tools are developed in a non-Indigenous setting and cultural applicability and adaptability are wrongly assumed. There is a high need for more of these tests to be validated (or not) with Aboriginal and Torres Strait Islander communities.
The work on quantifying the prevalence of disability types (Carroll, 2015; Fitzpatrick, 2015; Foreman, 2017; Gubhaju, 2015; Haysom, 2014) and patterns of service access/referral (Liddle, 2014) in Aboriginal and Torres Strait Islander communities is of significant importance. The scientific literature, coupled with the works published by the AIHW, will contribute to understanding the extent and nature of disability in Aboriginal and Torres Strait Islander communities.

**Impact and relevance of this body of literature**

Although there has been growth in the number of studies reported which specifically address Aboriginal and Torres Strait Islander people with a disability in Australia, given the rate of Indigenous people participating in research, projects and programs, 28 scientific papers are less than expected. Among the 28 papers there were more systematic literature reviews and policy commentary papers (n=11) than previously reported in the 2014 Audit (Balaratnasingam, 2015; Gilroy et al., 2017, 2013; Gooding et al., 2017; Green, 2014; King et al., 2014; Maxwell, 2013; McGaughet et al., 2017; Roy & Balaratnasingham, 2014; Stephens et al., 2014; Trimmer & Dixon, 2017). This left a much smaller body of fieldwork studies over the period of this Audit Update 2017. The systematic literature reviews and policy research potentially have limited direct impact on the lives of Aboriginal and Torres Strait Islander people with a disability.

**Ongoing gaps in research and ways forward**

As suggested in the 2014 Audit, there is a real need for an Aboriginal and Torres Strait Islander research agenda to help focus and direct research to meet community need. The current Audit Update 2017 has shown that Aboriginal and Torres Strait Islander disability research is undertaken with limited direction and input from Aboriginal and Torres Strait Islander people. The geographic coverage of research has not changed. There were many papers that had a national coverage, from Western Australian (WA) and also from NSW. There is a real need for more research in the Central Australia and Top End regions of Australia.

The research output does not reflect Australian government policy direction. There is a strong policy shift on the incarceration of Aboriginal and Torres Strait Islander people, however no studies were found on this topic. This demonstrates that policy may not be driven by community controlled research, and/ or the policy shift is yet to be followed up by data based studies to examine whether policy has had an impact in the desired direction.

**References**


Policy research

This narrative analysis of scientific literature related to disability and policy was undertaken by Associate Professor Jennifer (Jen) Smith-Merry who accessed and read all policy-related documents identified in the Audit Update 2017. The following analysis is limited to the papers accessed using the search strategies reported elsewhere in this report. As noted due to diverse understandings of disability and ways in which disability and mental health are indexed differently in scientific literature databases, it is likely there is an under-reporting on mental health policy which encompasses disability.

Grouping of documents and topics investigated

Perhaps unsurprisingly, given the major policy shift that is currently occurring 25 of the 56 papers relevant to the Audit Update 2017 spoke about the NDIS. The focus of these papers, and their potential impact, is discussed in detail below, however, generally the NDIS-related papers focused on concerns about the practical changes that must take place in organisations and amongst workers to allow for the NDIS, and theoretical papers which looked at the broader social and health policy context operating around the scheme.

Few papers spoke about a specific disability ‘type’. Those that did, focused on mental illness (Cashin, 2014; McCausland & Baldry, 2017; McNaught, 2013), cognitive impairment or intellectual disability (McCausland & Baldry, 2017; Weisel & Bigby, 2015; Wright et al., 2017), cerebral palsy (O’Connor, 2014), visual impairment (Whitburn 2015), acquired brain injury (Stephens et al., 2014) and neurological disability (Wright et al., 2015). Most papers instead focused on issues relating to disability policy more generally, or the impact on people with disability from other policy
frameworks, such as education and the introduction of the new Australian Curriculum (Garner & Forbes, 2015).

As in the previous 2014 Audit, education was the most frequent topic of research aside from the diverse range of papers that focused on the NDIS. Twelve papers spoke about education, including a limited evaluation of the Commonwealth Disability Standards for Education (2005) (Dickson, 2014), inclusive education (Anderson & Boyle, 2015; Hardy & Woodcock, 2015; Hartley, 2015; Kemp, 2016; Macauley et al., 2016; Whitburn, 2017), reasonable adjustments in assessment practice (Cumming et al., 2013), special education in the context of the new Australian curriculum (Garner & Forbes, 2015), seclusion and restraint in educational settings (Lyons, 2015), high school-community transition (O’Neill et al., 2016) and the impact of inherent requirements and mandatory reporting for health practitioner registration on students with a disability (McNaught, 2013).

Housing was the focus of five papers (Cashin, 2014; Ward & Jacobs, 2017; Wiesel & Bigby, 2015; Wright et al., 2015; 2017), which mainly focused on the inability of people with disability to find housing due to limitations associated with supply and appropriateness. These were linked to policy implementation failures and the failure of market forces to provide a range of appropriate housing options. A paper by Wiesel and Bigby (2015) looked at the history of deinstitutionalisation to understand the way particular housing-related narratives were successful in framing and directing the process.

Four papers (described below) focused on indigenous people with disability (Gilroy et al., 2013; McCausaland & Baldry, 2017; Stephens et al., 2015; Trimmer & Dixon, 2017).

Four papers examined current policies in relation to international human rights law. Papers focused on adult protection legislation (Chesterman, 2014), seclusion and restraint use with children in educational settings (Lyons, 2015), closed residential institutions (Frawley and Naylor, 2014) and the other on the values of the NDIS as clashing with human rights approaches to disability (Fawcett and Plath, 2014).

Of the other papers, two papers focused primarily on seclusion and restraint (Lyons, 2015; Wadiwel, 2017), two on remote and rural populations (discussed further below) (Dew et al., 2014; Stephens et al., 2014) and two on workforce change (Macdonald & Charlesworth, 2016; Moyle, 2016). Three papers focused on assistive technology (Ellis & Kent, 2015; Friesen et al., 2015; Layton, 2015) and one was a comparative macro-economic analysis of changes in the use of the Disability Support Payment (Burkhauser et al., 2014).

Other papers were concerned with employment (Scott, 2016), vocational rehabilitation (Buys et al., 2015); disability theatre (Hadley, 2017), social inclusion (Stancliffe, 2014) and policy decision making regarding newborn screening for disability (the Guthrie test) (O’Leary & Maxwell, 2015).

In comparison to the papers included in the 2014 Audit there was much less discussion of disability support payments, rights, and employment, but a much greater focus on policy implementation within services (see discussion below). This is likely due to the changes brought about by the introduction of the NDIS.
Contribution of this body of literature

In the 2014 Audit, a glaring omission from research was that which drew directly on the lived experience of those people whose lives were the subject of the policies being discussed. Only one paper drew directly on the experiential knowledge of people with a lived experience of disability (Whitburn, 2015). However other papers critiqued policy for omitting these voices from consultation (Thill, 2015) or choosing to omit recommendations about inclusion as part of policy design (Mellifont & Smith-Merry, 2016).

It was noted in the 2014 Audit that there were few papers which focused on indigenous disability policy and there were four included in this update. The paper by Gilroy et al. (2013) provided a framework for developing policy related to indigenous people and disability. McCausaland and Baldry’s (2017) paper highlighted the current legislative and policy regime regarding disability leading to the criminalisation of certain groups of indigenous people with a disability, and the great potential for this to lead to abuse. Other papers focused mainly on the implementation of the NDIS on indigenous services. Trimmer and Dixon’s (2017) paper focused in on the market-oriented framework used for administering the NDIS and its potential impact on specialist indigenous services for children with a disability. Stephens et al. (2014) paper looked at issues related to the implementation of the NDIS in remote indigenous communities and developed a set of issues that need to be addressed for the scheme to effectively meet the needs of people in these communities.

Another absence in the 2014 Audit was indicators for assessing policy success. Two papers in this Audit Update 2017 developed report cards or indicator sets against which to measure the effectiveness of policy. This included one paper that provided a report card of measuring inclusive education (Anderson & Boyle, 2015) and another which addressed the failure to implement inclusive housing standards by developing indicators for assessing housing design projects (Wright et al., 2017).

Unlike the 2014 Audit, several papers focused on practice implications of policy change. This included a focus on the impact of policy directions which developed a marketisation of services (Trimmer & Dixon, 2017; Macdonald & Charlesworth, 2016), the impact of a rhetoric of ‘choice’ on service design (Purcal et al., 2014), and the difficulties services have in ‘selling’ their specialist children’s services in a market where parents do not understand the evidence base for their practice (McDonald et al., 2016). The paper by Frawley and Naylor (2014) links policy to current practice to determine the conflict between current practice and human rights as identified in the Convention on the Rights of Persons with Disabilities (CRDP).

Although not noted in the 2014 Audit, there was limited policy-related literature focusing on rural and remote populations. In this Audit Update 2017, there were two papers that focused on rural and remote issues specifically. One paper provided a thorough evaluation of current policy in order to understand the way that rural and remote populations were included (Dew et al., 2014). The other paper focused on indigenous people with acquired brain injury (discussed above) (Stephens et al., 2014). Studies which focus on policy in relation to rural and remote populations are important particularly in the context of the NDIS where all issues related to implementation become more stark.
Impact and relevance of this body of literature

The main impact and relevance of this body of literature comes in the multi-faceted view it allows of the NDIS. Papers took both a practical approach to the NDIS, which linked policy implementation processes with service and workforce implications, and a theoretical approach which allowed for a broader understanding of the program as part of the wider Australian social and health policy context.

Consultation for policy was the focus for three papers (Hallahan, 2017; Mellifont & Smith-Merry, 2016; Thill, 2015). All of these papers examined which discourses were raised within the policy consultation processes and which then made it into the resulting policy. Thill (2015) looked at the extent to which people with a lived experience of disability were given a voice in the development of the NDIS. Two other papers looked at how groups of practitioners were able to develop their collective voice and influence policy (Friesen et al., 2015; Layton, 2015).

Most papers considered the NDIS in theoretical terms. Three papers spoke about the NDIS as a special or ‘aberrant’ policy ‘out of sync’ with other Australian social policy and the general direction of social policy in Organisation for Economic Cooperation and Development (OECD) countries. Marston et al. (2016) contrasted the values underpinning the NDIS with those underpinning income support payments and considered what income support might look like if it took on the NDIS values of individualisation, choice and control. Two other papers (Miller, 2017; Miller & Hayward, 2017) drew attention to the NDIS as an example of welfare innovation at a time of neo-liberal retreat from such programs more generally. They found that moving towards a discourse of ‘social insurance’, framing the policy in terms of marketisation and cash for care meant that the program was successful. However, another paper (Whitburn, 2015) critiques the neo-liberal discourses underpinning disability policy implementation. Hallahan’s (2015) paper analyses different voices included in the consultation process for the NDIS and raises concerns about the NDIS discourse becoming so hegemonic that it drowns out broader disability policy approaches. Another paper is concerned that there is disconnect between the values and practices of the NDIS and education policies for people with disability which must sit alongside it (Whitburn et al., 2017).

These papers may be seen as merely theoretical exercises however they are important because they consider why the NDIS may clash with other policies operating concurrently, and how to frame any attempts to change current practices within the NDIS. Other theoretically-oriented papers considered the conceptualisation of self-direction inherent in the NDIS (Crozier & Muenchberger, 2013) and the focus on personalisation and the NDIS (Fawcett, 2016).

One element worth drawing attention to in relation to the NDIS-themed papers was that many were either written early on in the implementation of the scheme or are written for an audience who are unfamiliar about the scheme. They therefore consider issues that may no longer be relevant or merely provide a description of the scheme and its utility (Crozier & Muenchberger, 2013; Harrison, 2013; Kendrick et al., 2017; O’Connor, 2014; Reddihough et al., 2016). One paper provides an inaccurate description of its operation in relation to the use of diagnosis for eligibility (Carey & Matthews, 2017).

Several papers develop theoretical or practical frameworks for assessing policy implementation. Henman and Foster (2015) consider different frameworks for disability support governance:
uncoordinated, casework governance, dwelling based, and user-coordinated. A framework for considering accountability in relation to the individualised funding provided by the NDIS was developed in one paper (Dickinson et al., 2014). Two papers provide frameworks for assessing or developing policy related to indigenous people with disability (Gilroy et al., 2013; Stephens et al., 2014).

A smaller number of papers focus on the practice implications of policy change related to the NDIS. Four papers look at the service and workforce changes brought about by a move towards marketisation and choice (Macdonald & Charlesworth, 2016; McDonald et al., 2016; Purcal et al., 2014; Trimmer & Dixon, 2017).

Only one paper uses existing datasets to understand the NDIS implementation. Cebulla and Zhu (2016) provide an estimation of NDIS eligibility based on the use of the Housing Income Labour Dynamics Australia (HILDA) dataset. One paper also provided a cost-benefit calculation related to the NDIS (Harrison, 2013) which questioned the model used to fund the scheme.

One paper drew on available data to understand the extent to which social inclusion was improving for people with disability in Australia more generally, but found that ongoing measurement of inclusion was made difficult by inconsistent data (Stancliffe, 2014).

Ongoing gaps in research and ways forward

The methodological rigour of the papers as expressed in their description of data collection and analysis is low. Over half of the papers could be classed as commentary or expert academic opinion and demonstrate no formal method or approach to data synthesis. Only ten papers included structured methods which demonstrated how the data used to develop paper findings had been gathered.

Although expert knowledge has its place in policy making and commentary and is therefore important, particularly when it comes with the added value of lived experience, data is also important because it gives weight to arguments that might otherwise be dismissed. As mentioned in one paper, in some cases there is currently no available data against which to measure policy implementation or social or practice changes in relation to policy (Stancliffe, 2014).

In addition, the following gaps remain:

- There is still limited indigenous-focused research taking place
- Rural and remote research is very limited
- There is currently no structured policy evaluation research
- There were no papers at all which spoke about CALD populations with a disability in relation to policy
- There is still little evidence of multi-disciplinary approaches to disability policy evaluation
- There is a lack of research which focuses on the experiences of consumers and carers as part of policy evaluation, and which draws on their knowledge in developing policy critiques.

References


Research utilising secondary analysis of administrative data

This narrative analysis was undertaken by Professor Anne Kavanagh accessing the documents from the scientific literature which utilised administrative data from a range of Federal and State jurisdictions to answer a diverse set of research questions.

Introduction to and grouping of documents

The administrative data in these studies came from health, justice, disability services, employment and education. Fourteen studies met the administrative data criteria with nine State-based (5 NSW, 3 Victorian and 1 Queensland) and five Australian-based. Seven of the studies relied on datasets from one sector (e.g., health), five on two datasets, and two on three or more datasets. Six studies used linked data. The studies are grouped below in terms of the sector from which data was drawn (i.e. health, justice) noting that seven of the studies could be in more than one sector.

The sectors of the data sources include:

- **Health** (8 studies) including hospital admissions, hearing, cardiovascular disease, mortality: (Driscoll et al., 2015; Florio & Trollor 2015; Fogden et al., 2016; Lee et al., 2016; Meehan et al., 2017; Reppermund et al., 2017; Sobey et al., 2015; Trollor et al., 2017)
Topics investigated

The topics covered and research questions asked with these data focussed on a range of outcomes including:

- **Health** (6 studies) including: family history as predictor of newborn hearing (Driscoll et al., 2015); relative mortality of people with intellectual disability compared with general population (Florio & Trollor 2015; Trollor et al., 2017); relative risk of hospital admissions for children with cerebral palsy compared to general population of children (Meehan et al., 2017); health service use among people with intellectual disabilities (Reppermund et al., 2017); and, relative risk of incident cardiovascular disease in people with Downs syndrome compared to unaffected population (Sobey et al., 2015)
- **Justice** (4 studies) including: prevalence of disability among people who commit arson crimes (Curtis et al., 2015); rates of victimisation and perpetration of violent and sexual crimes among people with intellectual disability compared to community sample (Fogden et al., 2016); prevalence of borderline intellectual functioning and intellectual disability among young people in custody (Haysom et al. 2014); and, rates of victimisation and perpetration of violent and sexual crimes among people with disability compared to community sample (Nixon et al., 2017)
- **Employment** (2 studies) including: the impact of individual placement and support on employment outcomes for people with mental illness (Parletta & Waghorn, 2016); and, employment outcomes of mothers of infants and toddlers with disability (Zhu, 2016)
- **Education** (1 study): changes in the enrolment of children with emotional disturbance and behaviour disorder in NSW (Van Bergen et al., 2015)
- **Disability** (1 study): forecasting the prevalence of intellectual developmental disorder in NSW until 2043 (Lee et al., 2016)

Contribution of this body of literature

Use of routine data is a rich resource that can be used for research. The range of questions asked was diverse from understanding associations between having a disability and health conditions, health service use, mortality, crime, attendance at special schools, and forecasting of future service needs relation to disability. Understanding the relationships was enhanced in situations where databases were linked across sectors (e.g., disability and health data and disability and justice data). Using existing data is a cost-efficient approach to conducting research.
Limitations and gaps

It appears from the papers sourced that NSW is more advanced in their capacity to utilise routine data (or possibly more frequently reporting their use of routine data) than other States and Territories (a notable exception is WA which also houses a number of case registers described in the next part of this Narrative Analyses section). With the opening up of routine data to researchers at a state and federal level and the linkage of routine data sources the range of important questions that can be answered will increase substantially.

While health and justice data were well represented other sectors were not prevalent such as education and employment. Notably there were no studies that used routine data related to housing. It is likely that many data sources do not collect disability data. One of the issues that will emerge in the future is lack of access to disability service data (the Disability Services National Minimum Data Set, DNMD) which was utilised in many studies to identify people with disability. With the move to the NDIS, the DNMDS and other registers of disability services may no longer be available potentially hampering future research.

Ways forward

Improvements in the collection of routine data on disability is badly needed. One potential solution is to utilise the disability identifier developed by the AIHW (AIHW, 2016) as a disability flag.

The other challenge for future research is the capacity to access NDIS data and to link this to data from other sectors. With the abolition of disability services registered in the states and territories research may be curtailed in the absence of a data development agenda.

The new Federal initiatives which involve opening up linked data across multiple sectors to trusted researchers offers considerable potential for disability research. This initiative is currently being developed under the Data Integration Partnership for Australia. Including NDIS in this linked data will significantly enhance the potential for important research.

References

Research utilising secondary analysis of case register data

This narrative analysis was undertaken by Professor Eric Emerson accessing the documents from the scientific literature sourced in the Audit Update 2017 which utilised secondary analysis of case register data to answer a diverse set of research questions.

Introduction to and grouping of documents

Impairment or disease specific case registers are maintained in Australia for a number of specific health conditions or impairments associated with disability. In the Audit Update 2017, we identified 24 scientific papers that were based on secondary analysis of data contained in a number of national or regional case registers. The registers used were:

- the Australian Cerebral Palsy Register (DeLacy, Louca, Smithers-Sheedy, & McIntyre, 2016; Delacy, Reid, & Australian Cerebral Palsy Register, 2016; Smithers-Sheedy, Raynes-Greenow, Badawi, McIntyre, et al., 2014; Smithers-Sheedy, Raynes-Greenow, Badawi, Reid, et al., 2014)
- The Victorian Cerebral Palsy Register (Reid, et al., 2016)
- the Australian Rett Syndrome Database (Andrews et al., 2014; Downs, Forbes, Johnson, & Leonard, 2016; Downs & Leonard, 2016; Downs et al., 2014; Mangatt et al., 2016)
- Western Australia’s IDEA (Intellectual Disability Exploring Answers) database (Bourke, de Klerk, Smith, & Leonard, 2016; Fairthorne, Hammond, Bourke, de Klerk, & Leonard, 2016; Fairthorne, Hammond, Bourke, Jacoby, & Leonard, 2014; Fairthorne, Jacoby, Bourke, de Klerk, & Leonard, 2015, 2016; Fairthorne, de Klerk, Leonard, & Whitehouse, 2016; Fitzgerald,
- Western Australia’s Down syndrome Needs Opinions Wishes database (Foley et al., 2013; Foley et al., 2014; Foley et al., 2015; Foley et al., 2016)
- Western Australia Register for Autism Spectrum Disorders (Whitehouse et al., 2017).

Topics investigated
The topics covered and research questions asked using these datasets were diverse. However, given the nature of case registers, all were restricted to specific health conditions or impairments associated with disability. Topics included:

- The prevalence (and changes in the prevalence) of specific conditions (Bourke et al., 2016; Reid et al., 2016; Whitehouse et al., 2017)
- Changes in the life expectancy of people with specific conditions (Glasson, et al., 2016)
- The prevalence of health conditions or impairments associated with specific conditions (Delacy, Reid, et al., 2016; Foley et al., 2015; Mangatt et al., 2016; Smithers-Sheedy, Raynes-Greenow, Badawi, Reid, et al., 2014)
- Identifying risk factors associated with an increased prevalence of specific conditions (Fairthorne, Hammond, et al., 2016; Smithers-Sheedy, Raynes-Greenow, Badawi, McIntyre, et al., 2014)
- The wellbeing of family carers of children with specific conditions (Fairthorne et al., 2014; Fairthorne et al., 2015; Fairthorne, de Klerk, et al., 2016)
- Health care utilisation by people with specific conditions (Fitzgerald et al., 2013)
- The effectiveness of interventions for health conditions or impairments associated with specific conditions (Downs et al., 2016; Downs & Leonard, 2016; Downs et al., 2014)
- Transition to adulthood among people with specific conditions (Foley et al., 2013; Foley et al., 2016)
- The association between employment and health for people with specific conditions (Foley et al., 2014)

Contribution of this body of literature
The fundamental contribution of these secondary analysis studies arises from their ability, through the use of large and well-constructed case registers, to present robust information on the situation of people with specific impairments associated with disability in Australia at a particular point in time and over time. In addition, most case registers either in themselves or through additional data linkage allow access to a great diversity of information on the living conditions, wellbeing and service use of people with (some) specific impairments associated with disability. In common with other approaches to secondary analysis, given the data have already been collected, secondary analysis of case register information represents an extremely cost-efficient approach to research.

Limitations, gaps and ways forward
The main limitation of secondary analysis of case register data is that, by definition, case registers are restricted to a small number of specific impairments and/ or health conditions associated with disability (e.g., cerebral palsy, Down syndrome, autism, intellectual disability).
Ways forward

1. Stimulating the use by disability researchers of available case register data.

References


**Research utilising secondary analysis of population data**

This narrative analysis was undertaken by Professor Eric Emerson accessing the documents from the scientific literature sourced for the *Audit Update 2017* which utilised secondary analysis of a wide range of existing population-based survey data to answer a diverse set of research questions.

**Introduction to and grouping of documents**

Secondary analysis of data that has already been collected in major surveys represents an extremely cost-effective approach to research. In this *Audit Update 2017*, we identified 42 research papers that
employed secondary analysis of data that has already been collected in major surveys. The majority of these used data extracted from nationally representative surveys including (in order of frequency of publications):

- **HILDA survey** (12 publications) (Aitken, Krnjacki, Kavanagh, LaMontagne, & Milner, 2017; Emerson, Kariuki, Honey, & Llewellyn, 2014; Jones, Mavromaras, Sloane, & Wei, 2014; Kavanagh, Aitken, Baker, et al., 2016; Kavanagh, Aitken, et al., 2015; Kenny, King, & Hall, 2014; LaMontagne, Krnjacki, Milner, Butterworth, & Kavanagh, 2016; Milner, Aitken, et al., 2015; Milner, Krnjacki, Butterworth, Kavanagh, & LaMontagne, 2015; Milner, LaMontagne, Aitken, Bentley, & Kavanagh, 2014; Patton, Ware, McPherson, Emerson, & Lennox, 2016; Polidano & Vu, 2015)
- **Growing Up in Australia: the Longitudinal Study of Australian Children (LSAC)** (5 publications) (Dillon-Wallace, McDonagh, & Fordham, 2016; Emerson & Giallo, 2014; May, Pang, & Williams, 2017; Phillips & Hogan, 2015; Spencer & Strazdins, 2015)
- **Australian National Survey of Psychosis** (5 publications) (Badcock, et al., 2015; Harvey, et al., 2016; Waghorn, Hielscher, Atyeo, & Saha, 2016; Waghorn, Hielscher, Saha, & McGrath, 2016; Waghorn, Saha, & McGrath, 2014)
- **ABS Personal Safety Survey** (3 publications) (Dowse, Soldatic, Spangaro, & Van Toorn, 2016; Krnjacki, Emerson, Llewellyn, & Kavanagh, 2016; Kutin, Russell, & Reid, 2017)
- **National Survey of Mental Health and Wellbeing** (3 publications) (Afzali, et al., 2017; Bosanac, Mancuso, & Castle, 2016; Liddell, Nickerson, Sartor, Ivancic, & Bryant, 2016)
- **Bettering the Evaluation and Care of Health (BEACH) programme** (3 publications) (Weise, Pollack, Britt, & Trollor, 2016a, 2017; Weise, Pollack, Britt, & Trollor, 2016b)
- **Australian Longitudinal Study on Women's Health** (1 publication) (Holden, Ware, & Lee, 2016)
- **National Aboriginal and Torres Strait Islander Social Survey** (1 publication) (Carroll, Townsend, Brown, & Nankervis, 2015)
- **National Health Survey** (1 publication) (Carroll, et al., 2015)
- **Footprints in Time: the Longitudinal Study of Indigenous Children** (1 publication) (Gilroy & Emerson, 2016)
- **General Social Survey** (1 publication) (Mithen, Aitken, Ziersch, & Kavanagh, 2015)
- **Ten to Men** (1 publication) (Kavanagh, Aitken, Emerson, et al., 2016).

Secondary analyses were also based on data extracted from well-constructed sub-national surveys including the NSW-based 45 and Up Study (Gubhaju, et al., 2015) and the Australian Child to Adult Development study (Gray, et al., 2014).

**Topics investigated**

The topics covered and research questions asked using these population datasets were diverse.

- The prevalence and/or incidence of disability or impairments associated with disability (Afzali, et al., 2017; Athanasou, 2016; Bosanac, et al., 2016; Carroll, et al., 2015; Gubhaju, et al., 2015; Liddell, et al., 2016; Spencer & Strazdins, 2015)


• The social, civic and cultural participation of people with disabilities (Aitken, et al., 2017; Badcock, et al., 2015; Emerson, et al., 2014; Gilroy & Emerson, 2016; Gray, et al., 2014; May, et al., 2017; Mithen, et al., 2015; Phillips & Hogan, 2015)

• Housing and people with disabilities (Kavanagh, Aitken, Baker, et al., 2016; Kavanagh, Aitken, Emerson, et al., 2016)

• The exposure of people with disabilities to discrimination, abuse and violence (Dowse, et al., 2016; Krnjacki, et al., 2016; Kutin, et al., 2017)

• Health and other services for people with disabilities (Harvey, et al., 2016; Weise, et al., 2016a, 2017; Weise, et al., 2016b)

• The wellbeing of informal carers of people with disabilities (Dillon-Wallace, et al., 2016; Kenny, et al., 2014; Lu & Zuo, 2017; Patton, et al., 2016)

• The wellbeing of siblings of children with disabilities (Emerson & Giallo, 2014).

Contribution of this body of literature

The fundamental contribution of these secondary analysis studies arises from their ability, through the use of large and well-constructed surveys, to present robust information on the situation of people with disabilities in Australia at a particular point in time. Repeated cross-sectional surveys (e.g., SDAC) and panel studies (e.g., HILDA) also allow researchers to investigate how the situation of people with disabilities is changing over time in Australia.

In addition, most of these data sources contain a great diversity of information on living conditions and wellbeing. As such, they can be of immense value in identifying and quantifying the extent of exposure and impact of exposure of people with disabilities to well-established social determinants of health and wellbeing. When compared to primary research, results from secondary analyses can often be undertaken within time limits that allow inclusion within emerging policy developments and within budgets that represent a very small fraction of funding new primary research.

Limitations, gaps and ways forward

First, (with the possible exception of secondary analysis of SDAC) population-based studies primarily address the ‘hidden majority’ of people with often less severe disabilities in Australia, rather than users of disability services. Indeed, given that general household sampling frames will often specifically exclude people with disabilities living in any form of institutional arrangement, there is an important gap in knowledge at a population level about people with disabilities who are disability service users and/or likely to be eligible for, or are participants in the NDIS.
Second, many of the population datasets that are available are cross sectional in nature. While these are useful for describing associations at a particular point in time and changes in prevalence over time, they do not allow for conclusions to be drawn about causality or allow for the identification of factors that are associated with changes in the wellbeing or social inclusion of people with disabilities in Australia. The analysis of data from longitudinal studies such as HILDA opens up new possibilities for policy relevant research. It is disappointing therefore that other potentially valuable longitudinal datasets (e.g., Longitudinal Study of Australian Youth) have not been utilised by disability researchers.

Third, (again with the exception of secondary analysis of SDAC) the surveys upon which secondary analysis has been undertaken were not designed to address issues specifically related to people with disabilities or disability policy.

Finally, and as noted above, secondary analysis of data that has already been collected in major surveys often represents an extremely cost-effective approach to research. Access to these data is relatively easy. It remains, however, a relatively under-used resource outside of a small number of disciplines (e.g., public health, economics).

In conclusion, there exists a small but growing body of disability research in Australia based on the secondary analysis of existing large scale population-based surveys. Given that these data have already been collected, secondary analysis can constitute an extremely cost-efficient approach to research. Existing research in this area has made significant contributions to better understanding the prevalence and patterning of disability in Australia, the social conditions under which Australians with disability are living and the impact this may have on their wellbeing and participation. This knowledge is fundamental to formulating and implementing disability policy.

Ways forward

1. Develop methods (through data linkage or the inclusion of a set of standardised questions for use in generic surveys) of identifying survey participants who are eligible and in receipt of NDIS support or services.
2. Ensure that all major national surveys contain a credible method of identifying respondents with disabilities.
3. Extend the sampling frame of selected surveys to include people living in various forms of supported accommodation and nursing homes.
4. Work in conjunction with Disabled People’s Organisations (DPOs) to develop a short-list of topics that are particularly relevant to understanding the wellbeing of people with disabilities that are not addressed in current surveys.
5. Support greater use by disability researchers of available cross-sectional, longitudinal and administrative datasets. As noted above, secondary analyses represent highly cost effective approaches to research and are much more likely than primary research to produce results within the time frames set by policy development. However, they continue to be underutilised. For example, neither the initial 2014 Audit nor this Audit Update 2017 identified any studies that utilised disability data from the Longitudinal Study of Australian Youth, a multiple-cohort longitudinal study that focuses on the transition from education to employment.
References


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

This narrative analysis was undertaken by Dr Rosamond (Ros) Madden accessing the documents sourced as identified in the method section of this Audit 2017 Update. This document updates the narrative analysis undertaken for the 2014 Audit. The approach here is not to repeat that analysis, apart from a brief explanation and update of the relevant statistical sources, but rather to focus on what has changed in the time period, with particular emphasis on:
• additional output of the same nature (e.g., updated statistics)
• new topics covered
• new work which fills the gaps identified in the 2014 Audit
• gaps previously identified that remain.

While this section is intended to be informative and ‘stand alone’ from the 2014 Audit analysis, the reader’s understanding of this field would be greatly enhanced by reading the original analysis. In this section, the reports referenced are numbered for ease of cross-referencing from the narrative text.

**Scope of this section**

**Australian population data** on disability come from three main ABS sources: the specialised Survey of Disability, Ageing and Carers (SDAC) ([http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4430.0.10.001~2015~Main%20Features~About%20the%20Survey%20of%20Disability,%20Ageing%20and%20Carers~2](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4430.0.10.001~2015~Main%20Features~About%20the%20Survey%20of%20Disability,%20Ageing%20and%20Carers~2)) which has been carried out regularly since 1981; the Australian Census of Population and Housing (since 2006); and a range of social surveys which have a disability module – enabling comparison of people and households with disability with the general population, in relation to health, housing, income and expenditure, time use and more. These data are analysed by the ABS, the AIHW and the PC, as well as many other users.

**Australian national data on community services** are collated, analysed and published chiefly by the AIHW, notably the national collection on disability support services provided under the National Disability Agreement (the Disability Services National Minimum Data Set: DSNMDS). Some national data on other disability services and assistance, e.g., relating to income support and disability employment, can be found on Australian government web sites and may also be used for secondary analysis by researchers. Since the rollout of the NDIS, the NDIA and Council of Australian Governments (COAG) have published some data relevant to participants in the Scheme, some of whom are transitioning out of the services funded under the NDA.

**The Productivity Commission** uses the above sources, among others, in its inquiries and reports. As well as its regular annual reports on government services (covering all Australian jurisdictions), the Commission has prepared major reports on disability services and the NDIS.

**Overview of findings**

In the time since the 2014 Audit, the overall pattern of statistical production has not altered significantly, although the NDIS has implications for the production of disability services data (as detailed in this analysis).

**Population data:** The ABS has regularly updated its important collections, notably the SDAC, with summaries of the overall findings and publications of special analyses from the survey. The General Social Survey has continued to have disability modules enabling the provision of new analyses. The AIHW has continued to analyse ABS data to provide policy-relevant statistics, e.g., on Indigenous disability and ‘healthy’ life expectancy.

**National data on disability support services and users, and NDIS participants:** The AIHW continues to provide annual national data on services provided under the NDA. The dataset has shrunk, slightly
so far, as people transition to the NDIS. The NDIA and COAG publish data on the new NDIS. A lack of comparability of the two DSNMDS and the NDIS datasets prevents analysis of a combined picture.

**Productivity Commission reports:** These reports remain heavily based on all the above data sources, where they deal with disability or disability services.

**What has changed and the gaps that remain**

**Additional output of the same nature (e.g., updated statistics)**

The ABS has continued to conduct and publish results from the SDAC:

- a summary of findings from the 2012 survey, including demographic characteristics, education and employment, income, long-term health conditions, and social and community participation of people with disability (ABS, 2013a)
- website and data cubes presenting information about informal carers (ABS, 2014a)
- data on young people with disability (ABS, 2014b) which is newly published data
- results from the 2015 SDAC (ABS, 2016a, 2016b) including the finding that there were improvements for older people such as increased physical activity and lower rates of disability; new data on discrimination were also reported.

The AIHW has taken on the responsibility for the publication of *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*, previously (until 2011) a joint publication with the ABS [29]. It is reported that ‘Indigenous Australians were twice as likely as non-Indigenous Australians to have severe or profound disability’.

Data on disability services provided and funded under the NDA continue to be published by the AIHW, covering the years 2011-12 to 2015-16 [4,10-12,20]. The reports are generally similar in structure, although some have examined trends over several years (e.g., the reports for 2011-12 and 2012-13 data). The 2015-16 report provides: numbers of service users, their age and sex, disability ‘group’, Indigenous status, country of birth, labour force status and income source, living arrangement, informal care, need for assistance in various life areas (now oddly referred to as ‘functional need’). Service group (nature of service) received, location (state, etc.), NGO provision, and governments’ expenditure are also reported. The number of people who transitioned to NDIS during the year was 3,500 in 2015-16. (Numbers transitioning from the NDA services to the NDIS are far lower than the increases to NDIS participants). Australian Capital Territory (ACT) data were not supplied in 2015-16 as the ACT is in process of transitioning existing service users to the NDIS.

The NDIA reports their administrative data quarterly to COAG, about the operation of the NDIS including basic data about participants (COAG-DRC-Report-2016-17-Q3). Data about participants included:

- Disability group (now reasonably similar to AIHW categories)
- Level of function (15-point scale not explained in the report)
- Age group
- Gender
- Aboriginal and Torres Strait Islander status
- Young Person in Residential Aged Care status.
Some limitations of the data are described in the NDIA report. Comparability with either ABS or AIHW data is not apparent. Some participant outcomes are described, e.g., in terms of choice and control, relationships, social/community participating, learning, work, home, and health.

While Australia’s Welfare 2015 continues to cover mandated topics such as disability services, it is not straightforward to piece together a ‘disability story’ because of the life course approach taken in 2015 [28]. For example, the index has entries under ‘disability and disability services’ referring to carers, employment, homeless people, income support, older people, Indigenous Australians, welfare indicators and more, with separate sections on children and young people. Disability information is thus dispersed through the report and data on disability and disability services are summarised briefly. Further, it is not clear that good use has been made here of some of the new information on disability and associated health conditions (published by the AIHW – see following) and on access to health services by people with disability. Indicators of Australia’s Welfare are reported in Chapter 8; indicators of ‘determinants’ (of demand for welfare services) include an item titled ‘personal resources’ and under this are listed ‘psychological resilience’ and ‘functional status’, an indicator of the latter being ‘disability prevalence’. This gives the appearance of a return to the personal model of disability (away from the social model) and a representation at odds with the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF). Perhaps equally retrograde (or using language more familiar in the aged care sector) is the index listing of “dependency of people with disability, see activity limitations” (p. 418). A useful feature of the publication is the inclusion of ‘snapshots’ summarising key data and often containing data quality commentary in the form of ‘what is missing from the picture’. However, a search for ‘data definition’, ‘data standards’ or ‘data dictionaries’ yielded no results, and ‘data development’ discusses data linkage and longitudinal analysis: that is, the development of data analysis, with no connection made to ‘what is missing’.

The practice of casting disability as an adverse outcome or a risk factor was also apparent in a study scoping ‘reportable measures for the National Framework for Protecting Australia’s Children 2009-2020’ [13].

The Burden of Disease studies, used for a range of health policy analyses, have relied on ‘disability weights’ and ‘disability adjusted life years’. The most recent Australian update does not describe the method of assigning weights in any detail [22]. Referring the reader to previous reports, it briefly explains: “The first step to estimate YLD is to define the major disabling sequelae associated with each disease in the disease list, and attribute disability weights that express the health loss on a scale from 0 (no health loss) to 1 (total health loss) associated with each sequelae” (p. 29). Compared to the non-linear, interactive ICF model, which recognises the effect of environmental factors, this methodology has tended to make these studies less appreciated in the disability field.

Life expectancy with and without disability have been re-examined, over the periods 1998 to 2012 and 2003 to 2015 [8,17] with the following findings:

- Disability-free life expectancy has increased
- Older Australians have seen increases in the expected number of healthy years
- The gender gap in the expected years living free of disability has reduced across most ages.

There are also three AIHW ‘fact sheets’ which examine trends using SDAC data on inclusion and participation, covering: community living, education, and employment [7].
The annual reports on government services produced by the PC (e.g., SCRGSP, 2017, 2015) follow a consistent pattern from year to year. The disability services chapter is introduced with a section outlining the field and the main changes. There is an overview of funding and sector structure. Performance indicators are specified and reported under the headings of: equity (e.g., in terms of access by Indigenous and CALD Australians), efficiency (e.g., cost per output unit and government funding) and outcomes (e.g., social and labour force participation). The chapter relies heavily on data and analysis from both the AIHW and the ABS. In 2017, it was noted that: “this chapter focuses on services funded under the NDA. Performance reporting on the NDIS will be developed and progressively introduced into future editions of this Report (p. 15.7).”

Data on the access of people with disability to other government services are included in other chapters of these reports. For example, in the 2017 report: early childhood education and care in volume B (chapter 3), school education in B (chapter 4), vocational education and training in B (chapter 5), mental health management in E (chapter 13), aged care in F (chapter 14), youth justice in F (chapter 17), 18 and sector overview G, and housing and homelessness in G (chapter 18). These attempts to analyse the access of people with disability to other government services have been a growing strength of these reports (SCRGSP, 2017).

**New analyses and new topics covered**

Mental health, disability and crime have been brought together in a new analysis of General Social Survey data (ABS, 2013b). The survey sought information on disability related to mental health conditions and a range of other long-term conditions and impairments. The results “show that of all these long-term disabilities, disability due to a mental health condition was the only one where the prevalence was significantly higher for victims compared to non-victims. There were no statistically significant differences in the prevalence of the other long-term disabilities included in the survey between victims and those who were not victims” ([http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4524.0Chapter60October+2013](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4524.0Chapter60October+2013)).

As also reported from the 2014 General Social Survey, people with disability were ‘far more likely’ than others to experience barriers in accessing healthcare (ABS, 2015). They also experienced lower rates of participation in sport and in selected cultural events, and in daily face-to-face contact with family and friends living outside the household; they were more likely to experience discrimination; and much more likely than others to assess their health as ‘poor’ or ‘fair’.

**Social and economic wellbeing of Aboriginal and Torres Strait Islander people with disability** was the focus of a new report from the ABS based on the National Aboriginal and Torres Strait Islander Social Survey (ABS, 2017). The ABS used an extended definition of disability and estimated that “45% of Aboriginal and Torres Strait Islander people aged 15 years and over were living with disability or a restrictive long-term health condition in 2014-15” ([http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Feature%20Article~Social%20and%20economic%20wellbeing%20of%20Aboriginal%20and%20Torres%20Strait%20Islander%20people%20with%20disability%20(Feature%20Article)~10000](http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Feature%20Article~Social%20and%20economic%20wellbeing%20of%20Aboriginal%20and%20Torres%20Strait%20Islander%20people%20with%20disability%20(Feature%20Article)~10000)). The publication explored disability ‘type’, cultural identity, family and community connections, health status and risk factors, access to health services, education and employment, crime, safety, housing and ‘overall life satisfaction’. While a number of outcomes were worse for people with disability, the
strong cultural connections, with little difference reported, appeared to provide a ‘levelling factor’ in peoples’ lived experience.

A new resource sheet, published by AIHW and the Australian Institute of Family Studies (AIFS) jointly, examined the evidence on what works to improve education and employment outcomes for Indigenous Australians, and the second identified key principles for doing this [26]. The study was informed by data from the ABS, AIHW, Commonwealth departments and a range of other sources including international evaluations.

Recent studies of health conditions from the AIHW have examined their relationship to disability, e.g., stroke, diabetes, incontinence, autism, juvenile arthritis, back problems, ‘chronic back problems’ and rheumatoid arthritis [1, 2, 5, 21, 23-25, 27]. These studies used a range of data and research literature, and produced interesting findings about the nature and extent of disabilities associated with these health conditions. Varying approaches were used to framing disability, with some studies referring to ‘quality of life’ outcomes including pain and disability, and some closer to the ICF framework.

There is also an AIHW study focussed on health status and risk factors which analysed data from key ABS surveys including SDAC and the National Health Survey (2007-08 and 2011-12) which contains a disability module [8]. It found that people with disability:

- experienced poorer health than other Australians
- had more long term health conditions and likely to have multiple health conditions
- had more obesity and were less likely to exercise
- were more likely to smoke daily
- experienced higher levels of psychological distress.

Another new AIHW report relating to health investigated access to health services by people with disability [18]. The analysis provided information on access to general practitioner (GP) services and dental services, waiting times, and difficulties with communication. Unmet need was reported for assistance with taking medication. People in outer regional or remote areas experienced poorer access to health services. Health indicators for Remote Service Delivery communities included disability and a wide range of population data, including Indigenous disability data, were analysed for this evaluation [19].

Housing data collections have for some time been ‘disability aware’ and effort is being put into improving the collections further. New questions have been included in the collection on Special Homelessness Services, with care to make the questions comparable to those in SDAC [14]. Of an estimated 254,000 Australians accessing specialist homelessness services in 2013-14, an estimated 26,655 clients had a long-term health condition or disability that restricted their everyday activities. Another new AIHW report explored the housing assistance provided to low-income households and ‘special needs’ groups (including people with disability) under the National Affordable Housing Agreement [3]. Findings include that 42% of tenants in the Social Housing Initiative had a disability and that many people with disability struggle with rent payments despite receiving the disability support pension (DSP).
Also on housing, two AIHW reports provided the results of: the 2016 National Social Housing Survey, a survey of tenants in public housing, community housing and state owned and managed Indigenous housing in Australia; and data on the services and clients of specialist homelessness services provided by the government in Australia in 2015-16 [30, 31]. People with disability are identified in these collections and recognised to be among those with complex needs.

Achieving greater equity in higher education has received considerable attention from all Australian governments, and the AIHW prepared a performance framework for monitoring progress [16]. One of the challenges to data quality relating to students with disability is that disability is self-reported; the choice of questions used on enrolment forms varied among states and the population data selected for comparison purposes lacked clear justification; further work on the ‘population reference points’ was proposed. Some interesting data analysis was included in the report, subject of course to the caveats about data quality and comparability.

There has been long-standing interest in discovering more about the ‘overlap’ between disability support services and services provided under the Home and Community Care program. Answers to many questions have now been provided as the result of a complex data linkage project between the two administrative collections [6, 15]. A total of 1.2 million people in 2010-11 received services from the Disability Services (DS) program and/or the Home and Community Care (HACC) (259,400 used only DS and 879,500 used only HACC services). Of these, around 54,800 people were known to have used both DS and HACC services. People using both service programs required higher, more complex and diverse supports. People using both service programs were more extensive users of the two programs.

A Special Disability Survey was funded by the Department of Foreign Affairs to enable the ABS to compare the results obtained from the SDAC with those obtained using the Washington Group ‘short set’ of six questions for use in censuses, developed for international use (ABS, 2016c, 2016d). This was important work for understanding the differences and what the Washington Group census questions (being promoted for use around the world) can and cannot do. The Washington Group questions were not intended to identify all people with disability (i.e. to provide prevalence estimates); nor designed to cover people with intellectual or psychological functioning difficulties or young children. The purpose was to produce internationally comparable national data. Just over one quarter of people in the SDAC were identified as having a disability in using the Washington Group questions.

The PC published a new report on NDIS costs (PC, 2017). The study report focussed mainly on cost implications of aspects of Scheme administration, the rollout, workforce challenges market issues and funding. Comments were made about the quality of the planning process for participants, and the need to deal with boundaries and interfaces of the Scheme with other services. Strong comments on data included that:

- “NDIA’s information and communication technology system needs to be fit for purpose to undertake the longitudinal data analysis, reporting and monitoring required to support the insurance approach of the NDIS” (PC, 2017, Overview, pg. 46)
- NDIA should use its legislative base to develop policies for data sharing with ‘other researchers’
• governments should provide funding for the SDAC and for ongoing data collection on disability services outside the NDIS.

‘Deep persistent disadvantage’ was the topic of a Productivity Commission Staff Working Paper (McLachlan, Gilfillan & Gordon, 2013). The paper explored many of the ‘traditional’ themes about poverty and the multifactorial nature of disadvantage. Analyses of various data sources illustrated these multidimensional relationships, including the disadvantages experienced by people with long-term health conditions or disability. Disability was considered as a component of disadvantage and also as a ‘risk factor’ (e.g., when discussing limitations of income measures as the sole indicator).

According to the PC (2016), introducing greater competition and informed user choice could improve outcomes in many but not all human services. The list of six priority services for attention did not include disability services; it was noted that, because of the NDIS, more competition and user choice was being introduced in this field; and that user choice requires information and data. A report on superannuation policy did not focus particularly on disability (in terms of its main findings) but nevertheless acknowledged disability as a factor in retirement incomes (PC, 2015). Disability may be a reason to access superannuation early on ‘compassionate grounds’, including to cover expenses (e.g., for equipment). People’s experience with long term disability affects the level of superannuation they acquire at working ages. DSP transitions to Age Pension were analysed in this report.

New work which fills the gaps identified last time

Some of the work outlined above helps fill some of the gaps identified in the previous 2014 Audit:

• There is new data and analysis of disability among Aboriginal and Torres Strait Islander people although there are inconsistent approaches and results about prevalence even within the ABS reports.
• Access to and use of mainstream services have also been investigated. Housing and homelessness data have for some time included data on people with disability (and indeed they are one of the disadvantaged groups identified in several housing policies). Analyses of access have expanded in health and potentially in education. Compendiums such as AIHW’s Australia’s Welfare 2015 and the PC reports on government services make serious attempts to report on a range of mainstream services including children’s services.
• People with chronic or fluctuating conditions have been the focus of a number of new AIHW reports, described above, which provide data on areas of disability related to these conditions.

Gaps previously identified that remain

Data on the impact of environmental factors remain scarce. It does not appear that the ABS is considering new questions on this topic, to include in the SDAC. In contrast Ireland incorporated the ICF Environmental Factors into its national survey (Kostanjsek et al., 2013; O’Donovan & Good, 2010). Irish Disability Survey results then were able to show that “attitudes, and the presence or absence of facilitating equipment, support services, flexible working arrangements and transport significantly affect participation of people with disabilities in Irish society” (Kostanjsek et al., 2013, p. 1065).
Analyses focusing on CALD groups have not apparently received much attention from these major organisations. In the previous 2014 Audit these data were said to be ‘startlingly absent from the data analyses, given their significant presence in the Australian population and the newly available data since the 2006 Census.’

Several reports of the AIHW have included trend analyses (over relatively short time spans). Long term trend data for the population can be attained with ongoing consistency of key items in the SDAC. Long term trends in disability services (and the need for these and their nature, the recipients and their outcomes) will be hard to attain without data standards which remain stable over time. The NDA disability services collection (DSNMDS) has been starting to sustain trend analysis, but continuity of the series is at risk without some coordination between AIHW and the NDIA.

New gaps may be appearing. Both the AIHW and PC note the potential fragmentation of data collections on disability support services, and on people requiring and receiving them (e.g., in Australia’s Welfare 2015 and the PC costs study as noted above).

A comment on ABS and AIHW referencing metadata. If the ABS and AIHW want their data to be found and used by academic researchers, they need to: include good (and identifiable) abstracts with key words, ensure their citations will be picked up correctly by search engines, and test their accessibility through some of the main search engines. Google Scholar would be a good start as it has been found to be a useful way to search for ‘grey literature’. Many statistical reports may be found in the so-called grey literature (e.g., Falagas, Pitsouni, Malietzis & Pappas, 2008; Miki 2009; Yang & Meho, 2006). Promoting such use of their data is an obvious responsibility of national statistical organisations as noted in the United Nations Principles of Official Statistics (2014):

“Principle 1. Official statistics provide an indispensable element in the information system of a democratic society, serving the Government, the economy and the public with data about the economic, demographic, social and environmental situation. To this end, official statistics that meet the test of practical utility are to be compiled and made available on an impartial basis by official statistical agencies to honor citizens’ entitlement to public information” (https://stats.oecd.org/glossary/detail.asp?ID=7019).

Conclusion
Research and statistics from the AIHW, the ABS and the PC collectively make a considerable contribution to Australia’s policy climate. Moreover, these organisations are updating and expanding their data collections and analyses in line with changes in the policy and service environment, as well as responding to new information needs from the wider community. The ABS continues to publish data from the SDAC and to explore disability through its other collections. It has also in the time since the 2014 Audit conducted an important comparison of the SDAC with an international census tool.

The AIHW has likewise updated key collections and expanded analyses. The greater focus of some of the ‘health’ publications on disability is a positive development. Nevertheless, there is some inconsistency (noted above) in disability conceptualisation, and an apparent absence of discussion of data development to overcome the potential fragmentation of disability data as the NDIS moves further into rollout and future state.
The PC likewise has updated the Reports on Government Services and reported on a range of disability topics including their NDIS costs study. Again, though, their identification of the need to continue two collections of data (NDIS and NDA) is not accompanied by recognition and acknowledgement that data quality and consistency should be greatly enhanced by efforts on common data definitions.

*Reports in Narrative*

AIHW (numbered)


29. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015  


31. Specialist homelessness services 2015-16  

ABS (references by date)
ABS. (2013a). Disability, ageing and carers: Summary of findings, Australia 2012. Canberra, Australia: ABS.
ABS. (2016b). Disability, ageing and carers, Australia: Summary of findings, 2015. Canberra, Australia: ABS. Cat 4430.0

Productivity Commission (references by date)


Other References


Attachment 1 Search Strategy

The 11 databases used in the 2014 Audit were searched using the eight domains of the conceptual framework reported in the 2014 Audit. These are Community and Civic Participation, Economic Participation, Education, Health and Wellbeing, Housing and the Built Environment, Safety and Security, Social Relationships, and Transport and Communication. The databases 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.

The search method was as follows:

- Search for the main concept and keywords on disability and geographical limits of Australia, then apply the date limit of 2013 to 2017
- Search for the domain keywords and subject headings and combine them with the Boolean operator of “OR”
- Combine the two searches using the Boolean operator AND to each of the eight domains separately. We tried, where possible to only search the Title, Abstract and Keywords fields, and limit to English language and journal article and/ reviews
- Export each completed search to the reference manager software EndNote X8.

Example search from Web of Science (TS= Topic Search on Title, Abstract and Keywords and PY=Publication year)

*Domain Search: Community and Civic Participation*

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND TS=("political participation" OR communit* OR "support group*" OR "self help" OR "self-help" OR organisations OR organizations OR recreation* OR leisure* OR sport* OR religio* OR volunteer* OR "civic participation" OR "arts" OR "culture" OR "social capital" OR "community capacity" OR (community AND participation))

*Domain Search: Economic Participation*

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south wales" OR "south austral*" OR "west* Austral*" OR "northern territory" OR "australian capital territory")
territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND
TS=(employ* OR job OR career* OR income* OR salar* OR retire* OR vocation* OR financ* OR staff*
OR occupation OR work* OR unemployment OR "cost of living" OR insurance OR "employment
participation" OR (employ* AND policy) OR (employ* AND policies) OR (employ* AND program*) OR
socioeconomic)

Domain Search: Education

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual
disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing
impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south
wales" OR "south austral*" OR "west* Austral*" OR "northern territory" OR "australian capital
territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND
TS=(educat* OR learning OR school* OR student* OR teach* OR training OR bullying OR curriculum
OR course* OR mainstreaming OR "education participation" OR (educat* AND policy) OR (educat*
AND policies) OR (educat* AND program*) OR (educat* AND inclus*))

Domain Search: Health and Wellbeing

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual
disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing
impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south
wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital
territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2014-2017) AND
TS=((mainstream AND health) OR (specialist AND health) OR "health promotion" OR "prevention
program*" OR wellbeing OR "well being" OR health OR (health AND choice) OR (access AND services
AND health))

Domain Search: Housing and the Built Environment

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual
disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing
impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south
wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital
territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND
TS=(housing OR (independent* AND liv*) OR (residential AND care) OR "built environment" OR
neighbourhood OR (housing AND policy) OR (housing AND policies) OR (housing AND program*) OR
accommodation OR "assisted living" OR "nursing homes")

Domain Search: Safety and Security

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual
disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing
impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south
wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital
territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND
TS=(security OR "safe care" OR (safe* AND home) OR (safe* AND environment) OR (safe* AND
neighbourhood) OR (safe* AND personal) OR victim* OR crime* OR bullying OR harassment OR
violence OR "restrictive practice*" OR (access AND legal) OR "legal services" OR "criminal justice" OR assault OR abuse)

*Domain Search: Social Relationships*

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing impairment*" OR "vision disorder*" OR "hearing disorder*")) AND TS=(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND TS=(marri* OR famil* OR marital OR "social network*" OR friends* OR "social participation" OR participation OR relationship* OR "interpersonal relation*" OR "social skill*" OR "social inclusion" OR "social exclusion" OR "social policy" OR peers)

*Domain Search: Transport and Communication*

(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing impairment*" OR "vision disorder*" OR "hearing disorder*")) AND TS=(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) AND TS=("public transport*" OR transport* OR (transport* AND policy) OR (transport* AND policies) OR communicat* OR (access* AND information) OR internet OR (communication AND augmentative) OR (communication AND alternative) OR aac OR "assistive technolog*"
Coding by domain

All included documents were coded exclusively into one of eight single domain categories taking into account the dimensions within each category as detailed in Attachment 1. The eight single domain codes as follows:

- DOM_COMM: Community and Civic Participation;
- DOM_ECON: Economic Participation;
- DOM_EDU: Education;
- DOM_HEALTH: Health and Wellbeing;
- DOM_HOUSE: Housing and the Built Environment;
- DOM_SAFE: Safety and Security;
- DOM_SOC: Social Relationships;
- DOM_TRANS: Transport and Communication.

The inclusion of a ninth domain present in the CADR Clearing House data protocol is Sector Development and Sustainability (DOM_SECTOR) was also coded. The terms considered in the document (title and abstract) search were the same ‘tagging’ terms used by the CADR Clearing House protocol. These terms were: capacity; market development; sector sustainability; legislation and policy; workforce profile and development; financial management; service marketing; governance; quality measurement, improvement and reporting.
Documents were coded by one only mutually exclusive type of investigation code. The 17 codes utilised were intervention studies (RCTs, study protocol only, observational studies), secondary analysis studies (administrative datasets, case registers, population data, file audit/ document review), literature reviews (systematic, narrative), measure development studies, questionnaire studies, qualitative studies, mixed methods investigation, policy analysis, legal analysis, historical analysis, media/ creative arts/ cultural analysis.

The study design/ type of investigation framework is not a hierarchy of evidence rather it provides a way to categorise disability research by type of investigation. Such a broad-based approach is unusual given that most audits of knowledge are disciplinary or field based. For example, in the health sector knowledge is typically scoped according to levels of evidence with standardised systems for example in relation to guideline development (https://www.nhmrc.gov.au/guidelines/information-guideline-developers).

**Intervention studies** were represented by RCTs, study protocols only, and observational studies. RCTs are where the participants/ subjects are allocated to either an intervention group or a control group, using a non-random method (such as patient or clinician preference/availability) and the outcomes from each group are compared. The study protocol only studies described the protocols to be used in upcoming studies typically RCT’s but not exclusively including for example case-control studies. Observational studies described all studies which involved an intervention and measurement of outcomes utilising quasi-experimental designs with or without a comparison group sampled opportunistically. Many such studies involve an intervention with children or adults with disabilities where data is collected pre and post the intervention on theoretically or empirically relevant outcome measures.

**Secondary analysis studies** were represented by studies utilising administrative datasets, case registers, population data, or file audit/ document review. The studies that utilised administrative datasets included datasets from Federal and State jurisdictions predominantly from the health sector but also including disability and disability services, welfare, education and justice administrative datasets. A subset of these studies primarily from Western Australia involved secondary analysis of linked data from multiple administrative datasets. The studies utilising population data included those using data from national or state based studies with representative sampling frames (such as SDAC). Studies utilising case registers which are datasets from specific subpopulations typically in relation to a diagnostic group (such as for example, Rett Syndrome). Case registers may be national or regional. The fourth type of secondary analysis studies came from file audits or document reviews for example, analysis of the case files of children entering foster care to determine children with disability or analysis of practitioner files in a disability organisation to determine practice issues in relation to a particular client group.

**Literature review studies** were represented by systematic reviews and narrative reviews. Systematic reviews are increasingly used across the health and social services sector to evaluate
evidence from the literature and to do so systematically in relation to a specific question and according to external established guidelines. Narrative reviews while also demonstrating internally systematic procedures are not subject to external established guidelines.

**Measures development studies** included all studies in which the primary purpose was to develop or test the psychometric properties of new assessment or screening tools; or to apply an existing tool to a new population; or to develop items for administrative databases or population surveys.

**Questionnaire studies** included paper-based, telephone, and internet based surveys typically to opportunistic groups such as families or carers, service providers and/or people with disabilities. These studies used self-report with standard instruments and/or purposely designed structured questionnaires. Typically these studies were designed to gather and quantify knowledge, attitudes or emotions (e.g., grief, burden, depression, stress) or experiences of a particular group of people on the topic of interest.

**Qualitative studies** included focus groups and semi-structured or open-ended interviews with specified groups of people typically opportunistically sampled. Some examples include parents of children with disabilities, young carers, university students, groups of professionals such as police officers, direct care workers, teachers, and therapists. The primary focus in studies of this type was to explore experiences, for example family or sibling experiences, or attitudes for example, the attitudes of university students to working with people with disability.

**Mixed methods investigation** included studies which utilised quantitative and/or qualitative data and/or file audit and document review. All studies which claimed mixed methods in the title or abstract were included in this category. Further, mixed methods investigations were differentiated from program evaluations to understand scope of research undertaken for the purposes of the Audit, however typically program evaluations also use a combination of methods and sampling frames across multiple stakeholders of the program under evaluation.

**Policy analysis** included all studies which analysed existing policy, proposed particular policy initiatives or evaluated the outcomes of specific policy initiatives in Australia or comparing Australian policy with that in selected countries.

**Legal analysis** included all studies which addressed specific Australian legislation at state, territory and federal levels. Frequently this was anti-discrimination or social security legislation analysed in particular contexts for example in employment or in relation to newer initiatives such as Facebook as well as claims through the courts for example in relation to wrongful life decisions. This did not include analysis of specific instances of tribunal or administrative appeal decisions which were excluded from the Audit as these did not meet research criteria.

**Historical analysis** included studies about earlier treatment regimens including institutionalisation, and developments of current approaches such as mainstreaming of children with disabilities as well as the history of how for example Aboriginal and Torres Strait Islander people with a disability have been and now are represented in the disability sector.

**Media/ Creative Arts/ Cultural analysis** This group of studies primarily addressed the way in which people with disability or concepts about disability are understood and represented in the media, or the creative arts or in particular societal texts such as applications to the Family Court for
sterilisation of minors. The unifying theme in this group of studies is analysis of the ‘discourse’
surrounding the topic under investigation irrespective of the medium – newspapers, websites, film,
theatre, system texts including philosophy or practice documents.


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Section 4: Assessing quality and reporting frameworks for the scientific literature

Introduction

Over the past two decades there has been increasing emphasis on evidence-informed approaches in the medical and health, and social welfare/social care sectors. Interest in bringing evidence to underpin clinical and social welfare programs, and policy across sectors has resulted in a substantial literature debating the nature of evidence, how evidence could or should be translated into policy, programming and practice, what constitutes evidence-based or evidence-informed policy, programming and practice, and how best to assess or judge the quality of evidence.

The initial phase of this emerging interest in evidence focused on the translation of scientific evidence in medicine for applied purposes in clinical practice. In this phase, it is possible to find one-off articles or a series of articles in medical journals which either debate the nature of evidence or propose particular frameworks or checklists to guide readers in assessing the quality of evidence in published studies (Mays, Pope & Popay, 2005). When it became apparent that it was difficult to apply the recommended checklists to many of the published studies, another literature developed, this time on frameworks and checklists for reporting research studies (Morris, 2008).

In 2017, a Google search on assessing quality of research studies brings up nearly one billion results (723,000,000 November 28th, 2017). As with any new area of scholarly endeavour, the field of assessing quality of evidence and reporting research studies has matured with flow on effects to requirements for publishing in scientific journals. Scientific journals in medical, health and social welfare fields are now more likely than not to prescribe the use of specific checklists to accompany manuscripts submitted for review. For example, the Disability and Health Journal, the official journal of the American Association on Health and Disability has clear instructions to authors considering submission about using widely accepted checklists for quality and reporting of research studies as follows:

“Research reports must contain sufficient information to allow readers to understand how a study was designed and conducted, including variable definitions, instruments and other measures, and analytic techniques. We recommend reviewing guidelines and checklists related to specific research at the EQUATOR Network to ensure sufficient detail is provided in the manuscript (http://www.equator-network.org). NEW: Submitting a checklist such as that from STROBE is now a requirement for submission (see editorials published in the April 2014 issue)” (Disability and Health Journal, Author Information, regularly updated and available in each issue, with the latest at https://www.elsevier.com/wps/find/journaldescription.cws_home/713446?generatepdf=true
Current state of assessing quality and reporting research studies

Initial scholarly endeavour in the development of systematic methods to assess quality of research studies focused on studies that employed a quantitative design. Quantitative studies, specifically RCTs, have long been considered the gold standard in medical research. Initially levels of evidence relating to research design were considered useful in judging research quality with Level 1 being RCTs. However, it quickly became apparent that if only evidence derived from RCTs was considered in the application of research findings to clinical practice, there would be no advance in applying research knowledge to many areas of medicine as well as to broader health and social welfare research. Not only are RCTs expensive, time consuming and limited by specific design criteria, they are inappropriate for many research questions and, in some cases, unethical to conduct. Researchers investigating the impact of childhood poverty on adult health are hardly likely to consider randomly allocating children to live in poverty for example. Many other well-developed observational research designs have long been employed in medical, health and social welfare sectors to address such issues. Scholars have been keen to design approaches to assess quality in other research designs, such as observational studies, that are not controlled trials.

At the same time, it also became apparent that judgements about research quality were only possible if research articles accurately reported key components of the methods applied (e.g., details of the sampling strategy, how variables were measured and the details of any randomisation process applied). This led to increasingly sophisticated attempts to develop checklists to guide authors in what to report in their manuscripts and to help reviewers make judgements on manuscript quality.

There is now a substantive and diverse literature on how to assess quality and what to report in research studies. For the most part, however, this literature consists of checklists and frameworks to be used with the particular methods in individual studies (research papers). These include checklists for observational studies and for systematic reviews of the literature on a particular topic including meta-analytic studies. There are also systems which employ multi-dimensional processes for particular purposes such as those employed by the Cochrane Collaboration or WHO (discussed below).

Before presenting information about the most commonly used and robust checklists for assessing quality of research studies and reporting research, we discuss the stand-out points about these checklists in the following section.

Stand-out points about checklists for assessing quality of research studies and reporting research studies

This section details the stand-out points from the literature on assessing quality of research studies and reporting research.

There are checklists which are about assessing quality of research studies. Quality equates to rigour in research design and execution.
1. These checklists are specific to particular research designs. There is no one checklist which can be applied across all study designs. This is because each study design has its own characteristics that determine quality or rigour, strengths and limitations which need to be assessed to generate a view of the quality of the evidence contained in the research study. Research designs are chosen as appropriate to the research question and it is not possible without multi-dimensional and sophisticated expert processes to bring together findings from diverse research designs.

2. Assessing quality of research studies checklists can be found in many ‘branches’ of the scientific literature in medicine, health and social welfare sectors. These checklists typically appear first (in their developmental stages) in a journal or series of journal articles. Later, as checklists grow in popularity, further development and reporting in the scientific literature is followed by launching a dedicated website, manuals for instruction in use of the checklist, additional resources including presentations and use cases, training courses, and in some cases the development of checklist software (e.g., Cochrane GRADEpro GDT at [https://gradepro.org/](https://gradepro.org/)).

3. Some of the most ‘popular’ checklists for assessing quality of research studies are now well developed and from their initial foundation form (usually refined over time) extension checklists have been developed for particular purposes. CONSORT (Consolidated Standards of Reporting Trials) which is a checklist for trials now has a suite of extensions for particular circumstances where controlled trials are utilised (Gagnier et al., for the CONSORT Group, 2006).

There are also checklists about **reporting research studies**. These checklists do not claim to assess the quality of the research study but rather to guide (and to evaluate) transparent and systematic reporting of key methodological aspects of research studies.

1. Reporting research studies checklists are particularly useful for authors preparing a manuscript and, as noted above, are now frequently required as an additional submission by scientific journals to ensure that the submitted manuscript conforms to best practice in reporting the key details of the design used in the study.

2. As with checklists which pertain to assessing quality of research studies, reporting checklists are specific to study designs. This is because each research design has its own components and methods and the reporting of these need to be systematically assessed to judge the reporting of the research study.

3. Clearinghouses, such as the EQUATOR Network, are becoming more prevalent ([http://www.equator-network.org/](http://www.equator-network.org/)). These contain comprehensive searchable databases of reporting guidelines and also links to other resources relevant to research reporting. They often provide a portal with a systematic approach to presenting checklists for reporting many research designs, with the most popular, well-developed checklists and their extensions easily accessible from the website’s home page, and an efficient search engine for website users who wish to check out the range of available checklist resources for each of the 11 study designs. The EQUATOR Network is further described in Appendix 1.
A cautionary note

In reality there is inevitably some overlap between checklists developed to assess the quality of a research study and guidelines for reporting research studies. This is because the checklists for reporting research studies include the components that are critical to the specific research design for which the checklist is designed. However, checklists for reporting research designs are ONLY designed to evaluate whether the design is reported correctly, with all required components identified. This is not the same as assessing quality (rigour) of the research study. For example, on a reporting checklist for RCTs such as CONSORT 2010, a reader could check yes to question 7a: How sample size was determined, which means a description of this is included in the research report. However, this does not indicate whether sample size was appropriate or determined correctly according to standard statistical procedures (and acceptable for the specific situation) and was fit for purpose to answer the research question.

Methods to review multiple studies on a selected topic

The checklists referred to above were primarily developed to either assess the quality of, or report about, individual research studies. It is rarely possible however to apply findings from one research study (paper) to inform programming, policy, or practice decisions or changes in practice. Applying evidence to programming, policy or practice requires understanding the body of evidence as a whole, and this requires approaches specifically designed to review and aggregate findings from multiple studies.

The best-known research designs for reviewing multiple studies are systematic review and meta-analysis. The increasing demand for evidence to underpin programming and policy in particular has ensured the popularity of systematic reviews and meta-analyses so that readers can understand the body of evidence on a particular topic or according to a specific research question. The EQUATOR Network provides information on approaches for reporting systematic reviews and meta-analyses at http://www.equator-network.org.

There is an extensive literature on conducting and reporting systematic reviews with many types of reviews now identified including scoping reviews, rapid reviews, and knowledge reviews. This literature is expanding to address systematising and developing standards for the various types of reviews which may be conducted to understand the gaps in the literature or to determine whether there is a literature on an emerging topic of interest. This is a developing field because of the need to present, in relatively accessible form, an overview of the body of literature in relation to particular topics over a particular time frame or a specific location (geographical or community) rather than a systematic review of all the evidence on that particular topic. There are scholarly papers debating the naming of such reviews and methods for conducting reviews (e.g., Arksey & O’Malley, 2005; Chambers & Wilson, 2012; Gough, Thomas & Oliver, 2012; Levac, Colquhoun & O’Brien, 2010).

Approaches to systematic reviews have been developed with the particular requirements of the social care/ welfare sector in mind. The best known comes from the United Kingdom (UK) Social Care Institute for Excellence (SCIE). SCIE has been producing knowledge reviews which are essentially a systematic review of the literature on a chosen topic. There are guidelines available for how to
conducted this type of knowledge review available at

Similarly, the EPPI-Centre is a specialist centre focusing on the development of methods for systematic reviews and the use of knowledge from these reviews in practice
(http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=53). This Centre has also developed software to manage and support the systematic review process which is available at

Multi-dimensional approaches to reviewing a body of evidence

Highly developed systems now exist for the purpose of assessing the quality of a body of evidence. The best known is the Cochrane Collaboration which provides an online library of reviews at http://www.cochranelibrary.com/. The aim of this international collaboration is to assess the findings on health and social interventions by using an international team of expert reviewers and a systematic process to assess published controlled trials. In essence, a Cochrane Collaboration review offers the findings to a review question about interventions for a particular purpose, e.g., prevention of risk of falls, from a rigorous process conducted according to standardised processes by an expert team of reviewers. The Cochrane Collaboration focus is on intervention studies, and predominantly those utilising RCTs. More detail about Cochrane from the website is included in Appendix 2.

The Cochrane Collaboration was built on the following premise:

“Healthcare providers, consumers, researchers, and policy makers are inundated with unmanageable amounts of information, including evidence from healthcare research. It is unlikely that all will have the time, skills and resources to find, appraise and interpret this evidence and to incorporate it into healthcare decisions. Cochrane reviews respond to this challenge by identifying, appraising and synthesizing research-based evidence and presenting it in an accessible format (Mulrow, 1994).” Available at http://handbook-5-1.cochrane.org/.

The Campbell Collaboration is a recent development along similar lines to Cochrane however its purpose is to publish systematic reviews of social and economic interventions. These are available in an online library at https://www.campbellcollaboration.org/. Additional information about the Campbell Collaboration is included in Appendix 3.

The Campbell Collaboration is distinguished by its concern to translate the findings from systematic reviews in multiple formats to promote social and economic change. One way is by online distribution of Plain Language Summaries of their systematic reviews. The second way is by online distribution of Policy Briefs. Policy Briefs outline the evidence reviewed, remaining (key) questions, and ideas for future research and policy work (https://www.campbellcollaboration.org/better-evidence.html). However, at this time not all systematic reviews have a Plain Language Summary and/ or Policy Brief.
Multi-dimensional approaches to developing recommendations or guidelines based on the evidence

Multi-dimensional approaches have been developed to meet the demand for specific guidelines to inform policy or practice and for recommendations to decision-makers. The demand for evidence to guide programs, practice and policy continues to grow in all fields including the disability support and services sector. However, as noted above, evidence cannot be produced from the review of one research study. A research study may be assessed as being of high quality, however the application of the findings may be limited to only the situation in which the findings were produced.

To understand the body of evidence on a particular topic to inform action requires trained teams using rigorous, highly skilled and systematic processes such as that developed by the WHO. This is because:

- Evidence is produced in, and is potentially only relevant to, the specific situation where it was produced
- Generating evidence uses multiple types of research designs, each of which have their own requirements for rigour (quality) which are essential for confidence in the findings produced
- The body of evidence available may be restricted to particular study designs, or small in quantity, or diverse in research design, or of varying quality requiring skilled appraisal of the body of evidence to determine confidence in the findings produced
- Assessing the quality of evidence requires training and skill in understanding the particular requirements of each study design and the capacity to accurately assess the quality of the evidence
- The above reasons underpin the rationale for trained expert teams to undertake assessing quality of evidence for confidence in the findings prior to any recommendation for action.

Guidelines or recommendations are the next step from a systematic review of the body of evidence. This is needed to turn the findings from a systematic review into guidelines or recommendations for action. Guidelines or recommendations development require multi-dimensional processes to systematically bring together disparate sources of evidence which have been subjected to gold standard systematic review and then subjected to processes to form recommendations of varying strength based on the quality of the evidence from these sources. The WHO has developed an approach now widely used for this purpose. The WHO Handbook for Guideline Development can be found at http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441_eng.pdf.

One component of the WHO guideline development approach is assessing the quality of the evidence. The method to do that is known as GRADE (http://www.gradeworkinggroup.org/). GRADE stands for the Grading of Recommendations, Assessment, Development and Evaluation. There are multiple resources to learn about GRADE available on YouTube and through the GRADE Working Group website. GRADE is a multi-dimensional process initially developed to assess the quality of evidence from RCTs. The primary purpose is to ensure that any recommendations or guidelines are based on a systematic, multi-dimensional approach to understanding the evidence.
With the expansion of qualitative research studies in the health care sector, there is now a companion to GRADE specifically designed for assessing the quality of qualitative research studies. This is called GRADE CER-Qual and is found at http://www.cerqual.org/. The process used mirrors GRADE in many respects. “The GRADE CER-Qual aims to provide a transparent process for assessing the confidence of evidence from reviews of qualitative research, and indicating this confidence to end users, such as guideline panels or decision makers” (http://www.cerqual.org/).

Challenges in applying quality assessment and reporting methods in disability

The major developments in frameworks for assessing quality and reporting have taken place in the medical and health field. Demand has ensured developments in systematic and transparent processes to assess rigour in research design and in the reporting of research studies, software to facilitate and support review purposes, and training programs to build capacity in policy makers, guideline developers, and practitioners seeking to employ evidence in practice.

There are four good reasons why there has been less activity in developing frameworks for assessing quality and reporting of research studies in the disability sector. First, there are many different understandings of disability. Disability may be understood from more medically oriented perspectives (impairment, health condition, chronic illness), as socially constructed, from a bio-psycho-social perspective, or using a critical studies or minority group lens. There are many disciplines involved in the study of disability such that Dan Goodley in his 2011 publication Disability Studies. An Interdisciplinary Introduction names the following: global disability studies, political disability studies, sociological disability studies, de-psychologising disability studies, critical psychological disability studies, poststructuralist disability studies, psychoanalytic disability studies, inclusive disability studies and critical disability studies. There is now a universal (although not universally accepted) description of disability in the United Nations CRPD. This comes primarily from the WHO ICF describes functioning as a ‘dynamic interaction between a person’s health condition, environmental factors and personal factors.’ In this approach, disability and functioning are understood as umbrella terms denoting the positive and negative aspects of functioning from a biological, individual and social perspective.

Despite widespread endorsement of CRPD by member nations signing and ratification, a multiplicity of theoretical approaches and models continue to influence personnel to adopt particular approaches with which they are familiar or bring a level of comfort, usually dependent on their disciplinary or professional background.

Second, there is overlap between the health and disability field, and for many working in the disability sector who come from a health background, the assessing quality and reporting approaches discussed above fit within an already familiar frame of reference and thus can be readily employed. For others without training in scientific method, and more familiar with evaluation approaches for example in education, or in social work, the robust and systematic approaches applied in the medical and health fields may appear overly prescriptive, mystifying, and not readily apparent as fit for purpose to their requirements.
Third, medical and health approaches are often a-contextual to the extent that the focus of research is usually on a medical or health condition or intervention rather than context. In contrast, in the disability field, context is typically diverse yet vitally important in conceptualising how disability is understood, the lives of people with disability, and the influence of health, social and economic policy on the systems and services with which people with disability interact – health systems, disability services, tax systems, welfare systems and supports and so forth. The applicability of some study designs and the quality assessment of rigour which are applicable in the medical and health fields are therefore not always appropriate to research questions or topics of relevance in the disability field.

Finally, for the most part the checklists and systems developed for medical and health sectors do not take into account inclusive study designs as part of the assessment of rigour. Ensuring people with disability have a voice is a fundamental principle in the disability field, and there are many developments in inclusive research where people with disabilities are researchers themselves, rather than simply being the subjects or objects of research. Clearly there is great potential to develop appropriate methods to assess quality (rigour) of emancipator and participatory study design and promote transparent and accountable reporting. These developments await significant resources and investment to be advanced as has been the case over decades in the fields of evidence-informed medicine and health.

Social sector approaches

In the initial Audit of Disability Research in Australia (Audit of Disability Research in Australia, July 2014 available at http://sydney.edu.au/health-sciences/cdrp/projects/auditresearch.shtml we identified TAPUPAS as a potentially promising approach to adding the dimension of utility to critical appraisal of evidence. We described this approach from the information available at that time. TAPUPAS was initiated by Pawson and colleagues for appraisal of knowledge in social care. Its developers state the importance of developing a standardised system in response to the wide diversity of views on quality within the social care community, and, one which could take into account the different types of knowledge from stakeholders in that community: organisations, practitioners, the policy community, researchers, and users and carers.

TAPUPAS was first reported in an Economic and Social Research Council (ESRC) UK Centre for Evidence Based Policy and Practice Working Paper authored by Pawson, Boaz, Grayson, Long and Barnes (2003). The Working Paper was commissioned by the SCIE.

The TAPUPAS developers argued that in social care there are different sources of knowledge and that each need to be taken into account. The five sources of knowledge they identified 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.

The TAPUPAS framework for critical appraisal incorporates a focus on study design as well as attempting to quantify other relevant sector-driven contextual considerations. TAPUPAS suggests using a generic set of questions. These questions are:
• **Transparency** – are the reasons for it clear?
• **Accuracy** – is it honestly based on relevant evidence?
• **Purposivity** – is the method used suitable for the aims of the work?
• **Utility** – does it provide answers to the questions it sets?
• **Propriety** – is it legal and ethical?
• **Accessibility** – can you understand it?
• **Specificity** – does it meet the quality standards already used for this type of knowledge?

Others writing in the social care field have described the potential utility of TAPUPAS (e.g., Sharland & Taylor, 2006). Since the time of the initial 2014 Audit, TAPUPAS has been cited in doctoral dissertations and by individual papers. However, despite extensive searching there does not appear to have been any further development of TAPUPAS as a critical appraisal framework. For example, a search of the SCIE website does not bring up any current references. It is possible to find a reference to TAPUPAS under the archived (last updated November 2012) Research Mindedness section noting that changes in policy and practice since the time of its development need to be taken into account. The Pawson et al. (2003) paper can still be downloaded from some websites such as [https://www.kcl.ac.uk/sspp/departments/politicaleconomy/research/cep/pubs/papers/assets/wp18.pdf](https://www.kcl.ac.uk/sspp/departments/politicaleconomy/research/cep/pubs/papers/assets/wp18.pdf)

Another UK approach to understanding a body of evidence and providing guidance to the health and social care sectors comes from the National Institute for Health and Care Excellence (NICE). NICE provides “national guidance to improve health and social care” ([https://www.nice.org.uk/about](https://www.nice.org.uk/about)). There are a range of resources available at this website, including a tab for evidence services which can be searched for guidance in multiple ways including by categories including conditions and diseases; health protection; lifestyle and wellbeing; population groups; service delivery; organisation; and staffing; and, settings.

NICE has a system for developing guidelines for the health and social care sectors. Information about how this is done is available at [https://www.nice.org.uk/process/pmg20/chapter/introduction-and-overview](https://www.nice.org.uk/process/pmg20/chapter/introduction-and-overview). A feature of their approach is that “Many guideline recommendations are for individual health and social care practitioners, who should use them in their work in conjunction with judgement and discussion with people using services”. NICE is also committed to providing information about the evidence upon which the guidelines are based and how the recommendations were derived from the evidence. The NICE process is systematic, employs methods developed and tested over time, involves teams of experts and requires regular updating. It is contextually specific and developed for the UK health and social care sectors, although international evidence is employed in developing the guidelines and recommendations. There is beginning work by NICE about topics and research questions that are relevant to disability. NICE does not claim to produce systematic reviews or meta-analyses of the scientific evidence base, rather it focuses more on practice and policy issues specific to the UK context. Not surprisingly, NICE relies heavily on RCTs for evidence generated by quantitative studies.
Conclusion

Our conclusions mirrors that presented in the initial 2014 Audit; that there exist:

- well-developed, systematic and standardised ways to assess the quality and reporting of evidence for individual studies from the scientific literature and these are specific to the research design

- a small number of well resourced, multi-dimensional and expert approaches to assessing evidence from a body of literature, typically controlled trials

- a smaller number of well resourced, multi-dimensional expert resource-intensive approaches to generating recommendations from a body of evidence which offer a standard approach to quality of evidence and strength of recommendations (e.g., as used in the development of WHO Guidelines)

- some developments more relevant to the disability field from the social care/social welfare sector. However, these are yet to reach the level of sophistication required to have confidence in their utility for guidance or decision-making for stakeholders in the disability field.

These conclusions suggest that the most appropriate way forward is to further support the developing practice in relation to providing scoping or rapid/knowledge reviews to provide overviews of evidence on designated topics in particular fields. This type of review does not aim to judge quality (rigour) of evidence but rather using the expertise of the reviewer/s to offer a systematic overview of relevant evidence frequently also pointing to gaps in knowledge in the extant literature. The Evidence Check Review and Knowledge Exchange services provided by a team of expert researchers at the NSW Sax Institute is one example of this type of approach (https://www.saxinstitute.org.au/category/publications/evidence-check-library/).

An example from the disability sector is provided by the work of NDS in initiating a Research to Action series.

The stand out feature of any approach to providing an interpretation of the scientific literature whether this be by way of rapid or scoping review, research to action practice guides, or plain English as with all other approaches discussed above, is the need to employ a team with expertise in scientific method, knowledge of the sector, and evidence assessment and reporting skills to conduct the rapid or scoping reviews required.

References


EQUATOR Network (Enhancing the QUAlity and Transparency Of Health Research)

http://www.equator-network.org/

Information from the website is as follows:

“The EQUATOR (Enhancing the QUAlity and Transparency Of health Research) Network is an international initiative that seeks to improve the reliability and value of published health research literature by promoting transparent and accurate reporting and wider use of robust reporting guidelines.”

“The EQUATOR Network is an ‘umbrella’ organisation that brings together researchers, medical journal editors, peer reviewers, developers of reporting guidelines, research funding bodies and other collaborators with mutual interest in improving the quality of research publications and of research itself”.

The EQUATOR Network has four national centres, the UK EQUATOR Centre, French EQUATOR Centre, Canadian EQUATOR Centre, and most recently opened the Australasian EQUATOR Centre (http://www.equator-network.org/2016/02/22/new-australasian-equator-centre-opening-in-march/). These centres focus on raising awareness and supporting good research reporting practices. Further information about the EQUATOR Network see http://www.equator-network.org/about-us/equator-network-what-we-do-and-how-we-are-organised/.

The EQUATOR Network website provides a searchable library of reporting guidelines and policy documents (http://www.equator-network.org/library/). The database has in total 387 reporting guidelines. These can be viewed at the link on the EQUATOR Network homepage. The EQUATOR Network Library homepage page (http://www.equator-network.org/library/) provides links to 11 reporting guidelines for the EQUATOR classification of main study designs.

The information is provided for each reporting guideline according to a proforma which has the following components:

- purpose of reporting guideline – study type
- full bibliographic reference
- additional references
- language
- explanation and elaboration papers
- availability in additional languages
- relevant more generic/ specialised reporting guidelines
- reporting guideline website URL
- reporting guideline acronym
• study design
• applies to the whole report or to individual sections of the report
• previous versions of this guideline/ guideline history
• additional information
• selected relevant editorials
• record last updated on ... 

More established and/ or widely used reporting guidelines typically have information in each section of the proforma, e.g., CONSORT. Less well known reporting guidelines particularly those which have only one or few mentions in the scientific literature have considerably less information and only in some sections of the proforma.

On the homepage of EQUATOR Network there is a list of 11 main study designs. For each there is one reporting guideline with click throughs, and also extensions if applicable. The third column called ‘Other’ clicks through to other guidelines which are available for this study type.

There are four of the eleven study designs relevant to this report. These are Randomised Trials, Observational Studies, Systematic Reviews and Qualitative Studies. The information below lists the main guideline for each of these study types by acronym and full name followed by the EQUATOR Network link and the home page web link for the reporting guideline.

**Randomised Trials**

<table>
<thead>
<tr>
<th>Name</th>
<th>CONSORT (Consolidated Standards of Reporting Trials)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Type</td>
<td>Randomised trials</td>
</tr>
</tbody>
</table>

**Observational Studies**

<table>
<thead>
<tr>
<th>Name</th>
<th>STROBE (Strengthening The Reporting of Observational studies in Epidemiology)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Type</td>
<td>Observational studies</td>
</tr>
<tr>
<td>STROBE homepage</td>
<td><a href="https://www.strobe-statement.org/">https://www.strobe-statement.org/</a></td>
</tr>
</tbody>
</table>
Systematic Reviews and Meta-Analyses

<table>
<thead>
<tr>
<th>Name</th>
<th>PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Type</td>
<td>Systematic reviews</td>
</tr>
<tr>
<td>EQUATOR Network link</td>
<td><a href="http://www.equator-network.org/reporting-guidelines/prisma/">http://www.equator-network.org/reporting-guidelines/prisma/</a></td>
</tr>
<tr>
<td>Guideline homepage</td>
<td><a href="http://www.prisma-statement.org/">http://www.prisma-statement.org/</a></td>
</tr>
</tbody>
</table>

Qualitative Research

<table>
<thead>
<tr>
<th>Name</th>
<th>SRQR (Standards for Reporting Qualitative Research)</th>
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<tbody>
<tr>
<td>Study Type</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>EQUATOR Network link</td>
<td><a href="http://www.equator-network.org/reporting-guidelines/srqr/">http://www.equator-network.org/reporting-guidelines/srqr/</a></td>
</tr>
<tr>
<td>Guideline homepage</td>
<td>Does not exist</td>
</tr>
</tbody>
</table>

For additional examples of particular reporting guidelines other than those listed on the Library homepage, ‘search the reporting guidelines’ on the EQUATOR network web link at http://www.equator-network.org/reporting-guidelines/.

Searches can be done by: study type, clinical area and and/or section of report, as well as in free text. For example, if wanting to search for all reporting guidelines for observational studies, select observational studies from the drop-down study type menu.

The EQUATOR Network website also provides a ‘guide’ to selecting the appropriate guideline. In the Toolkits tab from the homepage there is a


- The EQUATOR Wizard is an online wizard based on the above decision tree (https://www.penelope.ai/equator-wizard)
Appendix 2  COCHRANE

Cochrane at http://www.cochrane.org/

Cochrane is an international network of people who collect and summarise research evidence to inform and facilitate evidence based choices for health professionals. Information from the website is as follows:

“Our vision
Our vision is a world of improved health where decisions about health and health care are informed by high-quality, relevant and up-to-date synthesized research evidence.

Our mission
Our mission is to promote evidence-informed health decision-making by producing high-quality, relevant, accessible systematic reviews and other synthesized research evidence.

Our work is internationally recognized as the benchmark for high-quality information about the effectiveness of health care.” (http://www.cochrane.org/about-us/our-vision-mission-and-principles)

The group conducts systematic reviews which are held in the Cochrane Database of Systematic Reviews (CDSR). The CDSR “is the leading resource for systematic reviews in health care” (http://www.cochranelibrary.com/about/about-the-cochrane-library.html#CDSR). The database includes the systematic reviews and the protocols for the reviews. The Cochrane Library can be searched by searching terms within the review (http://onlinelibrary.wiley.com/cochranelibrary/search) or searching by topics (http://www.cochranelibrary.com/home/topic-and-review-group-list.html?page=topic). For example, a search for the topic ‘developmental, psychological and learning problems’ results in 205 items (http://www.cochranelibrary.com/topic/Developmental%2C%20psychosocial%20%26%20learning%20problems/). In addition to bibliographical information each item includes whether it is ‘new protocol/review’, ‘protocol’, ‘review’, and/ or ‘intervention’.

Reviews are prepared by teams with expertise in the particular field who have registered with a Cochrane Review Group (http://www.cochranelibrary.com/about/cochrane-review-groups.html).

The ‘Cochrane Handbook for Systematic Reviews of Intervention’ (http://handbook-5-1.cochrane.org/) provides details of the processes in preparing, maintaining and reporting of systematic reviews. Additionally, it details the methodological process required for each review, that is, stages of planning, searching and selecting studies, data collection, bias assessment, analysis, and the grading and interpreting of the results. Chapter 2 of the handbook details the format and processes that are required to be followed. All reviews go through the same processes and procedures and are formatted in the same way.
Appendix 3  Campbell Collaboration

The Campbell Collaboration vision statement is “Better evidence for a better world”. This is further elaborated in the mission statement as follows:

“The Campbell Collaboration promotes positive social and economic change through the production and the use of systematic reviews and other evidence synthesis for evidence-based policy and practice – Campbell Collaboration mission statement”


Currently there are seven Campbell Collaboration Coordinating Groups:

- Disability
- Social Welfare
- Knowledge Translation and Implementation
- Crime and Justice
- Education
- International Development
- Methods

These groups are responsible for production, editorial services and support to authors of registered Campbell Collaboration reviews. More information about the Coordinating Groups can be found at:

https://www.campbellcollaboration.org/about-campbell/coordinating-groups.html

The Campbell Collaboration review protocol involves a three-stage process which is described at https://www.campbellcollaboration.org/research-resources/writing-a-campbell-systematic-review.html. In brief, the author or team of authors (i) register a title with one of the Campbell Collaboration Coordinating Groups; (ii) develop a protocol, and (iii) complete a systematic review.

In addition to systematic reviews the Campbell Collaboration website also provides Plain Language Summaries (of the systematic reviews) and Policy Briefs. Policy Briefs outline the evidence reviewed, remaining (key) questions, and ideas for future research and policy work (https://www.campbellcollaboration.org/better-evidence.html). Note, not all systematic reviews have a Plain Language Summary and/ or Policy Brief.

The Campbell Collaboration Library (https://www.campbellcollaboration.org/library.html) can be searched by the Campbell Collaboration Coordinating Groups for Systematic Reviews, Plain Language Summary, Planned Publications (titles and protocols), or Method Series. For example, at Campbell Systematic Reviews heading at https://www.campbellcollaboration.org/library.html, a search of ‘see all reviews’ in the Systematic Review box will result in 138 reviews. For each review record the title, list of authors, published date, Campbell Collaboration Coordinating Group, and type of documents available (e.g., title, protocol, review, plain language summary, etc.) are listed.
At the library page, https://www.campbellcollaboration.org/library.html, it is possible to select by Campbell Collaboration Coordinating Groups, by Type of Document (e.g., protocol, policy brief, etc.), keyword, author, title and publication date.

The website also provides resources at https://www.campbellcollaboration.org/research-resources/research-for-resources.html. These include:

- information about how to write a Campbell Systematic Review
- links to resources such as an effect size calculator, methodological training materials, the WHO Knowledge Translation Toolkit
- available training including Campbell Collaboration courses and courses recommended by the Campbell Collaboration
- selected presentations about the Campbell Collaboration process.