Report of Audit of Disability Research in Australia

Supplement

Centre for Disability Research and Policy
Faculty of Health Sciences
University of Sydney, May 2014

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Art Studio

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Conceptual framework for Audit of Disability Research in Australia

Introduction

The current audit aims to provide a comprehensive picture of disability research evidence in Australia since 2000. The conceptual framework for the audit is drawn from the UN Convention on Rights of Persons with Disabilities (which now underpins most Australian disability policy) and specific Australian policy documents as follows: the National Disability Strategy (2010-2020), the National Research and Development Agenda (NDRDA, 2011), the Australian Framework for Social Inclusion (2010), and the Australian Gender Indicators Framework (2012). The frameworks adopted in the World Report on Disability (2011) and the Community–based Rehabilitation (CBR) Guidelines and Matrix (2010) have also been taken into account. In addition, the International Classification of Functioning, Disability and Health (ICF) has informed the dimensions identified in the conceptual framework. The ICF has been designed for use across sectors, countries and cultures and identifies functioning and disability as multi-dimensional concepts relating to body functions and structures, the activities of people, the participation and involvement of people as member of society and the environmental factors that act as facilitators or barriers to these experiences.

The above documents enshrine biopsychosocial- cultural-environmental model of disability. It is understood that attitudes, practices and structures act as potentially disabling barriers that prevent people from enjoying economic participation, social inclusion and equality (Commonwealth of Australia, 2011). The Audit of Disability Research in Australia focuses on social rather than medical research and covers research about people with disability in all age groups including children with disability, as well as family members and carers of people with disability. Furthermore, the scope of the Audit includes current transitions in the sector, the role of services in supporting families and the broader roles services have in building the capacity and social capital of communities.

The conceptual framework serves as structure to aid searching the literature. The conceptual framework also guides firstly the descriptive mapping of the scope of research about disability in Australia since 2000, and secondly, the analysis of all reports of research meeting the agreed definition for the purposes of the Audit and for which a title and abstract is available.

Conceptual framework

The conceptual framework is built on an understanding of social inclusion, equality and economic participation of people with disability in Australian society. At the centre of the conceptual framework is the person (child or adult) with a disability. The conceptual framework of the audit is based on an
understanding of disability consistent with the ICF in that disability is seen as a multidimensional construct relating to body functions and structures, activities, participation, and environmental and personal factors.

Surrounding the person with disability are their family (including parents, siblings, extended family), carers, friends and neighbours. The domains and dimensions of life for individuals with disability and their family and carers for the purposes of the Audit are illustrated in Figure 1. The eight domains and dimensions that are explored are described below in alphabetical order. Italicized dimensions were added as these became apparent during the coding of the scientific literature.

**Domains and dimensions**
There are eight domains. Italicised dimensions comprise those added once coding commenced to reflect unanticipated dimensions in the literature.

**Education.** This domain includes early childhood, primary, secondary and higher education, lifelong learning and vocational training dimensions. In addition, this domain includes aids and equipment to aid learning; levels of attainment; transport to access education; infrastructure to access education; education providers skilled to provide appropriate/ accessible learning; academic and social development in educational settings; disparity in educational outcomes; initiatives responsive to needs of people with disability; pathways from school to further education; recognition and adaptation to diversity; bullying; belonging; and policies, procedures and models to person-centred support and choice and control relevant to education.

**Economic participation and security.** This domain has a range of dimensions including skills development; employment rates (self and employee); accessibility and use of financial services; social protection/ income support and security of eligibility for income support schemes; retirement benefits and programs; vocational programs; economic participation; family duties; social mobility (capacity to exit poverty and low SE status); cost of living (additional disability costs); employment opportunities; financial stress; material deprivation; earnings; work/family balance; employment policies; taxation; and policies, procedures and models to person-centred support and choice and control relevant to economic participation and security; costs of disability to the community/governments/ families.

**Social relationships.** This domain includes dimensions personal assistance: need, accessibility, and provision; relationships, marriage and family; parenting, mothering; friends and social networks; social participation; attitudinal barriers; and policies, procedures and models to person-centred support and choice and control relevant to social relationships; sexuality; behaviour, behaviour support, challenging behaviours; spirituality.

**Community and civic participation.** This domain included dimensions of community access; community mobilization; political participation; self-help groups; disabled people’s organizations;
citizenship activities; sector partnerships and collaborations; complaints under DDA; participation in civic life; recognition and adaptation to diversity; accessible culture and arts; accessible recreation, leisure and sports; volunteering; community groups and institutional resources; religious participation; accessible communication and information; access to internet/technology; recognition and adaptation to diversity; access to justice; criminal justice responses that meet needs of people with disability; restrictive practices in institutional settings; community capacity building; social capital with and for people with disabilities; and policies, procedures and models to person-centred support and choice and control relevant to community and civic participation; plain English research translation.

Health and wellbeing. This domain is broadly based as in the national and international frameworks and policies cited previously to include dimensions of health from a state of wellbeing and from health promotion through to interventions and recovery; indicators of health status; need for and access to mainstream and specialist health services; inclusion in health promotion and health prevention programs; health service planning for people with disability; rehabilitation services and availability; consumer outcome measures of health and quality assurance in relation to health services; continuity and consistency of health services for people with disability; policies, procedures and models to person-centred support and choice and control relevant to health and wellbeing; bodily integrity, sterilization; subjective wellbeing, quality of life; diagnosis, genetic diagnosis, prevalence and incidence studies; co-morbidity; healthy/normal/delayed development in all areas – e.g. speech, mobility, fine motor, language; ageing with a disability; coping strategies and adjustment; anxiety, stress, depression; caregiving, caregiving strategies; work engagement and burnout.

Transport and communication. This domain focuses on information and transport systems that are accessible, reliable and responsive to the needs of people with disability, their families and carers and includes the dimensions of accessible public transport; financially and geographically accessible special transport schemes; accessibility and reliability of communication systems; alternative forms of communication; access to technology to facilitate communication; difficulties using public transport; and policies, procedures and models to person-centred support and choice and control relevant to transport and communication.

Housing and built environment. This domain includes the dimensions of home and housing and public space including suitable, affordable housing suitable to needs; housing stress; accessible and safe public spaces for work, leisure, social and community participation; security of tenure (renting or ownership); security of placement in supported accommodation; access to supports for living in public or private housing together with others or independently; residential care for people with disability who are ageing; residential care for people with disabilities of all ages; respite care; supported accommodation for
people with disabilities; and policies, procedures and models to person-centred support and choice and control relevant to transport and communication.

**Safety and security.** This domain includes the dimensions personal safety; neighbourhood safety; safety within personal and care relationships; safety of care arrangements; safety of home environment (related to accessibility/suitability etc); feelings of safety in the community and in public space; family and partner violence; violent behaviour of non-family including carers and community members; victim of personal violence, household crime and hate crime; restrictive practices in institutional settings; and policies, procedures and models to person-centred support and choice and control relevant to safety and security; harassment and discrimination; right to life; refugees/migration.

**Environmental /Contextual Factors**

The person with disability, their family/carers and the domains of everyday life outlined above exist within an environmental context. This context broadly includes services and systems, legislation and policy, products and technology, and the physical environment as outlined below:

**Services and systems:** Formal and informal systems and services within communities; role of systems and services in facilitating or restricting participation of people with disability; sustainability of service sector; models of services and funding.

**Legislation and policy:** Policies, procedures, legal, governance and social structures.

**Products and technology:** Assistive technology and equipment, communication and information systems.

**Physical environment (natural and built):** Australian standards; architectural characteristics; climate; geography; and terrain.

**Cross-cutting issues**

Cutting across all elements of the framework are three issues: empowerment, cultural and societal attitudes and beliefs, and discrimination and disadvantage.

**Empowerment:** Includes the extent to which people with disability have control over their lives and their participation in society; self-determination; sense of agency; role of self-help groups and Disabled People’s Organizations in promoting advocacy and empowerment; capacity building for individuals for groups either informal or formal organisations of people with disabilities; collaborative and inclusive
research; and policies, procedures and models to person-centred support and choice and control relevant to empowerment.

**Cultural and societal attitudes and beliefs:** Includes the attitudes and beliefs within cultures, society, groups within society and communities and individuals; negative attitudes and stereotypes including cultural differences in understandings of disability; beliefs about disability and how people with disabilities should be regarded; ways of knowing and beliefs about what research is and values given to different types of research; and policies, procedures and models to person-centred support and choice and control relevant to cultural and societal attitudes and beliefs.

**Discrimination and disadvantage:** Includes exclusion and barriers to community participation; segregation, marginalization and disadvantage (material and social) experienced by people with disabilities and their carers; multiple disadvantage (for example, disadvantage associated with experiencing disability and being Indigenous); colonization and cultural discrimination and people with disabilities; systemic and organizational discrimination; personal discrimination including harassment, bullying, violence and hate crime; and policies, procedures and models to person-centred support and choice and control relevant to empowerment.

The conceptual framework is presented diagrammatically as Figure 1, Section 1.
Attachment 2 Search Strategies and Results

Scientific Literature

Search Strategy
To identify relevant Databases, we used Ulrich’s TM Global Series Directory and searched for key journals in disability and major journals covering the domains of the conceptual framework. Databases were selected according to indexing of these journals and Research Team input.

We devised and applied the following keyword string in combination with Subject Headings (if these existed in one or more data bases). The data bases 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 2000 to the date of the search
- 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 8 domains separately. We tried, where possible to only search the Title, Abstract and keywords fields.
- Export each completed search to the reference manager software EndNote 7.

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

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=(2000-2014) 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 inclusi*)

Domain Search: Economic

(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=(2000-2014) 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: Social

(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=(2000-2014) 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: 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=(2000-2014) 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: 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=(2000-2014) 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: 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=(2000-2014) 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**")

Domain Search: Housing and 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=(2000-2014) 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

(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=(austr* 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=(2000-2014) 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)
Initial Search Results by Databases and Domain

Table 1. Initial search results by databases and domain before duplicate checking

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<tr>
<th>Initial search results by data base and domain</th>
<th>DOM_EDU</th>
<th>DOM_ECON</th>
<th>DOM_SOC</th>
<th>DOM_COMM</th>
<th>DOM_HEALTH</th>
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**Duplicate Checking**

As all domains were searched separately, the results (n= 25112) included a large number of duplicates within each database as well as across the 11 databases. All duplicates were removed using the ‘Find Duplicates’ function in Endnote. Several combinations of duplicate searches were conducted using different fields to account for the varying quality and format of the information in each database (for example, Author, Title, Year, Journal, Volume and Page Numbers).

**Initial Screening**

The team reviewed the aggregated results of searches with all duplicates removed. This led to further exclusions of material not meeting inclusion criteria. This was done by bulk deletions using keywords in the EndNote Libraries. The following key words were used: Obituaries, Book Reviews, Letter, commentaries, editorials, Not research including Technical Aid Journal, News Items and CEO reports, Items not about Australia, Golf and Mining both words unrelated to disability but containing the keyword handicap.

We also identified an incorrect subject heading used in the PsycINFO Database. The Subject Heading “Physical Disorders” which included the narrower terms of Blood and Lymphatic Disorders,
Cardiovascular Disorders, Digestive System Disorders, Endocrine Disorders, Genetic Disorders, Health Impairments, Immunologic Disorders, Infectious Disorders, Metabolism Disorders, Musculoskeletal Disorders, Neonatal Disorders, Neoplasms, Nervous System Disorders, Nutritional Deficiencies, Respiratory Tract Disorders, Sense Organ Disorders, Sensory System Disorders, Skin Disorders, Toxic Disorders, Urogenital Disorders and Vision Disorders. This term was broad and focused on research on medical conditions rather than the social research focus of the Audit.

To account for this, we filtered out all PsycINFO records that did not contain the keyword disab*. The subject heading of each record was examined manually to determine if meeting the inclusion criteria. Records that did not match were then removed (335).

Table 2: Results by data base and domain after duplicate checking and initial screening

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<td></td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Transferred from grey literature</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>3076</td>
<td>779</td>
<td>1660</td>
<td>973</td>
<td>1581</td>
<td>946</td>
<td>591</td>
<td>832</td>
<td>10438</td>
</tr>
</tbody>
</table>

Locating abstracts

Of the 10,438 items resulting from the search after duplicates removal and initial screening plus 6 from the grey literature, 1819 items did not contain an abstract in the search database. A manual investigation for each of the 1819 items was undertaken to identify if an abstract could be located. This was done on 1019 of the 1819 articles with URLs attached by EndNote Find Full Text function and 188 PDFs from the University of Sydney library subscriptions were located. The remaining 612 were searched for manually
either through the library databases or a Google search. The Abstract or Summary was then copied and pasted into the reference in the EndNote Library. Of the 1819 non abstract articles, an abstract or summary was found for (633); there was no abstract for a further (1052), and the remaining items were not accessible (134).

Results of searches

10,432 items were located for possible inclusion in the Audit using the processes described above. The analysis method relied on title and abstract therefore only documents with abstracts available were included for analysis. Of the 10,432 items resulting from the search after duplicates removal and initial screening, 1819 items did not have an abstract. Following procedures to locate abstracts potentially relevant documents (8491) were loaded into EPPI 4 Reviewer\(^1\).

Following duplicate removal and screening for accessible abstracts, 8491 documents remained and were loaded into EPPI 4 Reviewer software\(^2\), which was utilized for document analysis. Bulk searches removed a further 678 documents which included duplicates, those not relevant by type of paper (e.g. editorial, book review) and not relevant by target group (e.g. ADHD, frail elderly, low back pain) leaving 7813 for individual screening.

Individual screening resulted in a further 3158 documents excluded as not relevant by target group and a further 2201 documents which, although relevant by target group, were excluded by type of paper (e.g. autobiography, education –information piece only, service description). The number of excluded documents in each category by type of paper is illustrated in Figure 2, Section 1. Note that all documents were reviewed to ensure study reported was conducted in Australia or as part of cross country study including Australia data. If research method was not clear in abstract or abstract did not contain method where possible a PDF of full text was sourced. For 27 documents no full text PDF could be located.

The remaining 1658 documents met the Audit criteria (included documents) and were subjected to detailed review and coding as described in Attachment 3.

Technical difficulties and alternate solutions

- Domain searching. To ensure full coverage of domains across multiple disciplinary databases the search strategies were set up by domain. It was anticipated this would also aid in document coding. This required 8 searches per databases. Results indicated a high level of duplicated articles within each database as documents were selected more than once by keywords.

\(^1\) http://eppi.ioe.ac.uk/cms/Default.aspx?alias=eppi.ioe.ac.uk/cms/er4
Alternate solution: Combine all the domains to be searched with the Boolean operator “OR” and have one large search string

- Quality of Abstracts. Databases differ in quality of abstracts. We had high quality detailed abstracts from databases such as Medline and PsycINFO, to extremely brief or no abstracts from some of the databases searched in the Informit Database.

Alternate solution: Review the databases used for quality of their abstracts. Reconsider the order of searching the databases. Consider searching databases with full abstracts first so that referencing managing software remove duplicates function will remove last entry (poorer quality/ no abstract)

- Keyword Searching versus Subject Headings. Keyword searching and subject heading searching have advantages and disadvantages when conducting a multi-dimensional search such as this. Domain keywords were quite broad resulting in a large number of hits. Using subject headings and exploding them worked well in some of our concepts, as they were quite complex with the exception of the PsycINFO Database noted above.

- Australian material. Keywords on Australia and its States and Territories were used in the search strategies on Title, Abstract and Keywords. For the following reasons this is not accurate. There may be mention of Australia in the keywords or abstract although the research does not relate to Australia. A number of Australian journals put their Copyright notice (which includes Australia or Australian in the Abstract.

- The amount of non-research related material found. Without using a list of research designs in the search strategy there were a large number of non-research documents returned. Only some databases have a function to filter by type of research. For the purposes of the Audit research designs were purposely broad, limiting the capacity to use this function where it exists.

- Duplicate checking. Duplicate checking overall was made difficult by the small differences in how databases enter information. A semi colon or different format of authors and page numbers is not picked up as a duplicate. A number of duplicate searches on different fields was required in EndNote X7 with a final visual manual search which was time intensive.

Grey Literature

Data sources

The grey literature refers to items not published in the peer reviewed scientific literature. In line with the Audit parameters eight data sources were initially identified as follows:

- Federal, State and Territory Government Department Reports
- Federal, State and Territory Agencies and Commissions Reports
- Research Centre Reports
• NGO Research Reports
• Doctoral Theses
• Books and Book Chapters
• Published Abstracts/ Conference Proceedings
• Australian Standard® from Standards Australia (http://www.standards.org.au/Pages/default.aspx).

Results of all searches in each source were imported into mutually exclusive EndNote X7 libraries. Review of the EndNote X7 libraries for the last three sources Books and Book Chapter, Published Abstracts/ Conference Proceedings, and Australian Standards resulted in these categories not being included in the Audit. Review of doctoral theses revealed noteworthy findings. These four categories are presented prior to the search results and included documents data for the remaining four categories.

**Standards Australia:** The 54 disability relevant Australian Standard® identified did not meet Audit inclusion criteria. These items provide a useful resource to understand the breadth of Australian standards that address disability however do not meet criteria for research as determined by the Audit, thus were not included in the final agreed scope of the grey literature.

**Published Abstracts/ Conference Proceedings:** In total 608 published abstracts/ conference proceedings were identified (initially 593 with an additional 15 identified during review and coding phase in EPPI 4 Reviewer data base). Published abstracts and conference proceedings come in a variety of formats without standard approaches for whether or not the material has been peer reviewed, the availability of the documents (particularly from earlier years where conference proceedings may be held in archives which are not publically accessible), the inclusion of an abstract. Screening of a random selection of the items in the Published Abstracts/ Conference Proceedings EndNote X7 library revealed these inconsistencies and the difficulty with ascertaining whether any at all would meet Audit inclusion criteria, indicating full review would require intense resource effort for very little return. Consequently, Published Abstracts/ Conference Proceedings were not included in the final agreed scope of the grey literature.

**Books and book chapters:** 491 were initially identified in the scientific literature search as follows: ERIC (13), Informit (460), PsycINFO (10), Scopus (4), Sociological Abstracts (2) and Web of Science (5). Screening of the resulting EndNote X7 library revealed that of the 491 items, 140 did not meet content criteria for inclusion in the Audit. These items were about specific learning difficulties/ ADHD; biographies of people with disabilities; ageing and disability; literacy and numeracy in classrooms. Of the remaining 351, 103 were reclassified as conference abstracts or proceedings 19), reports from Department of Family and Community Services (and Housing and Indigenous Affairs) (17), reports from other government departments or statutory agencies (29), reports or discussion papers from Parliamentary/ Statutory agency inquiries (20), reports from Research Centres (14), and reports from NGOs (4). Of the remaining
248, 77 were practical manuals, resources and guides and 92 were text books or chapters in text book (review not research as defined by HERDC). The total 169 items were excluded from further analysis.

Of the remaining 77 potentially relevant items, there were 12 books and 64 book chapters. We endeavoured to identify whether an abstract (as per criteria) existed for the 64 book chapters. Review of the available abstracts lead to only 9 items as potentially relevant. Abstracts were not in sufficient detail to meet Audit criteria and therefore were not included in the final library of included documents from grey literature.

**Doctoral theses:** An advanced command search of published material in Libraries Australia http://librariesaustralia.nla.gov.au/ was undertaken using the following search string. Combinations of keywords (AW) were combined with the date period (DAT).

(AW = disab? Or AW = handicap? Or AW = "mental? retard?" Or AW = "development? disabilit?" Or AW = "intellectual disability?" Or AW = "learning disability?" Or AW = "learning disorders?" Or AW = "vision impairment?" Or AW = "hearing impairment?" Or AW = "vision disorder?" Or AW = "hearing disorder?") And DAT >= 2000 And (AW=thesis)

Unlike published works where records are copy catalogued, theses are usually catalogued at a local librarian level. In addition, many theses records come from user uploads to repositories. Therefore records frequently do not meet high levels of descriptive cataloguing. Because of this basic cataloguing it was decided to omit the keyword of “Australia” as a large percentage of theses did not contain the word “Australia” or any of the states. For example, ones from Murdoch University, Flinders University, and the University of Sydney did not contain descriptive keywords for Australia.

The total theses records retrieved were 1433. An additional 31 Thesis records were found in the Scientific Literature and transferred to the Theses EndNote X7 Library. Initial screening was undertaken to: (i) remove duplicate records. When multiple holdings or separate records existed the electronic record was kept in preference to the print record as the former contained the direct URL; (ii) remove studies not related to Australia. All records that did not contain the keyword “Australia” were manually checked. Together duplicate records and studies not relating to Australia resulted in 400 records being removed; (iii) remove books and conference papers that contained the keyword “thesis” in their records resulted in 589 records being removed.

The 444 potentially relevant theses were screened by title and abstract or in the absence of an abstract by keywords. A further 230 theses were excluded on content: content including ageing only, educational disadvantage, specific learning difficulties, gifted children, developmental coordination disorder, sensory processing in children, medical, surgical and pharmaceutical interventions, animal models and studies conducted outside Australia (at Australian institutions), musculo-skeletal disorders/ pain/ fatigue/ low back pain, war disability (WWII).
The scientific literature was searched to identify any publications arising directly from the 214 relevant doctoral theses. There were 85 theses with at least one publication directly drawn from the thesis work. These 85 were not subjected to further analysis as the research would be considered in the scientific literature analysis. Of the remaining 129 theses, 91 did not have an abstract that met inclusion criteria and were therefore excluded. In total, 38 theses met criteria for inclusion as grey literature in the Audit.

Federal, State and Territory Government Department Reports

The DPRWG provided the list of federal, state and territory focal point for disability government departments with contact details. The website and/or publications section of each department was searched using terms appropriate to the website including Research report, Disability, Study, Participants, Methodology. Where possible Boolean operators, usually AND, were used. All identified publications were screened with an Excel spreadsheet prepared with details and URL for publications that met inclusion criteria. Contact persons from each department confirmed the listings and added further documents that met inclusion criteria.

Table 3. Number of identified documents by website and department

<table>
<thead>
<tr>
<th>Department</th>
<th>Website identified</th>
<th>Department identified</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department of Families, Housing, Community Services, and Indigenous Affairs</td>
<td>9</td>
<td>no response</td>
<td>9</td>
</tr>
<tr>
<td>Disability ACT</td>
<td>0</td>
<td>no response</td>
<td>0</td>
</tr>
<tr>
<td>Department of Health, NT</td>
<td>0</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Department of Communities, QLD</td>
<td>2</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td>Department of Family and Community Services, NSW</td>
<td>30</td>
<td>35</td>
<td>65</td>
</tr>
<tr>
<td>Department of Human Services, Vic</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Department of Health and Human Services, Tas</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Department for Communities and Social Inclusion, SA</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Disability Services Commission, WA</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>51</td>
<td>67</td>
<td>118</td>
</tr>
</tbody>
</table>

The 118 records were further screened resulting in 69 records being excluded as not meeting inclusion criteria including 8 with insufficient detail in abstract. In total, 51 government reports met criteria for inclusion in the Audit.
Federal, State and Territory Agencies and Commissions

The same website process used for government reports was utilized for federal, state and territory agencies and commissions with the exception of the Australian Institute of Health and Welfare (see below).

Table 4. Number of documents identified by website and statutory agency

<table>
<thead>
<tr>
<th>Government commission or agency</th>
<th>Jurisdiction</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Human Rights Commission</td>
<td>Federal</td>
<td>4</td>
</tr>
<tr>
<td>Victorian Equal Opportunity and Human Rights Commission</td>
<td>VIC</td>
<td>5</td>
</tr>
<tr>
<td>ACT Human Rights Commission</td>
<td>ACT</td>
<td>1</td>
</tr>
<tr>
<td>Office of the Public Advocate</td>
<td>VIC</td>
<td>7</td>
</tr>
<tr>
<td>Office of the Senior Practitioner/Office of the Primary Practitioner</td>
<td>VIC</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>30</td>
</tr>
</tbody>
</table>

Six references were then removed from this library as they were published in the scientific literature. A further 9 were removed during the review process as these did not meet inclusion criteria. In total, 21 reports from statutory agencies and commissions met criteria for inclusion in the Audit.

Australian Institute of Health and Welfare

Given the specific remit of the Australian Institute of Health and Welfare the documents from this statutory agency were collated in a separate EndNote X7 library. Relevant documents were identified by manually searching the AIHW website (79), an Informit Database Search limiting the author field to AIHW (103), items in Libraries Australia search of research centres with AIHW listed as an author (94). Following duplicate removal and screening, 115 documents met the inclusion criteria for the Audit.

Research Centre Reports

Initially it was anticipated that research centre reports could be located by website search. As indicated below in Non-Government Reports there were major difficulties in utilizing websites to identify reports/documents that met the inclusion criteria for the Audit. An alternative process was then followed for Research Centre Reports. An advanced command search of published material in Libraries Australia http://librariesaustralia.nla.gov.au/ was undertaken using the following search string. Combinations of
keywords (AW) were combined with the date period (DAT) and searching for the words “Centre” or “Institute” in the author keyword (NW) field, excluding Annual Reports.

(AW = disab? Or AW = handicap? Or AW = "mental? retard?" Or AW = "development? disability?" Or AW = "intellectual disability?" Or AW = "learning disability?" Or AW = "learning disorders?" Or AW = "vision impairment?" Or AW = "hearing impairment?" Or AW = "vision disorder?" Or AW = "hearing disorder?") And DAT >= 2000 And (NW=institute* OR centre*) AND (NOT AW=annual)

225 records were located. An additional 33 records were transferred into Research Centre Reports (14 from Book/Book Chapter, 19 from the scientific literature). In total, 117 met the criteria for inclusion in the Audit.

**NGO Research Reports**

Multiple processes were used to identify potentially relevant documents from Non Government Organisations (NGO). These included (i) key disability umbrella/peak organization websites and listed member organisations were searched for lists of disability peak NGO (n=92); (ii) review of this list by the Research Team and Advisory Group resulted in 18 additions (n=110); and (iii) state based organisations were removed where there were national organisations to reduce likely duplication (national organisations typically include state and territory based information). Searching of the final listing of 64 NGOs websites was undertaken between the 4th December 2013 and the 20th January 2014. People with Disabilities Australia (PWDA) and National Disability Services (NDS) were members of the Research Team and undertook to provide lists of documents meeting Audit criteria from their respective websites.

Manual searching of NGO websites using research and/or publications was not productive due to inconsistent website formats. A Google domain search string using Google Chrome was refined as follows: Disability AND Research OR study OR studies OR evaluation -bulletin -form -annual -newsletter* - “fact sheet*” –submission - communique site:nsw.org.au

Multiple NGO websites however did not allow for Google domain searches additional necessitating manual searches. Identified documents were screened for inclusion criteria with specific attention needed to presence of abstract or executive summary. The final listing of potentially relevant documents was sent to each organization for review. The results of this process are documented in Table 5.
### Table 5: NGO documents and review outcomes

<table>
<thead>
<tr>
<th>Organisation/association</th>
<th>Google domain search</th>
<th>Met inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Disability Network NSW</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>ARAFMI</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>ARBIAS</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Arts Access Australia</td>
<td>124</td>
<td>6</td>
</tr>
<tr>
<td>Autism Spectrum Australia (ASPECT)</td>
<td>43</td>
<td>7</td>
</tr>
<tr>
<td>Association of Blind Citizens of NSW</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Australian Advisory Board on Autism Spectrum Disorders</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Australian Deaf blind Council</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Australian Rehabilitation and Assistive Technology Association</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Australasian Society for Autism Research</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Australasian Society for the Study of Brain Impairment</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>Australian Federation of Disability Organisations</td>
<td>42</td>
<td>1</td>
</tr>
<tr>
<td>Blind Citizens Australia</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>Brain Foundation</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Brain Injury Australia</td>
<td>160</td>
<td>1</td>
</tr>
<tr>
<td>Brain Injury Matters</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Carers Australia</td>
<td>149</td>
<td>7</td>
</tr>
<tr>
<td>Cerebral Palsy Alliance</td>
<td>321</td>
<td>5</td>
</tr>
<tr>
<td>Children with Disability Australia</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Cystic Fibrosis Australia</td>
<td>35</td>
<td>0</td>
</tr>
<tr>
<td>Carers NSW</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Deaf Society of NSW</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Deaf Blind Association NSW</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Deafness Council (NSW)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Australian Hearing (formerly Deafness Association of NSW</td>
<td>66</td>
<td>0</td>
</tr>
<tr>
<td>Deafness Foundation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Disability Advocacy Network Australia</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Organization Name</td>
<td>Mandarin</td>
<td>English</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Disability Foundation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Disability Care Australia</td>
<td>30</td>
<td>0</td>
</tr>
<tr>
<td>Disability Rights Now</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Disability Services Australia</td>
<td>24</td>
<td>0</td>
</tr>
<tr>
<td>Down Syndrome NSW</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Epilepsy Society of Australia</td>
<td>35</td>
<td>0</td>
</tr>
<tr>
<td>Head west</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Homes West Association Inc</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Institute for Family Advocacy</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Intellectual Disability Rights Service</td>
<td>70</td>
<td>1</td>
</tr>
<tr>
<td>International Association for the Scientific Study of</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Intellectual Disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life Without Barriers</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lowitja Institute/Cooperative Research Centre for</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander Health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health Council of Australia</td>
<td>84</td>
<td>10</td>
</tr>
<tr>
<td>Machado Joseph Disease Foundation</td>
<td>40</td>
<td>1</td>
</tr>
<tr>
<td>MND Australia</td>
<td>104</td>
<td>0</td>
</tr>
<tr>
<td>MS Australia</td>
<td>418</td>
<td>2</td>
</tr>
<tr>
<td>Multicultural Disability Advocacy Association</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Muscular Dystrophy Association</td>
<td>50</td>
<td>1</td>
</tr>
<tr>
<td>National Council on Intellectual Disability</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>National Disability and Carer Alliance</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>National Disability Services</td>
<td>34</td>
<td>26</td>
</tr>
<tr>
<td>National Ethnic Disability Alliance</td>
<td>22</td>
<td>3</td>
</tr>
<tr>
<td>Physical Disability Australia</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>People with Disability Australia</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Prader Willi Association of Australia</td>
<td>24</td>
<td>0</td>
</tr>
<tr>
<td>Secretariat of National Aboriginal and Islander Child Care</td>
<td>56</td>
<td>5</td>
</tr>
<tr>
<td>Mental Health in Multicultural Australia</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Siblings Australia</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Side by Side Advocacy Incorporated</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Spinal Cord Injury Network Australia</td>
<td>33</td>
<td>0</td>
</tr>
<tr>
<td>Synapse Incorporated</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The Fragile X Association of Australia</td>
<td>10</td>
<td>0</td>
</tr>
</tbody>
</table>
The final number of documents included in the Audit from the grey literature was 353. Included documents by source, number and percentage are illustrated in Table 6.

Table 6. Sources and frequency of research documents in the grey literature

<table>
<thead>
<tr>
<th>Source</th>
<th>Number</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government reports</td>
<td>51</td>
<td>14</td>
</tr>
<tr>
<td>Statutory agency reports</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>AIHW/ ABS reports</td>
<td>115</td>
<td>33</td>
</tr>
<tr>
<td>Research Centre reports</td>
<td>65</td>
<td>18</td>
</tr>
<tr>
<td>Non-government organisations</td>
<td>63</td>
<td>18</td>
</tr>
<tr>
<td>Doctoral theses*</td>
<td>38</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>353</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

*theses with no publications in scientific literature

**Technical difficulties and alternative solutions**

We tried to find a systematic and time efficient approach to hand searching non-government organisation websites. We first started going to each website and searching for publications via their homepage links. Almost no websites had a clear link to research publications or a search function to facilitate searching in this manner. As an alternate we used a Google Domain search limited to web pages from a particular domain using the “site:” command. We created a broad search string which we later refined however because of the way search engines use full text searching there were a lot of hits for very few results.

- The list of websites searched was comprehensive but not exhaustive relying largely on input and checking from the Research Team and Advisory group
- A lack of suitable/accurate abstracts or summaries for many publications meant that it was difficult to screen and code these without extensive time spent following links to publications and searching through full text copies of the report
- Some NGOs replied to our requests for publications by sending web-links to relevant publications or to relevant pages on their websites. For some of these organisations the web-links changed regularly, resulting in additional time spent searching for these publications
Some NGOs require membership to access ‘back sections’ of their websites and /or payment for accessing research publications which severely limits wide distribution

Some websites used frames, which meant that their content was not searchable through search engines

As the process was repetitive (copying and pasting the search string into Google) websites repeatedly blocked access

Unstable URLs. This means that the URL changes once additional documents are added, therefore the previous weblink URL is no longer accurate and/ or active

Search functions on ABS and AIHW are not specific to detailed information on a particular topic or employ Boolean operators. This means that the word disability will return multiple results. These results will include any publication in which the word disability appears. To locate documents that specifically focus on disability requires hand searching unless the titles of these documents are already known.

Alternative solutions:

• Maintaining a list of non-government organisations directly addressing disability and producing research. The data base developed for the Audit would provide an excellent foundation
• On homepages, display an easily accessible tab which links directly to research publications. This will facilitate ease of access for everyday users
• Provide concise and accessible summaries/abstracts for publications listed on websites to enable readers to be able to determine the content of the publication easily
• Ensure more permanent web-links to publications or attach PDF copies of publications for downloading
• Employing the use of metadata in online resources to increase visibility across popular search engines. The Australian Government Locator Service (AGLS) Metadata Standard has a basic standard that could be adapted for this purpose http://webguide.gov.au/finding-content/metadata-agls/
• Not using frames in websites where there are online resources. It is probably the case that many organisations are not aware that their website is not searchable using a search engine search string.

Final reflections

• In Australia disability is understood as a social construct which crosses disciplinary and sectorial boundaries. This is in direct contrast to the scientific literature which is organized by disciplines and/or sectors.
• The ‘lead’ approach in the current Australian policy context is to define disability in terms of functioning within a social equity and human rights context. Such an approach inevitably misaligns with the state of knowledge development in the scientific literature due to the time lag between the conceptualization and actualization of research studies. As a result, a significant proportion of contemporary scientific study reflects historical conceptualisations of disability rather than those currently accepted. This is most obvious in the strong focus on people with disability by diagnostic group rather than according to functioning or barriers to participation.

• The International Classification of Functioning, Disability and Health (ICF) and the UN Convention on the Rights of Persons with Disabilities recognizes disability as arising from interactions with various barriers that may hinder full and effective participation in society on an equal basis with others. This understanding of disability is not readily apparent in the Australian research in the scientific literature in this time period. The most commonly encountered description of people with disability in this literature was by health condition, impairment and/or illness rather than in relation to activities or participation. This is seen most starkly in relation to people with mental health conditions and mental illness where typically research focuses on specific diagnostic conditions and their sequelae (even though the research is not primarily medical in nature). Psychosocial disability and/or severe and persistent mental illness and its disabling effects are rarely mentioned or addressed.

• To isolate only research conducted in Australia (or where Australia was included in cross-country studies) as required by the Audit was particularly resource intensive. This is because the scientific literature is international by nature and location of research is not always mentioned in a title or abstract. A great deal of checking of author affiliation and/or method and sampling by reference to a full text document was required.

• Using comprehensive search strategies for the scientific literature as required by the Audit parameters led to a large number of initial returns equaling 10,438 (after duplicate checking and initial screening). In depth screening to identify potentially relevant documents was particularly resource intensive given lack of standardization in data base construction, diverse abstract construction based on journal-specific abstract requirements, unstable URLs for many aspects of the grey literature and other technical matters. Despite employing multi-dimensional search strategies in collaboration with the DPRWG, the disability sector and with federal and state and territory statutory agencies and commissions to locate grey literature, this process was four to five times more resource intensive than for the scientific literature and for proportionally less return. In total the number of research investigations that met the Audit criteria were 1658 in the scientific literature and 556 in the grey literature.
• As appropriate to an audit of relevant research in a multi-dimensional field analysis relied on title and abstract only. Some potentially relevant research investigations were not able to be included due to there being no abstract available or a poorly constructed abstract which did not meet Audit criteria.

• Most concerning given the desire to build capacity in disability research in Australia, gaining access to doctoral theses was particularly problematic. This is due in part to no mandatory requirements for digital repository and non-standard approaches to abstract construction. Worryingly, there were no publications in the scientific literature for approximately 60% of the theses identified as relevant. This means that the findings of studies conducted in two thirds of doctoral theses produced in the disability field are virtually not accessible to the community. This is a substantive waste given the significant personal, financial and infrastructure resources that go into the production of a doctoral thesis.
Attachment 3 Coding Processes

Coding by domain

All included documents were coded exclusively into one of 8 single domain categories or 2 multiple domain taking into account the dimensions within each category as detailed in Attachment 2. The 8 single domain codes as follows: DOM_COMM: Community and Civic Participation; DOM_ECON: Economic Participation and Security; DOM_EDU: Education; DOM_HEALTH: Health and Wellbeing; DOM_HOUSE: Housing and the Built Environment; DOM_SAFE: Safety and Security; DOM_SOC: Social Relationships, and DOM_TRANS: Transport and Communication. Studies that addressed multiple domains were coded as DOM>1butnotALL: ‘More than One Domain but Not All’ or as DOM_ALL: ‘All Domains’.

Coding by family/carers or services

Documents that specifically addressed family/ carers or service providers were coded by these categories to differentiate these studies from those addressing people with disability. In the scientific literature where documents addressed both groups coding followed the primary focus specified in the title and abstract as either EPPI_FAMILY/CARERS or EPPI_SERVICES. In the grey literature a small proportion of documents were coded to include both family/carers or service providers using the code EPPI_DOUBLEFOCUS.

Coding by diverse and/or disadvantaged groups

Documents that specifically focused on one or more of the four NDRDA nominated diverse and/or disadvantaged groups was coded as Aboriginal and Torres Strait Islander peoples; People from culturally and linguistically diverse backgrounds; Women with disability; and People living in regional, rural and remote areas.

Coding by study design/ type of investigation

Documents were coded by one only mutually exclusive type of investigation code. The 17 codes utilized were intervention studies (RCT, study protocol only, observational studies), secondary analysis studies (population data, administrative data sets, file audit/ document review, literature review (systematic review, narrative review), measure development studies, questionnaire studies, qualitative studies, mixed methods investigation, policy analysis, legal analysis, historical analysis, media/creative arts/ cultural analysis.

The study design/ 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. So for example in the health sector knowledge is
typically scoped according to levels of evidence with standardized systems for example in relation to

**Intervention studies** were represented by *randomized controlled trials* (RCTs), study protocols only, and observational studies. Randomised controlled trials 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 utilizing 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 utilizing population data or administrative data sets or file audit/document review. The studies utilizing *population data* were of two types: those using data from national or state based studies with representative sampling frames such as the Survey of Disability, Ageing and Carers and those utilizing population data sets from specific subpopulations typically in relation to a diagnostic group such as for example, Rett Syndrome. The studies that utilized *administrative data sets* included data sets from Federal and State jurisdictions predominantly from the health sector but also including disability and disability services, welfare, education and justice administrative data sets. A subset of these studies primarily from Western Australia involved secondary analysis of linked data from multiple administrative data sets. The third 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 organization 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 data bases 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 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 institutionalization, 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 sterilization 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.
Coding by environmental/ contextual factors

Documents that specifically addressed any one or more of the following were coded in line with the four inter-linked quadrants in the Conceptual Framework as legislation and policy, physical environment, attitudes/ disability identity, and products and technology.
Attachment 4 Narrative Analysis

This attachment contains detailed findings from the narrative analysis undertaken by members of the Research Team on topics of particular interest. These 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 population data
- Research from Australian Institute of Health and Welfare, Australian Bureau of Statistics and Productivity Commission

Aboriginal and Torres Strait Islander research

This narrative analysis was undertaken by Dr John Gilroy who accessed all included documents in the scientific and grey literature which specifically addressed Aboriginal and Torres Strait Islander peoples. It is possibly the case that Aboriginal and Torres Strait Islander people were also included in other studies as part of study design and sampling. Thus there is potentially more research conducted which includes Aboriginal and Torres Strait Islander peoples. First, analysis of the documents from the scientific literature is presented followed by analysis of documents from the grey literature.

Grouping of documents and topics investigated

The 39 papers identified in the scientific literature specifically addressing Aboriginal and Torres Strait Islander peoples are grouped by disability types. Intellectual, cognitive disability and developmental disability were the most common disability types. These studies have helped bring to light the prevalence of these impairments within the Aboriginal population. In particular, AIHW’s analysis of the NATSISS data and Glasson et-al study using the Western Australian Government databases have painted a statistical picture of the prevalence of intellectual disability within the population of Aboriginal and Torres Strait Islander peoples\(^1,2\).

Sensory disability is the second most common disability type researched\(^3\text{--}10\). Much of this research has focused on the education and learning outcomes and experiences of children and young people with hearing impairments. Only one study\(^3\) focused on visual impairments. Expectedly, the hearing impairment research was primarily focused on hearing loss from otitis media and its impact on education outcomes of children and young people. The studies provided evidence of some successful culturally competent approaches to diagnose and support children with hearing loss\(^4,5\).

A surprising finding is the limited emphasis placed on acquired disability, such as ABI. Data shows that ABI is one of the leading acquired disability types, with alcohol and substance misuse being one of the leading...
causes. There was only one publication on ABI\textsuperscript{11} and two on stroke\textsuperscript{12, 13} and cognitive impairment. These studies on acquired disability provide evidence of the need to identify strategies to improve access to culturally competent services for Aboriginal and Torres Strait Islander people with acquired disabilities.

There has been a strong emphasis on children with disabilities\textsuperscript{5-11, 14-17} over recent years. The literature provides evidence on ways to improve the education and learning outcomes of Aboriginal and Torres Strait Islander children with disabilities. Graham’s study\textsuperscript{16} on the representation of Aboriginal and Torres Strait Islander in “special schools” in NSW has identified some factors that lead to the over-representation of this group in special education. Some studies\textsuperscript{18} have provided evidence on the characteristics of disadvantaged children. The emphasis on appropriate assessment and screening tools and approaches will help improve the level and types of in-school supports for children with disabilities. This collection of research has shed some light on the challenges ahead for the NDIS and the Closing the Gap (CTG) in improving support and services for children with disabilities.

There have been a small number of critical literature analyses and reviews focusing on Aboriginal and Torres Strait Islander people’s disability service participation\textsuperscript{14, 19-22}. Gilroy\textsuperscript{20} and Hollinsworth\textsuperscript{21} provide critical historical analysis of disability in Aboriginal and Torres Strait Islander communities to help understand how disability is contextualised at the cultural interface between Aboriginal and non-Aboriginal communities. The literature reviews\textsuperscript{15, 22} on barriers to accessing disability services have identified many factors that influence the participation rates of Aboriginal and Torres Strait Islander peoples and provide suggested solutions to overcome these barriers.

Data have been collected and analysed through \textit{existing datasets} (such as NATSISS) and \textit{qualitative research}\textsuperscript{1, 2, 13, 17, 18, 23}. It is encouraging to see many researchers opting to analyse existing data sets. Utilising existing data sets, where possible, reduces \textit{consultation burnout} in the population of Aboriginal and Torres Strait Islander peoples. The NATSISS data \textsuperscript{1, 23, 24} was the most frequently used data set. Interestingly, it was only used to explore the prevalence of ID and employment of Aboriginal and Torres Strait Islander people with a disability or health condition. Other papers \textsuperscript{13, 17, 23} utilised existing datasets in the criminal justice, education and health sectors.

Qualitative methods were the most commonly used approach to data collection, accounting for over a third of all the studies on Aboriginal and Torres Strait Islander peoples in the scientific literature. Interviews and focus groups with Aboriginal and Torres Strait Islander people with a disability, their communities and disability service staff were the most common methods adopted. Qualitative researchers have recruited Aboriginal people or Aboriginal community controlled organisations to facilitate the interviews and focus groups. These studies contribute to empowering Aboriginal and Torres Strait Islander people with a disability by allowing them to voice their experiences as a person with a disability. For example, Armstrong’s study on people who have experienced a disability resulting from a stroke presents the stories of men living with aphasia\textsuperscript{25}.
**Contribution of this body of literature**

The recent research \^[8, 26-28]\(^\text{\textsuperscript{0}}\) on diagnostic assessment and screening is of primary importance. Such research will help specialists and practitioners develop culturally appropriate approaches to improve diagnosis and screening of disabilities for Aboriginal and Torres Strait Islander peoples. There is widespread concern in many sectors including family support and care and protection of the application of potentially culturally inappropriate assessment practices and diagnostic tools. For example, D’Aprano\(^\text{\textsuperscript{26}}\) concluded in his study of a screening tool for developmental disability that “language and cultural relevance, and the method of administration limit the use of this screening tool. However, we cannot ignore the uniformly poor performance on a mainstream tool used with children expected to succeed in a mainstream educational setting” (p.1). This research direction is quite recent with little opportunity to identify whether these endeavours are having an impact at the level policy and practice.

Given the previously limited focus on intellectual disability in Aboriginal and Torres Strait Islander peoples, the current growth in emphasis on intellectual disability, cognitive impairments and developmental delay is highly valuable. In particular, some of the research\^[2, 8, 26, 27]\(^\text{\textsuperscript{0}}\) on culturally appropriate assessment and screening tools will assist in developing a shared understanding of disability between Aboriginal and Torres Strait Islander communities and the services sector. Developing culturally competent assessment and screening models will also improve understanding on the prevalence and incidence of disability within the population.

The work on quantifying the prevalence of disability types in Aboriginal and Torres Strait Islander communities and their engagement with the disability services sector is of significance. The scientific literature, coupled with the works published by the ABS and AIHW, all contribute to the profile on disability in Aboriginal and Torres Strait Islander communities.

The research on supports and services for people with a disability will contribute to developing a culturally responsive service system for Aboriginal and Torres Strait Islander peoples. The research has not only identified some service participation barriers but has also identified successful strategies to overcome these barriers \^[4, 15, 21, 29, 30]\(^\text{\textsuperscript{0}}\). Some of the publications have voiced Aboriginal and Torres Strait Islander people with a disability and their communities’ lived experiences in accessing services and supports. The research on children with a disability will assist in achieving the objectives of the CTG. Identifying and addressing vocational barriers for Aboriginal and Torres Strait Islander children will help improve the employment opportunities of Aboriginal children later in life.

Overall the research has the potential to contribute to knowledge in four areas. The first is on improving assessment and diagnosis of disability within Aboriginal and Torres Strait Islander communities. This is a much needed area, given that many traditional approaches to diagnosis and screening are established on Western pathological standpoints. Second, there is increasing research aimed at identifying and
addressing barriers to service participation. Third, there is a recurrent theme where researchers are aiming to help establish a culturally responsive service system for Aboriginal and Torres Strait Islander peoples. The concepts ‘cultural appropriateness’ and ‘cultural competence’ are well rehearsed specifically referring to the barriers and challenges faced by Aboriginal and Torres Strait Islander people in accessing disability services. Fourth, the research on improving education and learning outcomes for Aboriginal and Torres Strait Islander people with a disability will provide the foundation to address disadvantage in Aboriginal and Torres Strait Islander communities. In particular, this research will assist the government to achieve the objectives set out under CTG.

Gaps, limitations and ways forward

It is disappointing to unearth the limitations of the evidence base on disability and Aboriginal and Torres Strait Islander peoples. The quantity of scientific research that specifically addresses Aboriginal and Torres Strait Islander is in direct contrast to the inclusion of multiple strategies in the NDIS, the NDS and the CTG to address the high levels of unmet need for people with disability within the Aboriginal and Torres Strait Islander population. Achieving these strategies requires quality trustworthy research that involves Aboriginal and Torres Strait Islander peoples and relevant stakeholders.

As noted earlier, there has been a strong focus on sensory, intellectual, developmental and cognitive disabilities. It is disappointing to note that despite the increase in funding for disability services across the board, there has been limited research emphasis placed on other disability types. The prevalence of disability in the population of Aboriginal and Torres Strait Islander population is around twice that of the non-Indigenous population. Furthermore, Aboriginal and Torres Strait Islander people are amongst the most disadvantaged and unhealthiest populations in Australia [31].

Fundamental to examining the quality of evidence on disability and Aboriginal and Torres Strait Islander peoples is invoking the value embedded in Australian governance and policy documents of opportunity to participate in decisions which affect their lives. To achieve this researchers need to work in participatory ways and directly with Aboriginal and Torres Strait Islander people and Aboriginal community controlled organisations. Only a few studies [15, 25] mention collaborative processes with agencies or peoples. Armstrong[25] reported that the data “were collected by an Indigenous researcher” and Digiacomo et al.[15] reported that “two community forums ... were held at an Aboriginal Community Controlled Health Service”. This finding demonstrates a need to improve awareness within the disability studies academy and to further develop the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e52.pdf). At a foundation level this requires researchers to engage with Aboriginal and Torres Strait Islander communities in the planning and implementation of culturally appropriate research as also referenced in the Agenda.
A collaborative approach between Aboriginal and Torres Strait Islander peoples and governments and research institutions is needed to achieve the objectives set out under the Agenda. Such an approach will ensure that the research is undertaken with local Aboriginal and Torres Strait Islander people with a disability and their communities. Furthermore, this approach will assist in establishing a shared understanding of disability and a culturally responsive service system. The First Peoples Disability Network, led by Dr John Gilroy (a Koori from the Yuin Nation), is currently developing a national network of Aboriginal disability researchers. This network consists of Aboriginal and non-Aboriginal researchers, research institutions and disability and Aboriginal peak bodies. This network could be used as a collaborative mechanism to increase the quantity of research in this field as well as developing guidelines and processes for culturally appropriate and relevant research for all disability researchers.

Grey literature

Similar to the scientific literature, the Audit found limited research focus on Aboriginal and Torres Strait Islander in the grey literature with only 26 publications. Of the 26 publications, 14 were statistical reports published by AIHW, ABS and the Centre for Aboriginal Economic Research.

Grouping of documents and topics investigated

The work undertaken (14 publications) to establish a statistical picture of the population of Aboriginal and Torres Strait Islander people with a disability in Australia has quantified the prevalence and incidence of disability. These reports also report contextual factors such as socio-economic disadvantage and environmental circumstances of people with a disability in Aboriginal and Torres Strait Islander communities. Many of these publications utilised the NATSISS surveys undertaken over the last few decades. These publications are highly sourced and referenced in this field. There was one audit, funded under the Australian Government’s recent Practical Design Fund scheme, on the prevalence of disability undertaken by the MJD Foundation[32] in the top end of the Northern Territory. The study provided a statistical snap-shot of disability in Aboriginal communities and the challenges they face in accessing services.

Surprisingly there has been limited focus on the diversity of disability types. Contrary to the scientific literature, ABI was the only disability-type specific research undertaken with Bohanna[33] and Burton[34] focusing on identifying culturally appropriate assessment and screening tools for local Aboriginal peoples. Similar to the scientific literature, there was a strong focus on children and young people with a disability[35-37]. These studies discuss the challenges Aboriginal and Torres Strait Islander people with a disability face in accessing services and supports to live independently on Country. Bell and Libesman[35] study provides an international critical literature review on child protection matters for Indigenous people with a disability.
Some of the publications \cite{35, 38, 39} and the works from AIHW/ABS \cite{40-49} in the grey Literature are general studies that have either made conclusions that impact on people with a disability or have included people with a disability within their scope. Disability was often included in the definition of “risk factors” for disadvantage.

Similar to the scientific literature, the grey literature \cite{50-53} included research on establishing a culturally competent disability services system. This research identifies solutions to establish a disability services system that is responsive to the cultural needs of Aboriginal and Torres Strait Islander people with a disability. For example, National Disability Services \cite{54, 55} has provided examples of ways to increase the number and representation of Aboriginal workers in the disability services workforce as a means to make a culturally competent disability service.

**Contribution of this body of literature**

The works undertaken by AIHW and the ABS are highly important to determine the nature and environment of disability in the Aboriginal and Torres Strait Islander populations. More statistical work is needed particularly in relation to rural and remote regions. The statistical work has informed a large proportion of sources obtained under this Audit.

The reports on establishing a culturally competent disability services sector will be useful to informing the development of the NDIS. Many of the reported service access barriers were related to differences in cultural and environmental approaches and behaviours between service providers and local Aboriginal peoples. Implementing effective approaches and models of cultural competence, such as recruitment of Aboriginal people into the workforce, are proven to improve Aboriginal and Torres Strait Islander service participation rates.

Similar to the scientific literature, the works undertaken on assessment and screening of disability types are a welcomed contribution. Improving the number and types of culturally appropriate assessment and screening tools for Aboriginal and Torres Strait Islander will help establish a shared understanding of disability.

**Relevance to current policy context**

The statistical papers have been referenced in many of the publications produced at government level. It is refreshing to note the strong research focus on cultural competence in disability service provision. This research will help the Australian Government establish a disability service system that is culturally responsive for Aboriginal and Torres Strait Islander peoples.

Some of the research papers presented in the grey literature have involved Aboriginal and Torres Strait Islander peoples in the planning and implement of the project. This is a good sign on how far the practice of research has come to be inclusive of Aboriginal and Torres Strait Islander people with a disability.
However, we cannot conclusively make the statement that this is common place as we only analysed the abstracts of the papers. There has been limited focus on carers amongst the sources obtained under this Audit. Only one paper [53] emphasised this matter. This is a significant gap in the field.

**Gaps, limitations and ways forward**

There is a lot of research energy going into establishing a statistical profile of Aboriginal and Torres Strait Islander people with disabilities. It is quite surprising that there is limited research, particularly qualitative research, to place these statistics into the reality and lives of Aboriginal and Torres Strait Islander peoples. The Audit highlights the knowledge gap is in respect to people’s everyday lives living with disability. There are several other limitations mentioned here with suggested ways forward.

First, many of the publications in the grey literature have discussed, briefly, that Aboriginal and Torres Strait Islander people were involved in the planning and implementation of the research project. The research/academic community need to work together to establish this as common practice with guidelines developed to ensure quality standards of inclusion practice. Research should be undertaken with people. Research should not be about people or on people or for other people.

Secondly, many of these research papers did not discuss how their findings will be applied in practice. We cannot safely assume that any Aboriginal community has adopted the findings of the research in practice. Research is a means to an end. That end is the implementation of the findings of the research with Aboriginal and Torres Strait Islander communities.

**Ways forward**

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

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37. People with Disability Australia, *Falling Through the Gaps. A Report on Access to HACC Services for Young Aboriginal People with Disability Living in NSW*.
52. Swinburne University of Technology, *Building Culturally Secure Services for Indigenous Australians with a Disability*, 2007, DPRWG
53. Taylor, J., *Practical ways to overcome isolation for Aboriginal and Torres Strait Islander carers: A literature review*, 2013, Carers Australia.
Policy analysis research

This narrative analysis was undertaken by Dr Jennifer Smith-Merry utilising the policy analysis documents from the scientific literature. Policy research which focuses on disability has the potential to put in place high-level strategies and values for the operation of services and other interventions which meet the individual needs of people with a disability.

Introduction to and grouping of documents

The research on policy can be divided into that which primarily reports on data collected to make policy recommendations [1-5], that which critiques current policy [5-47], theoretical work on policy [48-54] and that which comparatively critiques policy approaches used in Australia and overseas [55-71]. Only five papers use empirical data collected specifically for the purposes of analysing or developing policy recommendations [1-5], and one paper draws on data collected for other purposes by the Productivity Commission [72].

The vast majority of the policy research identified aligns in at least some way with the values expressed in the United Nations Convention on the Rights of Persons with Disabilities. However there is a distinct lack of research which utilises the experiences of people with a disability to influence policy development, either through voicing their experience, or through surveys or other data collection methods. Only one paper utilises personal accounts from people with a lived experience of disability [5] as a source of evidence. This significantly limits the utility of research for the development of policy appropriate to the needs of people with a disability as it will likely not address the reality of their situations.

There are no instances where the experiences of those who provide care and services to people with a disability are included in the research. This is also a significant gap as it means that the policy options provided may not match the reality of the needs of carers or those employed in the field. These individuals are in a special position within the field as they come into daily contact with consumers who may be unable to voice their experience through either the nature of their disability or their marginalisation within policy and service networks.

Topics investigated

The research contained in the papers clusters around several topics including the legal context of disability or rights of people with a disability [2, 5, 14, 16, 17, 31, 41, 42, 46, 66], housing [2, 3, 12, 46, 57], education (particularly primary school and vocational education) [5, 7, 14, 17, 19, 25, 43, 47, 54-56, 59, 62, 64, 66, 67, 69], legislative issues related to disability policy [5, 15, 16, 20, 31, 36, 66], employment and ‘workfare’ policies [4, 8, 24, 33, 35, 42, 44, 46, 51, 60, 61, 67, 68, 71], pension rates [6, 8, 18, 24, 32, 36, 41, 53], telecommunications [15, 28-30, 33, 34] and issues related to service funding (particularly purchase-provider arrangements and funding contracts) [12, 40, 51, 52]. It appears that much of this research has been driven by academic interests within disciplines and research centres whose primary interest is not disability, for example social policy, law and education. There is no evidence of research on disability policy which takes health policy, consumer advocacy or service development and
implementation as its starting point. This would reflect the lack of a clear disciplinary ‘home’ for these interests. Policy is by necessity a multidisciplinary research topic and a lack of disciplinary base significantly limits the knowledge base, research personnel and research funding which can be applied to consider the policy issues holistically.

**Contribution of this body of literature**

Several papers provide recommendations for policy change that will lead to improved service provision [14, 16, 35, 36, 57]. This is helpful as a starting point for policy reform, but recommendations are most useful when they have been utilised successfully in other contexts and their impact evaluated through research. A useful approach is that provided in comparative studies of policy settings and practice outcomes which compare Australia and other similar countries (e.g. [57, 58, 60-68, 70, 71]). These will often provide ready made recommendations from settings where policy has been successfully implemented and evaluated.

Several papers examine disability policy from an economic perspective [4, 8, 18, 24, 32, 36, 53, 71]. This is useful although important cost-effectiveness research is missing. Cost-effectiveness research offers policy makers a tool that can be used to argue the effectiveness of programs in a policy environment that tends to favour economic justification above more human-centred outcomes.

Theoretically, where this can be identified, the papers variously critique policy through a focus on neo-liberalism, deprivation, inclusion and dependency (e.g. [50, 51, 53, 54, 60]). This theoretical research may be useful for developing a set of values to underpin the implementation of policy, however is of only limited utility in assisting policy makers in their task of developing policy on a day-to-day basis. In a few instances, disability is only used as a mechanism to critique the operation of the welfare state as a whole – the aim is thus overall policy reform, rather than the specific needs of people with a disability (e.g. [52]).

Purely descriptive research which just describes the policy setting and its practice implications may be useful to practitioners, consumers and activists in assisting them to negotiate the field (e.g. [46, 55]). That research which is least helpful is that which merely critiques current policies without offering recommendations for change (e.g. [48]).

While all of the research contained in the papers may be relevant to some areas of practice, the research which is specifically useful to policy makers is that which can be drawn on quickly for the development of policy ‘on the go’. Information needs to be readily available, clearly written in language accessible to lay readers, present recommendations for policy action and provide data on numbers of cases or examples of effective outcomes from evaluated case studies of policy or service implementation. Practice needs to be understood broadly and policy actors working within government as practitioners in this context.
Impact of this body of literature

Whether this corpus of policy research has led to improved practice outcomes is very difficult to gauge. Despite the many recommendations for policy reform, there are no studies which reflect retrospectively on the results of these recommendations as implemented in practice.

It is worth noting that much of this research is only available from journals which are not open access. This limits the ability of practitioners and consumers to access the research and draw on the findings. Further it is important to note that policy research and analysis per se is not necessarily relevant to policy development, improvement or change. Research that is of most relevance is that which evaluates service models mandated by policy, economic research examining the impact of policy directions and user research which collects the perspectives of consumers, carers or practitioners experiencing particular policy environments and implementation.

Relevance to current policy context

Much of the policy research included in the Audit period is dated and does not address the current policy framework that includes the NDA, NDS, NDIS and Agenda (only 22 papers since 2010). There is only one study that specifically mentions the needs of these policies. That study focuses on the importance of the Productivity Commission’s recommendations for a National Injury Insurance Scheme in relation to individuals living with cerebral palsy ([36]). The ‘datedness’ of the majority of the policy studies identified exemplifies the ‘lag’ context of the scientific literature and the critical importance of policy researchers moving to the open access and on line environment to disseminate their findings in accessible and timely ways. Although other studies may be relevant to the current policy context, particularly those that focus on individualised care packages, only three studies touch on this in passing ([3, 64, 70]). Prince (2011) provides a comparative analysis which includes a discussion of individualised service provision in Australia, Canada, New Zealand and the United Kingdom [70].

Gaps in the research and ways forward

An obvious gap to be filled is the lack of research which draws on the knowledge held by services and practitioners in particular policy environments and uses this to identify areas of innovation which can be incorporated into policy, or barriers for the effective implementation of policy within practice settings. There is no research which specifically links consumer or carer experiences of disability to policy design (either as a source of knowledge for policy or as a reflection of the success of, or problems associated with, a particular policy).

No studies attest to the importance of experiential knowledge for policy formation or give examples about the use of this knowledge to develop policy. The research does not critique or evaluate policy from a consumer perspective as can be found, for example, in the mental health literature. Useful research would collect the experiences of consumers, carers and practitioners in relation to existing policy and
practice interventions and use these experiences to make recommendations about policy development and implementation.

Disappointingly, there were no policy studies identified that provide a thorough evaluation of current or past policy. Policy is critiqued theoretically or practically but this falls short of evaluation and does not provide an effective basis from which to reform policy. There is very little research examining the practice implications of policy innovations. This is a significant gap because the effectiveness of the policy will be measured in how effectively practitioners are able to implement it to meet the needs of their clients. Evaluation is often conducted internally to government, but this is rarely shared publicly as governments and services are reluctant to advertise policy problems. This limits policy learning and encourages the repetition of policy mistakes.

There is little cost-effectiveness research in any of these studies. Policy makers find great utility in cost-effectiveness research as many policy decisions are made or refined by finance departments and value for money is an important factor in decisions about prioritisation.

There is a small amount of policy relevant research which highlights the utility of indicators for policy development and monitoring or investigates those indicators or classification systems which could be used in policy implementation or evaluation (e.g. [37, 38]). There is no research which shows the utility of current indicators for improving system performance or reaching policy goals.

There is only one paper which specifically speaks about indigenous issues related to disability policy [23]. This paper focuses on decision making for indigenous people with impaired decision-making capacity. A lack of research beyond this is obviously a significant gap in the disability policy literature.

Ways forward

- Dedicated funding for research focusing on multidisciplinary approaches to disability policy evaluation
- Funding of disability research to include funds for the dissemination of research in open access journals
- Stimulating the disability research which explores the experience of policy from the perspective of consumers, carers and practitioners
- Stimulating the development of cost-effectiveness research in disability to inform policy
- Stimulating the development of research on monitoring and performance indicators in order to allow for effective evaluation and innovation
- Developing disability policy research which focuses on the needs and experiences of indigenous Australians
Policy analysis references from the scientific literature


Research utilising secondary analysis of administrative data

This narrative analysis was undertaken by Professor Anne Kavanagh accessing the documents from the scientific literature which utilized secondary analysis of administrative data sets.

Introduction and grouping of documents

Analyses of routinely collected administrative data may sometimes be conceived of as sub-standard as the data may not have been collected for the purposes for which the researchers are using it. A particular challenge is that rarely is data on disability collected in a detailed manner, and further the way in which disability is defined typically varies from data set to data set. A further difficulty can be the fidelity with which the data on disability is collected unless there is clear specification and standard rules and forms for data collection. Thus understanding exactly how disability is defined and collected in administrative data sets is important in understanding the contribution to knowledge of research studies using this study design.
That said, administrative data sets may be particularly useful for providing detailed information on the topic of interest; they enable of comparisons between people with and without disabilities; and comparisons between people with different types of disabilities according to demographic characteristics such age, gender, ethnicity and Indigenous status. This information can be relevant to policy and practice as well as addressing questions regarding the causes and effects of different disabilities.

A range of databases were used across different domains in the studies using secondary analysis of administrative data sets. Study designs utilising administrative datasets included cross-sectional studies, time series cross-sectional, longitudinal, case control and intervention studies.

Below is a list of the datasets used and their domains of which most were from the health sector.

1. Health
   a. The WA Hospital Morbidity Dataset
   b. WA midwives notification of births
   c. Cancer registry
   d. Medicare data
   e. Death register
   f. BreastScreen WA data
   g. Victorian Admitted Episode Dataset
   h. Victorian Perinatal Data Collection

2. Disability and disability services
   a. Western Australian Disability Services Commission Register
   b. Victorian State Trauma Registry
   c. Transport Accident Commission Data
   d. Commonwealth/State Disability Agreement Minimum Data Set
   e. Birth defects register WA and Vic
   f. Cerebral palsy WA
   g. National database of Australian Hearing and Records
   h. Health and Community services

3. Welfare
   a. Centrelink data (income support such as DSP)

4. Education
   a. Australian Early Development Index

5. Justice system
a. Police data such as Western Australian Police Services Apprehension record
b. Court system

Topics investigated
Administrative data sets were used in three ways: (i) to describe prevalence and trends over time; (ii) to examine associations and relationships between variables; and (iii) to assess the outcome of an intervention study.

Prevalence and trends over time
Databases were used to describe the prevalence of conditions; an example is the study by Petterson et al. (2005) which describes prevalence and causes of in intellectual disability1. A number of studies used aggregate data on income support payments, specifically the Disability Support Pension (DSP) to describe trends over time (i.e. time series analyses), demographic profile of recipients and patterns of claims (e.g. spells on DSP) (see for example2,3). The Commonwealth/State Disability Agreement Minimum Data Set was used to describe patterns of service use8.

Linkage of databases
Linkage of individual data from a range of databases enabled the capacity to address a range of important questions. Because many of the databases were linked over a period of time this, in effect, created a longitudinal data set which could be examined to ascertain and establish potential causal relationships. Linked individual data were used to address questions about:

Health outcomes: The data sets were linked to health datasets (e.g. deaths) to examine health outcomes among people with particular impairment types. Examples include mortality rates among people who acquired a traumatic brain injury9; comparison of cancer incidence in people with and without intellectual disabilities10 and co-existence of neuropsychiatric and neurodevelopmental conditions11.

Service use: Examples include comparisons of hospitalisation rates among children with and without intellectual disabilities12 and trajectories of human service use and contact with criminal justice system for prisoners with and without cognitive disabilities13.

Relationships between parental characteristics and childhood disability: In Western Australia there was a body of work that linked maternal health with child health outcomes using datasets such as the WA midwives notification of births and the Western Australian Disability Services registers. These linkages offered enormous potential to provide insights into the causal relationships between maternal health and childhood impairments. Examples included the presence of neuropsychiatric disorders (bipolar and unipolar depression and schizophrenia) and neurodevelopmental disorders in offspring13 and the contribution of maternal alcohol disorder to intellectual disability of non-genetic origin15.
Most of the linked data was from two or more health databases with disability (e.g. birth defects) registers. It was unusual for these to be linked to another database. An exception to this is the study conducted by O’Donnell et al. (2010) who linked children protection, health and disability services databases and found that children with intellectual disabilities were more likely to experience maltreatment.¹⁶

**Evaluation of interventions:** In a randomised trial of a health assessment intervention among people with intellectual disability the participants’ data was matched to Medicare care records to assess service use.¹⁷

**Contribution of this body of literature**

In summary, the linkage of datasets offered many fruitful avenues of enquiry. These studies were most often found in Western Australia and, again, were predominantly in the health area. Western Australia has the well-established Western Australia Data Linkage Unit which provides the necessary infrastructure for this work and covers a range of health and social services data sets - [http://www.datalinkage-wa.org/data-linkage/data-collections](http://www.datalinkage-wa.org/data-linkage/data-collections).

It is notable that much of the research was from Western Australia. Much of the research from Western Australia using linked data was published in top tier journals indicated both the scientific quality and value of WA system. It is also notable that WA has a number of relevant disability registers; the Disability Service Commissioner database for Intellectual Disability has existed since 1953 and the Telethon Kids Institute had now established the Intellectual disability exploring answers (IDEA database [http://telethonkids.org.au/our-research/projects-index/i/idea-intellectual-disability-exploring-answers.aspx](http://telethonkids.org.au/our-research/projects-index/i/idea-intellectual-disability-exploring-answers.aspx)) which receive information on intellectual disability from the Disability Services Commissioner and the Department of Education in Western Australia. From an academic’s perspective, most of these papers were published in peer-reviewed journals however most of these were in lower impact Australian journals with the exception of those that use the linked data.

The secondary analysis of administrative data sets offers a useful contribution by providing an important picture of the extent of the problems experienced by people with disabilities. Currently this focuses primarily on health with other domains covered less extensively.

**Gaps and ways forward**

While these contributions are important the potential of secondary data has perhaps not been fully realised. This may be for a number of reasons including: the lack of knowledge of the data by researchers, the tendency for researchers to work within their own silos (e.g. health, justice), privacy provisions preventing access and linkage of data, lack of quality data on disabilities collected in standard datasets such as ABS surveys, and the lack of comparative data for people without disabilities. The last point pertains to the Survey of Disability, Ageing and Carers which collects detailed information on people with disabilities.
disabilities and carers but collects a limited suite of data on people without disabilities. This means that there is not the capacity to make comparisons between people with and without disabilities. This is important in understanding the relative inequalities that people with disabilities experience.

Administrative datasets have the potential to address many of the key foci of the Agenda including a greater understanding of the experiences of particular groups with disabilities (women, Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse groups, and people in regional, rural and remote areas). The data is also critical to describing demographic profile and trend information, including access to social and economic inclusion data. However, given the limitations of the datasets described above and the lack of linkage of data this potential is not being realised.

Most of research on disability does not present results separately according to sex (male/female) yet while the overall prevalence of disabilities is similar for males and females the prevalence of different types of impairments vary. In addition, the potential effects of having a disability, such as the social and economic conditions in which people with a disability live, may be different for males and females. For example in the summary report from the 2012 SDAC survey the findings were only disaggregated by sex for the overall prevalence of disability and labour force participation (http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4430.0Main%20Features120127).

Reporting these sex differences is critical in developing gender-specific strategies to improve the living conditions of girls/women and boys/men living with a disability and has been recommended in key policies and strategies including the National Disability Strategy, the World Report on Disability and the World Health Assembly resolution on disability.

Other points worth noting in relation to gaps in this type of investigations are first, the minimal research on the experiences of children and young people with disabilities perhaps due to the absence of data on this age group. The exception to this is the work in Western Australia on the causes, co-morbidities and service use of children with intellectual disabilities.

Second, few of the studies make gender comparisons and very few detail the experiences of Indigenous people with disabilities. There is an urgent need for more data on young people with disability and on priority groups such Aboriginal and Torres Strait Islander people with disabilities. There were no studies that concentrated on the needs of culturally and linguistically diverse groups or people living in regional, rural and remote areas.

Third, it is notable that this type of secondary data analysis tends to occur in isolation of DPOs however DPOs are often reliant on this data for advocacy, policy development and service delivery.
Fourth, none of the studies addressed issues of violence which perhaps is not surprising given the fact that until last year the ABS Personal Survey did not collect information on disability. This demonstrates the critical importance of the inclusion of questions on disability in all routine surveys.

Finally, while secondary data may not include all the information of interest, it is currently the only way to be able to obtain data on large samples enabling more fine grained analyses and it is important that it continue to be used in that way. There is no dataset currently available in Australia that enables questions to be asked about the multiple and interacting domains of people’s lives (e.g. health, housing, employment) and over their life course. Importantly, no dataset enables comparisons to be made between people with and without disabilities across these multiple domains and over time. Without the capacity to understand the experiences of people with disability longitudinally and over the life course and to compare these to people without disability; without this data we are unable to answer critical questions for both people with disability and society more broadly about how current life experiences, investments, services and so forth influence future health and social and economic wellbeing outcomes for people with disability.

Ways forward

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

17. Gordon Louisa G, Holden L, Ware Robert S, Taylor Miriam T, Lennox N. Comprehensive health assessments for adults with intellectual disability living in the community: Weighing up the costs and benefits. *Australian Family Physician* 2012;41:969-72

Research utilising secondary analysis of population data

This narrative analysis was undertaken by Professor Eric Emerson accessing the documents from the scientific literature which utilized secondary analysis of a wide range of existing population data to answer an extremely diverse set of research questions.

Introduction to and grouping of documents

The majority of research used data from just four datasets:

- The Survey of Disability Ageing and Carers;[73-83]
• The National Survey of Mental Health and Wellbeing,\textsuperscript{84-97}

• The Longitudinal Study of Australian Children,\textsuperscript{98-109}

• The annual Household Income and Labour Dynamics in Australia survey.\textsuperscript{110-117}

Other data sets used in secondary analysis included: the Australian Longitudinal Study on Women’s Health also known as Women’s Health Australia,\textsuperscript{128}[118, 119] the National Aboriginal and Torres Strait Islander Social Survey;\textsuperscript{120, 121} the Australian Time Use survey;\textsuperscript{122, 123} the Census;\textsuperscript{124} the Families Caring for a Person with a Disability Survey;\textsuperscript{125} the Household Expenditure Survey;\textsuperscript{126} the National Health Survey;\textsuperscript{127} the New South Wales Health Survey;\textsuperscript{129} the 45 and Up Study;\textsuperscript{130} the Health of Young Victorians Study;\textsuperscript{131} and the TAFE Student Outcomes Survey.\textsuperscript{132} A number of other population-based datasets contain information on people with disabilities in Australia, but were not used by researchers within the Audit timeframe. These include: the Longitudinal Study of Indigenous Children; the Longitudinal Study of Australian Youth; and the General Social Survey.

**Topics investigated**

The topics covered and research questions asked using these population data sets were extremely diverse. A significant body of research addressed the overall prevalence of disability (especially mental health problems)\textsuperscript{75, 82, 88-91, 93-95, 105, 117, 120, 133} and the prevalence of disability among sub-groups of particular interest (e.g., ATSI, rural, men/women, income support recipients, single parents).\textsuperscript{75, 82, 84, 110, 117, 120, 130}

Secondary analysis was also used by a range of studies that investigated the association between disability and indicators of health/wellbeing,\textsuperscript{80, 102, 105-109, 113-116, 120, 128, 131, 134} and the association between disability and broad social determinants of health/wellbeing (e.g., income, housing, education, violence and especially employment)\textsuperscript{74-76, 78, 79, 83, 85, 86, 88, 96, 97, 101, 102, 106, 107, 109, 112, 116, 120, 121, 124, 127, 128, 132, 134-144} including among sub-groups of particular interest (e.g., ATSI, rural, men/women, CALD).\textsuperscript{112, 120, 128, 129, 134, 137, 138}

Other research topics included: the costs of disability,\textsuperscript{126} the association between disability and access to healthcare,\textsuperscript{128} the association between disability and service utilisation/need,\textsuperscript{81, 87, 92, 129, 145}; barriers to workforce participation;\textsuperscript{73, 76, 112} the association between disability and social participation;\textsuperscript{134, 137, 146-148}; patterns of informal caring;\textsuperscript{77, 98, 111, 118, 125, 149-151}; the association between informal caring and economic\textsuperscript{77, 98, 104, 111, 118, 123, 125, 149, 152} and social participation\textsuperscript{104, 122} and carer wellbeing,\textsuperscript{103, 104, 119, 153, 154} characteristics of educational provision of children with disabilities,\textsuperscript{99, 100} and community attitudes towards people with disabilities.\textsuperscript{155}
Contribution of this body of literature

The fundamental contribution of this suite of secondary analysis studies is their diversity and the range of valuable information on the social context experienced by people with disabilities in Australia and of informal carers. This is particularly useful as descriptive information in relation to either people with disabilities as a (homogenous) group\textsuperscript{[73, 75, 76, 79, 98, 105, 112-116, 126-128, 130, 134, 137, 149]} or specific impairment groups such as people with mental health problems,\textsuperscript{[77, 78, 84-95, 110, 117, 129, 135, 136, 139-144, 147, 148, 156]} people with intellectual disability,\textsuperscript{[82, 102, 107, 120]} people with hearing impairment,\textsuperscript{[74, 80, 108, 124, 131, 157]} visual impairment,\textsuperscript{[133]} communication impairment,\textsuperscript{[109]} neurodegenerative disease\textsuperscript{[150]}.

Information on the prevalence of disability can be used to evaluate the ‘reach’ of disability services and can be used to track changes in the nature and patterning of ‘need’ within the Australian population. Information on changes in the social context experienced by people with disabilities in Australia can be used to monitor progress and provides valuable information on the broader social context within which disability policies are implemented.

It is important to keep in mind, however, three important limitations regarding the information contained in these studies.

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,\textsuperscript{[158]} there is an important gap in knowledge at a population level about people with disabilities who are disability service users and for the most part likely to be participants in the NDIS.

Second, many of the population data sets 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 The Longitudinal Study of Australian Children and the annual Household Income and Labour Dynamics in Australia survey opens up new possibilities for policy relevant research. It is disappointing therefore that other potentially valuable longitudinal datasets (e.g., the Longitudinal Study of Indigenous Children and the 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. As a result, they cannot contribute to further knowledge on some key issues (e.g., the extent to which people with disabilities in Australia are exposed to disability related
discrimination and the impact this may have on their wellbeing). The development of a longitudinal disability-specific survey in the UK (the Life Opportunities Survey) has proven extremely valuable in contributing to the development of policy relevant evidence, and pilot work has already been undertaken to develop a similar survey in Australia.

In conclusion, there exists a robust 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 and the social conditions under which Australians with disability are living, knowledge that is fundamental to formulating and implementing disability policy. The implementation of the above recommendations would significantly strengthen the further development of policy-relevant evidence.

**Ways forward**

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

- Stimulating the use by disability researchers of available longitudinal datasets.

- Further development of a longitudinal disability-specific survey in Australia.

**References**


130. Gubhaju, L., et al., The overall health and risk factor profile of Australian Aboriginal and Torres Strait Islander participants from the 45 and up study. BMC Public Health, 2013. 13.

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

This narrative analysis was undertaken by Ros Madden on the 115 publications of official statistics, chiefly of the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of statistics (ABS). There are a small number of related official publications, for instance by the Productivity Commission. The reference list here identifies these publications. However, because of the non-standard and basic classification approaches used in some data bases (as noted in the section on Grey Literature - Search Strategies and Results in Attachment 2 Search Strategies and Results); the list does not always use the recommended citation for the publication. This results in citations which attribute authorship to names found early in the document, thus sometimes leading to erroneous or misleading citations. Currently there is no one simple way when comprehensively searching the literature to avoid these inconsistencies.

Introduction to and grouping of documents

Australian population data on disability come from three main ABS sources: the specialised Survey of Disability, Ageing and Carers (SDAC)¹ which has been carried out regularly since 1981; the Census (since 2006); and a range of social surveys which have a disability module – enabling understanding of people and households with disability in comparison with the general population, in relation to their health, housing, income and expenditure, time use and more².
The AIHW and the ABS have both carried out extensive analyses of ABS sources, focussing in turn on topics considered to be of social or policy interest (as is described in the following). There are other useful sources of population data on functioning and disability some of particular interest because of their longitudinal information.

Australian national data on services are collated, analysed and published chiefly by the AIHW. Some national data on other services and assistance, e.g. relating to income support and disability employment, can be found on Australian government web sites and are also used for secondary analysis by researchers.

The AIHW biennial publications – *Australia’s welfare* and *Australia’s health* – are mandated to be prepared and presented to Parliament, and represent comprehensive biennial summaries of population and services data reflecting the health and welfare status of the population, their needs, risks, outcomes and services provided. As the wide range of national statistical sources used mature, these analyses can also include long term trend data.

The ABS series on *Australian social trends* takes a broad approach in examining a wide range of topics about Australian life, with disability one of the factors included.

In recent years there have been more AIHW publications on indicators, some agreed by national committees (e.g. on children and some informing and monitoring national frameworks and funding agreements (e.g. on the Aboriginal and Torres Strait Islander health performance framework and on disability services). The inclusion of a number of reports on ‘health’ and ‘health performance’ in the retrieved literature indicates a distinction that can be made in these official statistics. There are many analyses focused entirely on disability and the disability experience; there are others which are focussed on ‘population health’ and often include disability briefly as just an indicator of a ‘health outcomes’ or ‘health status.

Many of these documents, whether relating principally to disability or including disability as one among many indicators, are essentially statistical outputs; commentary included usually takes the form of explanation of content (in the Australian disability context) and interpretation is focused on statistical interpretation and technical information. This reflects the mandate of the ABS and AIHW: they produce socially and policy relevant documents, sometimes policy or service evaluation but not policy advisory documents.

The Productivity Commission, in reporting for senior national intergovernmental committees on a wide range of states and national government services, makes extensive use of ABS and AIHW sources and analyses.
Because of their mandated responsibilities for official statistics, both the AIHW and the ABS also produce reports and initiatives on data standards, data quality and data development. They and the Productivity Commission recognise the value and additional analytical power that is obtained when national and international data standards such as the ICF are used to promote data quality and consistency across place, time, and sector. Similar efforts in the wider research community would reap similar rewards; some basic conceptual consistency across disability data sets would improve the national data suite and accordingly the understanding of disability.

**Topics investigated**

From the array of national data outlined above, the ABS and AIHW produce publications of varying focus and with varied multi-factored analyses.

Disability prevalence is disaggregated by ‘type ’of disability (often according to ‘main disabling condition’). The implications of multiple disabilities and the related needs for assistance have been explored. Demographic analyses include childhood disability, age and ageing, and geographic location. Disability is also considered alongside other factors such as health, the use of health services, the need for therapy or equipment, or the use of aids and the role of environmental factors broadly. Indigenous disability is an important topic on which data have improved in the last decade; these data have been reported in specific publications, and as part of broader publications. A milestone was the first official estimate of Aboriginal disability – over twice the rate of that of other Australians - in the joint ABS-AIHW biennial report on the health and welfare of Aboriginal and Torres Strait Islander people.

Participation by people with disabilities is explored – sometimes attempting to use all domains of the ICF, sometimes focusing on one area such as education, employment, communication or sport. People’s needs for assistance in activities and participation are regular features of ABS and AIHW disability publications, and also an occasional topic for a specific publication. Analyses which inquire into disability and disadvantage may find indications of multiple disadvantage, for instance, the use of homelessness services by people with disability.

Disability services data include a range of information on the person receiving services (age, sex, location, living arrangements, carers, income sources, main disabilities) and also on services and supports received. Innovative services at the borders of aged care have been evaluated and unmet need for disability support services estimated.

The importance of informal care is reflected in several publications of the ABS and the AIHW, as well as being a regular inclusion in the biennial AIHW reports.
Where series are long enough, prevalence trends have been analysed\(^75\) and future scenarios of informal care modelled\(^76\).

Data in expenditure on disability is regularly reported, for instance in the AIHW ‘welfare expenditure’ series\(^77, 78, 79, 80\), as well as in the biennial reports.

**Contribution of this body of literature**

To the extent that people with disability wish to see their experiences reflected in the national statistical picture, the documents have value. To be useful to people with disability it could be inferred that they should be: *relevant and applicable* to the broad rights-based approach of the UNCRPD (and key Australian policy documents such as the NDIS which are consistent with it); and *accessible for use* by people with disability. Given that ABS and AIHW make their publications freely available on the web, there is reasonable accessibility of all documents (leaving aside any accessibility improvements needed on their websites). The rest of this discussion will accordingly focus on relevance and applicability of the outputs in the context of the UNCRPD and the NDIS, first indicating positive aspects of the ABS and AIHW publications.

The use of the ICF as a framework for examining disability is relevant to UNCRPD because of ICF’s emphasis on participation and its recognition of the role of environment. Thus the use of the ICF by ABS and AIHW is a good start to providing data capable of monitoring people’s participation in all areas of life, as mandated by UNCRPD. That the ABS SDAC\(^1\) can support analyses of people’s participation across many areas of life was illustrated in an AIHW 2005 analysis\(^5\); the analysis showed it is possible to say something about all ICF domains of activities and participation (despite some limitations of the data). A full use of the ICF model was used in a detailed analysis of several surveys in ‘Disability and its relationship to health conditions and other factors’\(^55\). Recognition of the role of *environment* in disability creation was also reflected in the publication of a special AIHW analysis on ‘Disability: the use of aids and the role of the environment’\(^58\).

Other important developments and contributions include: (i) public lobbying, including by DPOs, led to the *inclusion of a disability question* in the Australian Census in 2006; (ii) the national data enabled *estimation of unmet need* for disability services\(^73\) and of the *costs* of the proposed NDIS (Productivity Commission and others); (ii) *analyses of social surveys* enabled the exploration of health of people with disabilities\(^56\), their education, labour force participation and sport\(^61, 62, 63, 65\). (iii) *multiple disability* and associated difficulties and disadvantages have been examined\(^49\); (iv) *diversity of disability* has been recognised with the definitions of major disability groups developed in consultation with DPOs used in the national disability services collection and for AIHW analyses of disability prevalence (e.g. the definition and prevalence series and updates\(^44, 45, 46, 75\)); (v) disability has also been examined in relation to *particular health conditions* e.g. juvenile arthritis\(^47\), or *particular participation restrictions* e.g.
communication; (vi) disability in particular population groups is the subject of other publications e.g. Aboriginal and Torres Strait Islander peoples, children; (vii) ‘Geography of disability and economic disadvantage’ was the topic of another AIHW analysis.

Regular attention to disability and disability services is maintained in the AIHW biennial reports (Australia’s Welfare series). The regular chapter on ‘disability and disability services’ contains: policy overviews to describe the context of the data; disability prevalence, the profile of the relevant population and their needs; the services received; informal care; and outcomes (e.g. social and economic participation). Over the years they have covered Indigenous disability, population trends, service trends; and have analysed other social surveys e.g. income and expenditure, housing, time use, to indicate outcomes and disadvantage of people with disability.

Impact of literature

Traditionally it is considered that national statistics are essential infrastructure for an informed, democratic society (e.g. UN Principles of Official Statistics). However statistical reports do not themselves point to their own direct relationship to specific improved outcomes. To establish this relationship the application and frequency of their use would need to be explored, for instance by examining citations of such general resources in policy or service development documents. Nevertheless there are sound reasons for the critical contribution that national statistics on disability deliver for knowledge and also for researchers in the field. Some relevant examples of contribution of Australian national disability statistics follow:

- source data for estimation of unmet need for disability support services (AIHW) and for estimation by the Productivity Commission of NDIS costs.
- cited in the World Report on Disability which is being used worldwide as evidence of disadvantage and the need for improvement.
- first national estimates of Indigenous disability which represent a key step in acknowledging the extent of disadvantage in this area, and planning for improvement (as such figures have been used in the health field).
- Evaluation of the efficacy of targeting and new expenditure under the CSTDA.
- Monitoring of a national program to move or keep younger people with disability out of residential aged care could be carried out based on existing frameworks.
Relevance to current policy context

For national data to be relevant to key current policies – the NDA, NDS, NDIS and the Agenda – themselves making reference to the UNCRPD - two mechanisms are needed: the first is that the documents are relevant and applicable to the broad rights-based approach of the UNCRPD and these key Australian policy documents which are consistent with it; the second that the documents are accessible for use by policy makers and stakeholders.

A robust contribution of the Australian national statistics collection and analysis approach is that ABS and AIHW make their publications freely available on the web [http://www.abs.gov.au/ and http://www.aihw.gov.au/]. Thus there is reasonable accessibility of all documents (leaving aside any accessibility improvements needed on their websites).

The relevance and applicability of the ABS and AIHW publications can be gauged by the preceding outlines of their contents of national data collections and the nature of their analyses. Relevance to is evidenced, for instance, by:

- the analyses of participation by people with disability broadly in Australian society (many examples previously discussed) as envisioned by national policies
- recognition of the role of environment in disability creation, which was reflected in e.g. publication of a special AIHW analysis on ‘Disability: the use of aids and the role of the environment’
- detailed analysis of several surveys – in ‘Disability and its relationship to health conditions and other factors’ – relevant to the health/disability interface.

The ABS SDAC was considered useful by national administrators for planning purposes and they accordingly funded higher frequency of the collection, and bigger sample sizes

Both the ABS and the AIHW have (or have had) advisory and consultative mechanisms including membership of DPOs, and both organisations attempt to respond to multiple stakeholder interests.

Gaps, limitations and ways forward

- Requiring disability researchers to become familiar with these main sources of national data on disability, and consider the value of secondary analysis of them, or of collecting data that can be related to them or the national disability data standards.

The areas where there is room for improvement in the available national data and analyses include:
• In population data there would be benefit in (i) better data on Environmental Factors (e.g. technology, attitudes); (ii) fuller data on participation e.g. use of the national data standard on ‘satisfaction’ with participation, so as to indicate feelings of choice and control in each life area; (iii) continuing effort to improve data on Aboriginal and Torres Straits Islander people, in partnership with Aboriginal researchers and thinkers; and (iv) new effort in analyses of disability and service access among people of culturally and linguistically diverse background – startlingly absent from the data analyses, given their significant presence in the Australian population and the newly available data since the 2006 Census.

• Currently there are inadequate data on the use of mainstream services by people with disability which is an important consideration in relation to the NDIS and the NDA. The ongoing search for a ‘disability identifier’ that can be adopted by mainstream services has not yet not yet successful, despite efforts of AIHW working with policy makers. This is troubling given that administrative data on access to these mainstream services are largely missing. Administrative data currently available from mainstream services can be difficult to access, inconsistent in whether or not information is available on people with disabilities (and with different criteria for evaluating disability). Further discussion on the current limitations of administrative data for research and suggested measures to overcome these is found in the section Secondary Analysis – Administrative Data.

• The disability requirements of the NDIS require 'permanent' impairment and support needs, which may nevertheless ‘vary in intensity’ or be fluctuating or episodic. The term 'permanent' (as distinct from long-term) raises questions. First: some health conditions associated with severe disability (e.g., severe depression, psychosis, PTSD) may be very long term, but may not be lifelong; their subsequent absence does not reflect the fluctuations of underlying 'pathology'. Second, it is not possible to forecast what interventions may become possible in the future, so that requiring sign-off on lifelong prediction may be difficult in many cases. Research on these issues, among people with chronic and fluctuating conditions, would be of value in ‘future proofing’ the NDIS.

• National data require ongoing commitment both to improve them so as to fill gaps, and also to preserve them (and the underlying data standards), so as to ensure the integrity of key long term trend data. With significant changes in the disability field [the NDIS launch, changes at State level and other changes at Commonwealth level], balancing these countervailing commitments requires special attention.
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