Mapping Disability Research in Australia 2018 - 2020

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THE UNIVERSITY OF
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FOREWORD

By the NDRP Research Agenda Oversight Committee

What is the National Disability Research Partnership (NDRP)?

The National Disability Research Partnership has been funded for two years, 2020-2022, by the Commonwealth Department of Social Services to build the case for large-scale ongoing investment in a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice.

The NDRP is guided by five principles: deliver high quality, collaborative research; recognition of the knowledge of people with disability in research; valuing all forms of knowledge; and building research capacity. More details on these principles can be found at this link: **NDRP Principles.**

A **Working Party** which is made up of people with disability, researchers and independent advisors is facilitating the establishment of the NDRP.

At the end of two years the NDRP will have:

1. Developed a national disability research agenda
2. Proposed a governance model to support the long term NDRP
3. A plan for developing disability research capacity in Australia
4. A practical guide to research funded by the NDRP
5. Piloted a research funding round to build the evidence base and to demonstrate and refine NDRP processes.

This report relates to the first of these deliverables – the National Disability Research Agenda.

What is the National Disability Research Agenda?

The disability research agenda is intended to guide research conducted through the NDRP following the conclusion of the establishment phase.

The NDRP went through a competitive tender process and appointed a consortium led by the University of Sydney (co-leads Professors Jen Smith-Merry and Mary-Ann O'Donovan) to develop the research agenda. The large consortium includes academics from across Australia and non-government organisations including Disabled People's and Representative Organisations. The Consortium is conducting a three-stage process to develop the research agenda which includes:

1. Mapping of recent research related to people with disability

2. Consultation with people with disability and their representative organisations; researchers; families and supporters; service providers; government and other stakeholders to identify key issues
3. Refinement of research agenda

This report documents the research mapping exercise, the first phase. This research mapping focussed on research conducted between 2017 and 2020 updating on research audits published in 2014 and updated in 2017.

What did the research mapping involve?

The Consortium conducted a rigorous process to identify the amount and extent of research related to disability in Australia that had been published in academic journals as well as government and community reports. They searched electronic databases to find articles, books and book chapters and reports on research that related to people with disability and that was not laboratory or clinical research. They also asked researchers to send them papers that might have been missed by the search processes.

Consortium members coded all the relevant publications in terms of the age group of participants in the study, domain of life covered (e.g., health and wellbeing, education), disability types (e.g., all people, autism), study design, and funding source. They took a deeper look at studies about Aboriginal and Torres Strait Islander Australians with disability and people with disability from Culturally and Linguistically Diverse backgrounds as well as policy research, studies using large datasets, studies about children and adolescents with disability, and papers that took a rights-based approach.

What did they find?

They identified over 1200 publications about disability research. Their report describes their findings in some detail but from the NDRP's point of view there are some findings we'd like to highlight.

- Only 50 of the publications mentioned lived experience as central to their approach.
- There is a dearth of research that looks at the experiences of people with disability from Culturally and Linguistically Diverse backgrounds
- There has been an increase in the number of publications about Aboriginal and Torres Strait Islander people with disability, some authored by Aboriginal and Torres Strait Islander researchers.
- Only one percent of studies concentrated on people over 65 years indicating a major gap in research on disability and ageing

- Health and wellbeing (19%) and education (10%) were the most common topics of research articles and service development (16%), health and wellbeing (14%), and policy (13%) were the most common among research reports
- Like the current research mapping exercise, 2014 and 2017 audits found that health and wellbeing and education were common topics however the methods to organise topics were different - the current audit coded outputs across 29 topics while the previous audits coded outputs across eight life domains
- Nearly half (47%) of the publications mentioned one or more funding sources with nationally competitive grants (ARC, NHMRC) comprising 30% of all funding sources and government funding such as contracts making up 21% of all funding sources reported. Of note, investments in programs of research (e.g., NHMRC Centre of Research Excellence Scheme; fellowship funding (ARC, NHMRC) and projects that are conducted in partnership (e.g., ARC Linkage) were productive in terms of research outputs.

These findings provide some insights for NDRP, for development of a National Disability Research Agenda, and for the Consortium team in the next stages of their work. First, it is troubling that lived experience and inclusive approaches were so infrequently mentioned. It is possible that some journals do not encourage detailed descriptions of inclusive approaches and so studies may have used inclusive approaches without outlining them in publication, and/or inclusive research is harder to publish in academic journals. Nonetheless this finding suggests that there is a lot that needs to be done to ensure disability research in Australia centres the voices of people with disability, one of the core principles of NDRP.

Second, the findings highlight the need to enhance funding and research capacity in research about specific population groups who are underrepresented, a finding that is consistent with the 2014 and 2017 audit reports. The increase in research about the experiences of Aboriginal and Torres Strait Islander peoples with disability is promising and may in part reflect the emergence of more First Nations researchers with disability, capacity that continues to need investment. Investment in building the capacity of researchers with disability from Culturally and Linguistically Diverse backgrounds may increase research outputs focussing on this group.

Third, nationally competitive funding schemes are critical to building the quantity and quality of disability research. NDRP has a role in advocating for the existing well-known schemes such as ARC and NHMRC to adopt approaches consistent with NDRP principles as well as fostering the uptake of approaches consistent with NDRP principles in all schemes that address research about disability in Australia. In terms of where NDRP invests resources in the future, the findings also demonstrate the importance of larger scale investments in programs of research and in people through fellowships to build a substantive evidence

base rather than focussing on individual and likely to be one-off projects. This is something we will take up in our work on building research capacity.

Where to from here?

This is the first of three reports from the Consortium who are conducting the Research Agenda setting exercise. Two further reports on the consultation and refinement of the research agenda will be released in the coming months. The three reports will form deliverables of the NDRP in the establishment phase.

The NDRP Research Agenda Oversight Committee (in alphabetical order)

Professor Bruce Bonyhady

Ms Tessa de Vries

Professor Helen Dickinson

Professor Anne Kavanagh

Professor Gwynnyth Llewellyn

Executive summary

This mapping report provides a comprehensive picture of the current state of disability research in Australia in the period since the Audit of Disability Research Update Report was published in 2017. We conducted a systematic search of journal articles, book chapters and reports to identify Australian disability research published over the 2018-2020 period. We searched 8 academic databases and searched for research in reports via google. In order to address possible limitations of the search strategy we undertook a secondary process in which we sent the initial list of identified papers to a broad range of stakeholders and asked them to send us the details of papers that may have been missed. Included research papers and research reports met the following criteria:

- At least one aim of the study was related to people with disability.
- The paper reported disability research including Australian participants/topics and results on those participants/topics. This included international comparative studies.
- Was not research that was primarily lab-based and related to genetics, clinical treatment, diagnosis or cure (e.g., surgical, clinical and basic science).
- The results of the paper included conclusions related to people with disability.

Summary of Findings

We identified 1241 journal articles and book chapters (referred to hereafter as 'research papers') and 225 publicly available reports (referred to hereafter as 'research reports') produced over the 2018-2020 period. We undertook a deeper, narrative analysis on key topics. These topics were chosen because they built on the categories used in the original audit reports (Aboriginal and Torres Strait Islander People with disability, policy and secondary use of data), along with areas raised by our consortium as important for understanding the breadth of disability research in Australia (people with disability from culturally and linguistically diverse communities, children and young people, rights-based approaches, and co-research and inclusive research). We also added in an in-depth analysis of funding cited in papers. The in-depth narrative analysis provided the following insights:

- *Aboriginal and Torres Strait Islander research.* There were 75 research papers and 15 research reports relating to Aboriginal or Torres Strait Islander people with disability. A significant proportion of papers were written by Aboriginal and Torres Strait Islander authors. The 2017 Audit, which covered a larger period of time of five years (2013-2017), located only 28 papers that focused on Aboriginal and Torres Strait Islander people with disability (3%), where this mapping located more than double that number over 3 years, at 6% of all research papers identified. There was a concomitant increase in the number of empirical (rather than theoretical or

review-based) research papers and research reports focusing on Aboriginal and Torres Strait Islander people with disability.

- *Culturally and linguistically diverse communities.* There were only 17 research papers and 8 research reports that focused on people from culturally and linguistically diverse communities. This represents only 1.3% of research papers and 3.5% of research reports. This remains a significant gap in disability research in Australia.

- *Policy analysis research.* Policy research has greatly increased inn comparison with the 2017 Audit, which included 56 policy papers (5.9% of overall papers), 119 research papers were identified for the current three-year period (2018-2020) (9.6% of overall papers). There were 43 research reports (20% of research reports) focusing on policy.

- *Co-research and inclusive research.* 50 research papers were identified which specifically included people with lived experience participating in carrying out the project. These comprised first-person auto-ethnographies (n = 10) or took a participatory action (n = 17), or co-research/ inclusive research approach (n = 23).

- *Rights-based approaches* were utilised in 87 research papers and 5 research reports. Twenty-nine research papers specifically structured their paper aims and findings in relation to the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

- *Research utilising secondary analysis of large data sets.* As with the 2014 Audit and 2017 Audit reports there were a significant number of research papers (n = 101) which undertook secondary analysis of administrative data and other large data sets. Administrative and population datasets remain an important source of disability data and their use needs to be facilitated through access and research training.

- *Children and young people.* We defined this group as those aged birth to less than 30 years (see Children and Young People section of the report for rationale of this age group) to include children, adolescents and young adults. There were 318 research papers (25.6% of the total number of research papers) and 36 research reports (16% of research reports) which focused on children and young people. A quarter of all research on children and young people with disability focused specifically on autism. Education was the most frequent focus of papers, with 132 research papers (41% of children and young people research papers, 10% of all research papers) and 17 research reports (47% of children and young people reports, 7.4% of all research reports) focusing on education. 21 research papers and one research report focused on educational inclusion and educational experiences were explored in 53 research papers and 8 research reports. Twenty-nine research papers examined experience from the student's perspective, 11 from the parental perspective and 18 from a teacher's perspective.

Of the research papers identified for the 2018-2021 period, 582 (47%) papers had one or more funding sources noted. A total of 765 funding sources were associated with these papers. For research reports a much higher proportion, 170 (76%) reported a funding source. Overall funding by Australian government bodies via direct funding, ARC, NHMRC and CRC grants and postgraduate awards made up the vast majority of funding producing research papers, with 487 mentions, followed by university-sector funding (n = 112), NGO funding (n = 99) and Private (n = 17). Governments were the primary funder of research reports (n = 98), followed by the NGO sector (n = 57).

Conclusion

This report is one component of the Research Agenda project funded by the National Disability Research Partnership. The aim of the agenda setting project is to determine a set of key areas for disability research in Australia over the next 10 years. This mapping phase determined the Australian disability-related research published from 2018-2020. This mapping phase is built on by two subsequent phases: a national consultation on disability research priority areas as identified by the disability community and an exercise to determine key areas that must be addressed in Australian disability research.

Contents

List of abbreviations

AASE	Australian Association of Special Education
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ADHD	Attention deficit hyperactivity disorder
AEDC	Australian Early Development Census
ARC	Australian Research Council
AIHW	Australian Institute of Health and Welfare
BEACH	Bettering the Evaluation and Care of Health
CADR	Centre for Applied Disability Research
CALD	Culturally and Linguistically Diverse
CDRP	Centre for Disability Research and Policy
CDS	Centre for Disability Studies
CID	Council for Intellectual Disability
CRC	Cooperative Research Centre
CRPD	Convention on the Rights of Persons with Disabilities
DANA	Disability Advocacy Network Australia
GP	General Practitioner
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
HACC	Home and Community Care
HILDA	Housing Income Labour Dynamics Australia
ICF	International Classification of Functioning
LSAC	Longitudinal Study of Australian Children
MACA	Mobility and Accessibility for Children in Australia
NDA	National Disability Agreement
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
NSW	New South Wales
RCT	Randomised Control Trial
SCIE	Social Care Institute for Excellence
SDAC	Survey of Disability Carers Ageing and
SSI	Settlement Services International
UN	United Nations
WA	Western Australia
WHO	World Health Organization

Introduction

In 2014 an Audit of Disability Research in Australia, funded by the Australian government, was the first attempt to map disability research in Australia[1]. The report of this Audit was updated in 2017[2]. These documents are referred to in this report as the 2014 Audit and 2017 Audit Update documents. The 2017 Audit Update included published research papers and research reports selected using a conceptual framework based on eight "domains of everyday life" for people with disability. As with the 2014 Audit report, the 2017 Audit Update report identified that gaps remained in relation to Aboriginal and Torres Strait Islander people with disability, people with disability in rural and remote settings, along with gaps in "structured policy evaluation, policy studies addressing culturally and linguistically diverse populations (CALD) with a disability, multi-disciplinary approaches to policy evaluation, and research on lived experience bringing the perspectives of people with disabilities, families and carers to policy critiques" (p 7).

The current Research Mapping Report 2020, hereafter referred to as Research Mapping 2020 was conducted by an inclusive and inter-disciplinary consortium to inform the development of a National Disability Research Agenda, as part of the multiple-component work for the National Disability Research Partnership. *The main aim* of this report was to produce a comprehensive picture of the current state of disability research in Australia since the Audit Update 2017 document.

Structure of this report

This report provides an overall summary of the existing research areas, mapped to the domains of the 2014 Audit and 2017 Audit Update, but also extending these where the research team collectively judged that the domains did not sufficiently capture research in all key areas. The report then provides a narrative description of ongoing research in the key areas identified in the previous Audit and Audit Update reports and extends this narrative into other areas, including rights, children and adolescents and inclusive research (research led by a team which includes or is led by people with disability). Collectively the research team felt that an understanding of these areas would give the users of this report a larger number of examples of the breadth of disability research in Australia. Topic areas are not meant to be

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[1] 2014 Audit of Disability Research in Australia https://sydney.edu.au/health-sciences/cdrp/Report%20of%20Audit%20of%20Disability%20Research%20in%20Australia%20_July%202014.pdf
[2]
2017 Audit of Disability Research in Australia Update Report https://sydney.edu.au/health-sciences/cdrp/publications/technical-reports/Audit%20of%20disability%20research%20in%20Australia%20update%20report%202017.pdf

exhaustive, but to provide an example of key areas related to different demographic variables and issues. We also include a section describing the findings of an analysis of funding sources for all research identified between 2018-2020. Descriptive statistics are presented. The report begins with a description of the methods used to undertake the research mapping.

Method

Project aim

The aim of the Research Mapping 2020 project was to map disability research in Australia over the 2018-2020 period and describe published research during that period. This mapping project will assist in developing a national disability research agenda for the coming decade by the National Disability Research Partnership (NDRP)[3]

Research Team

The overall lead for the mapping phase was Jen Smith-Merry from the Centre for Disability Research and Policy at the University of Sydney, co-lead of the Research Agenda Consortium. The consortium was contracted to great a body of work to inform the development of a research agenda for the National Disability Research Partnership. A working group of interested partners was formed from the broader Research Agenda Consortium membership to develop and advise on the research mapping project. They contributed to this phase of the project by setting the methodology, including search terms, inclusion and exclusion criteria, assisting with the data extraction and analysing the results to write up the narratives contained in the report. Member organisations and their representatives on this working group are:

Non-government organisations and representatives:
Nathan Despott (Inclusion Melbourne); Catherine McAlpine (Inclusion Australia); Tadgh McMahon (Settlement Services International); Rahul Ganguly (Australian Association of Special Education (AASE)); Nicole Rogerson (Autism Awareness Australia); Rachel Spencer (Council for Intellectual Disability (CID)); Mary Mallett (Disability Advocacy Network Australia (DANA)); David Moody (National Disability Services); Cecile Elder (Family Advocacy); Janice O'Connor (Onemda); Maxine Buxton(Deaf Victoria); Helen Lindner (Mobility and Accessibility for Children in Australia Inc. (MACA))

Academic research team members:
Kate Anderson (Australian Catholic University), Michelle Banfield (Australian National University), Gemma Carey (University of New South Wales), Simon Darcy (University of Technology Sydney), Kathy Ellem (University of Queensland), John Gilroy (University of Sydney), Adam Guastella (University of Sydney), Bronwyn Hemsley (University of Technology Sydney), Christine Imms (University of Melbourne), Manjula

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[3] National Disability Research Partnership **www.ndrp.org.au**

Marella (University of Melbourne), Keith McVilly (University of Melbourne), Mary-Ann O'Donovan (University of Sydney), Jen Smith-Merry (University of Sydney).

External advisors: Gerard Goggin (Nanyang Technological University, Singapore), Elizabeth McEntyre (Independent expert), Priscilla Ferrazzo (University of Alberta, Canada).

Research assistants and data extraction team: University of Sydney - Ivy Yen, Gisselle Gallego, Caitlin Jameson, Valentina Merzetti, James Cann, Erin Whittle, Greta Westermann; Deakin: Jenny Plumb; Murdoch Children's Research Institute: Jacky Lipson.

Definition of Disability

The mapping team used the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) definition of disability "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." (United Nations, 2006).

Identification of relevant papers and reports

Different strategies were used to identify published research papers and research reports over the period 2011-2020. While this report on focuses on 2018-2020 period, the papers were identified from 2011. Because of the broader scope of our search terms compared to the initial audits we thought it was important to include all papers from this time period so that the papers identified could be used more broadly as a resource in the sector for putting together literature reviews and so forth.

Published research papers

In December 2020, a systematic search of 13 scientific databases was performed to identify (a) journal articles and book chapters papers published between January 2011 and December 2020. Databases searched were: AMED, Avery, CINAHL, Compendex, Embase, ERIC, Global Health, Medline, PsycINFO, Scopus, Sociological Abstracts, Web of Science Core Collection and Informit (which includes 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) .

The search strategy was designed through discussion within the research mapping team listed above. Members worked together to update the eight domains used in the previous 2014 Audit and 2017 Audit Update to increase the list of areas that could be identified in relation to disability research. This was done to ensure that our mapping of the research captured the anticipated current breadth and diversity of disability research, policy, service, lived experience and community priorities as identified by the research mapping team.

The methodology from the 2014 Audit and 2017 Audit reports involved using a set of nine core terms to identify relevant papers in addition to a range of terms under each of these nine domains.

- Education
- Economic Participation
- Social Relationships
- Health and Wellbeing
- Community and Civic Participation
- Transport and Communication
- Sector Development and Sustainability
- Safety and Security
- Housing and the Built Environment

For example Web of Science search strategy 2017 Audit Update (bolded terms show specific search strategy to identify *Domain Search: Community and Civic Participation*):
(TS=(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "vision impairment*" OR "hearing impairment*" OR "vision disorder*" OR "hearing disorder*") AND TS=(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR tasmania) NOT TS=(disable OR disabling)) AND PY=(2013-2017) **AND TS=("political participation" OR communit* OR "support group*" OR "self help" OR "self-help" OR organisations OR organizations OR recreation* OR leisure* OR sport* OR religio* OR volunteer* OR "civic participation" OR "arts" OR "culture" OR "social capital" OR "community capacity" OR (community AND participation))**

This methodology was discussed at length as part of the development of this current Research Mapping 2020 project, both within the project development phase prior to the EOI acceptance and the research mapping team identified above. It was decided that a methodology based around a search strategy which limited identified papers to terms under these domains may potentially limit the range of papers identified. We therefore took a different approach and used a broad search strategy and then identified topic areas (some of which fit within the original audit domains) in order to characterise the papers by paper focus. We also collectively worked to update the list of terms for disability in order to ensure that our search captured relevant research which might not have used the term disability. The database search strategies were developed with the assistance of a university librarian with experience in systematic reviews. The full search strategy is included (Appendix 1).

Current Research Mapping 2020 exercise Web of Science search strategy:

TS = (disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" OR "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR *mute OR deaf* OR "sign language" OR Auslan OR "special education*" OR "hard of hearing" AND TS = (austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria)

The original domains and list of topics identified in identified papers are listed in the following table:

Table 1: Original Audit Domains and updated Topic areas used in this report.

Domains used in the 2014 Audit and 2017 Audit Update	Topic areas in this report
- Education - Economic Participation - Social Relationships - Health and Wellbeing - Community and Civic Participation - Transport and Communication - Sector Development and Sustainability - Safety and Security - Housing and the Built Environment	- Health and Wellbeing - Education - Lived experiences of disability - Policy - Service development and evaluation - Workforce development and leadership - Law, criminal justice and rights - Employment, volunteering, work experience - Disability accommodations - Social and community involvement. Leisure, sport and physical activity - Safety, security, discrimination, violence and abuse - Quality of Life - Technology - Disability research and research methods - Social care - Housing and the Built Environment - Community and Civic Participation - Economic security and social security payments - Intersectional approaches (e.g. race and disability, gender and disability) - Public attitudes to people with disability - Self-determination, choice and control - Communication - Prevalence studies - Economic Cost - NDIS - Transport - Critical theory, philosophy and religious consideration of disability - Sexuality and reproductive rights - The arts, culture and literature

	• Retirement, ageing, aged care, end of life • Behaviour support • Media - traditional and social

Inclusion criteria

- Published between January 2011- December 2020[4]

- Published in English in a peer reviewed journal or published book chapter

- A full paper which documented the results of an investigation and/or secondary analysis of existing data reporting the aim of the investigation, method, findings and conclusions and/or recommendations

- At least one aim of the study related to people with disability

- Disability research including Australian participants/topics and reporting results on those participants/topics. This included international comparative studies. 'Topics' referred to studies such as those about Australian disability policy, social context and services where there were no participants

- The results developed conclusions related to people with disability.

Exclusion criteria

- Not a full paper (e.g., conference abstracts) or not available in full text format

- Not written in English

- Not a research paper (e.g., commentaries, viewpoints, editorials)

- A review paper that does not include Australian studies from the previous 10 years

- Disability was acute and/or transient (an excluded study would be on rehabilitation from an acute injury such as short-term limb dysfunction after a fracture)

- Research that was primarily lab-based and related to genetics, treatment approaches, diagnosis or cure (e.g. surgical, clinical and basic science) which did not also consider the broader functioning, disability, health and wellbeing of people with disability

- The aims of the paper did not relate to people with disability or disability is mentioned only in passing.

Research reports

To initially identify research reports, web-based searches using the Internet search engine google.com.au were conducted as well as a web search of partner organisations and key websites identified by the team, e.g. from NGOs, government websites or research centres (see Appendix 2). Members of the

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[4] Please note that although the criteria covers the period 2011-2020 this report only reports on the data from the 2018-2020 period, which is the target of this report.

mapping team were also asked to identify any research reports that they are aware of which would meet the inclusion criteria.

Part 1 search: We searched google.com.au using a search string of relevant key words combined with the operator filetype:pdf

Part 2 search: Web search of partner organisations and key websites e.g., AIHW for reports and publications potentially containing original research.

Inclusion criteria

- Published between January 2018- December 2020
- Published in English
- A full report which documented the results of an investigation and/or secondary analysis of existing data reporting the aim of the investigation, method, findings and conclusions and/or recommendations
- At least one aim of the study related to people with disability
- Disability research including Australian participants/topics and reporting results on those participants/topics. This included international comparative studies. 'Topics' referred to studies such as those about Australian disability policy, social context and services, where there were no participants
- The results developed conclusions related to people with disability

Exclusion criteria
- Not publicly available
- Not written in English
- Does not contain any original research (e.g., commentaries, viewpoints, policy submissions which do not contain original research)
- Disability is acute and/or transient (an excluded study would be on rehabilitation from an acute injury such as short-term limb dysfunction after a fracture)
- Research which was primarily lab-based and related to genetics, clinical treatment, diagnosis or cure (e.g., surgical, clinical and basic science) which did not also consider the broader functioning, disability, health and wellbeing of people with disability
- The aims of the report and conclusions did not relate to people with disability or disability is mentioned only in passing

Identification of missed research papers and research reports

A restriction was added to each search string to locate papers referring to Australia (see Appendix 1). This meant that some studies were missed from the search results where authors had not included a word related to Australia or an Australian state in the abstract, keywords or titles. For that reason, we collated a
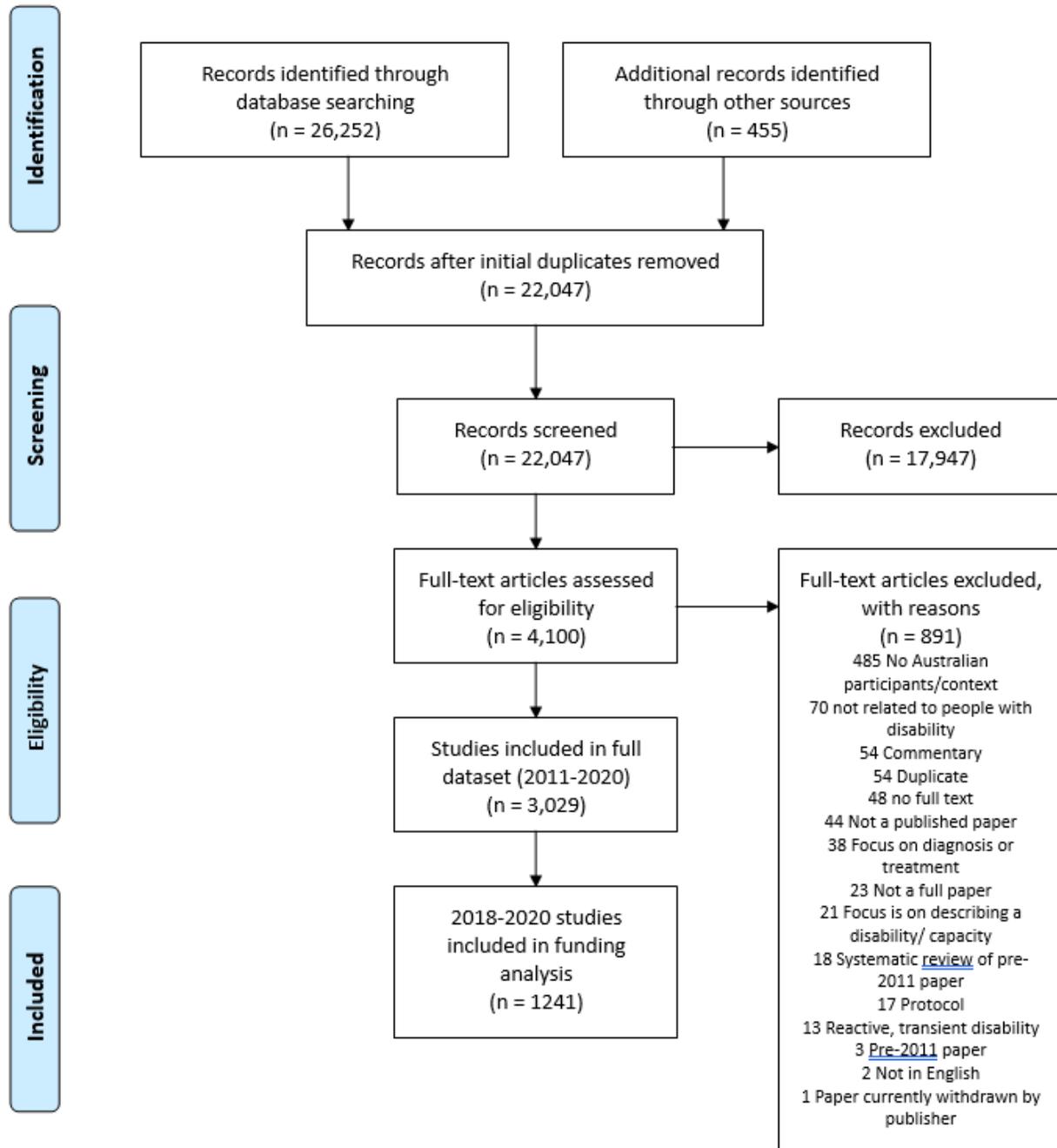
list of the research papers and reports and distributed the list throughout the broader consortium, the NDRP stakeholder communities including via an email to all those on the NDRP outreach database and via the networks of the Research Mapping team identified above. People were invited to send the research team papers and reports which met the inclusion criteria. These papers and reports were checked against the inclusion and exclusion criteria and duplicates removed. All new papers were then analysed with the process for other papers (process explained below).

Identification and selection of research papers and research reports

The titles and abstracts of all papers and reports generated through the combined database searches were uploaded to Covidence a systematic review program, and duplicates removed. Three team members independently screened search results against the eligibility criteria. 21,692 papers were initially assessed on title and abstract by two independent members of the research team (JSM and either IY or GG). This resulted in 3,633 full-text papers being assessed for eligibility. These were each individually screened by two independent members of the research team (JSM and either IY or GG). Disagreements at both the abstract screening and full text screening stages were resolved via a third member. 2804 research papers were assessed as being eligible from the full text screening. Of these 1043 research papers were from the 2018-2020 period.

We then conducted an additional search of papers via a call out to researchers in the field. This identified 455 research papers and 32 research reports. Of these 225 met the inclusion and exclusion criteria and were not duplicates of research papers or research reports previously identified. The combined search strategy and study selection processes are documented in the PRISMA study flow diagram in Figure 1. All research reports identified were examined for inclusion at the point of data extraction (see below) so skipped the title and abstract screening stages.

Figure 1: Prisma flow chart

Identification

Records identified through database searching
(n = 26,252)

Additional records identified through other sources
(n = 455)

Screening

Records after initial duplicates removed
(n = 22,047)

Records screened
(n = 22,047)

Records excluded
(n = 17,947)

Eligibility

Full-text articles assessed for eligibility
(n = 4,100)

Full-text articles excluded, with reasons
(n = 891)
485 No Australian participants/context
70 not related to people with disability
54 Commentary
54 Duplicate
48 no full text
44 Not a published paper
38 Focus on diagnosis or treatment
23 Not a full paper
21 Focus is on describing a disability/ capacity
18 Systematic review of pre-2011 paper
17 Protocol
13 Reactive, transient disability
3 Pre-2011 paper
2 Not in English
1 Paper currently withdrawn by publisher

Studies included in full dataset (2011-2020)
(n = 3,029)

Included

2018-2020 studies included in funding analysis
(n = 1241)

Please note: although the criteria for research papers covers the period 2011-2020 this report only addresses the data from the 2018-2020 period, which is the target of this phase of work.

Data extraction

The data extraction task was shared by six members of the research mapping team based on a set of guidelines. Checking was also completed of extraction for each member of the extraction team when they began in order to assure that extraction was cohesive across the extraction team. A standardized data extraction form was used to extract data from the included studies for assessment of evidence synthesis (See Appendix 3). Extracted information included: title, year of publication, abstract, study population, focal group of participants, main type of disability being discussed, age group, aim of the paper, focus topics, study design, further details, and study founding sources. Topic primary focus areas were determined based on reading the paper abstract and scanning through the paper for further information. At least one primary focus was allocated either from the topics listed in Table 1 or, where these were not relevant, extractors entered an alternative focus in free text. Where there was a second prominent focus area listed in the paper this could be identified as a second focus topic. Where there was a third or further focus area this could be entered into the free text section of the extraction sheet. The same data extraction tool was used for both research papers and research reports.

Data synthesis

The identified studies were categorized by GG and JSM according to study and population characteristics. Extracted data were then analysed, integrated, synthesized, and presented both quantitatively and qualitatively. Narrative synthesis, themes identified during the course of the literature search, study limitations and knowledge gaps were identified, along with preliminary directions for future research where these could be identified. The narrative syntheses were produced by:

1. Gathering all research on an identified topic area or via the study design categories or other categories identified in the extraction sheet, supplemented by additional text-based keyword searching for papers where an approach or topic may have been used but was not identified as a key topic (e.g., searching for discussion of the Convention on the Rights of Persons with Disabilities or the use of a particular dataset such as the BEACH dataset).
2. Determining, where relevant, the main topics and interest groups (e.g. disability types discussed, age groups) of all papers identified for a particular group of papers.
3. Examining this information, where possible, in relation to the discussion in the 2014 Audit and 2017 Audit Update reports.
4. Bringing this information together in descriptive statistics and narrative form, with relevant examples and, where possible, identifying gaps or areas of strength.

5. Discussing the findings with expert advisors from the research mapping team to review the analysis.

Findings

Overall summary of papers

There were 1241 relevant research papers and 225 research reports identified throughout the 2018-2020 period. Numbers for each year are illustrated in the following graph, reflecting a growing number of papers by year. There was an average over this period of 488 papers or reports per year.

Figure 2. Number of identified research papers and research reports published per year (2018-2020)
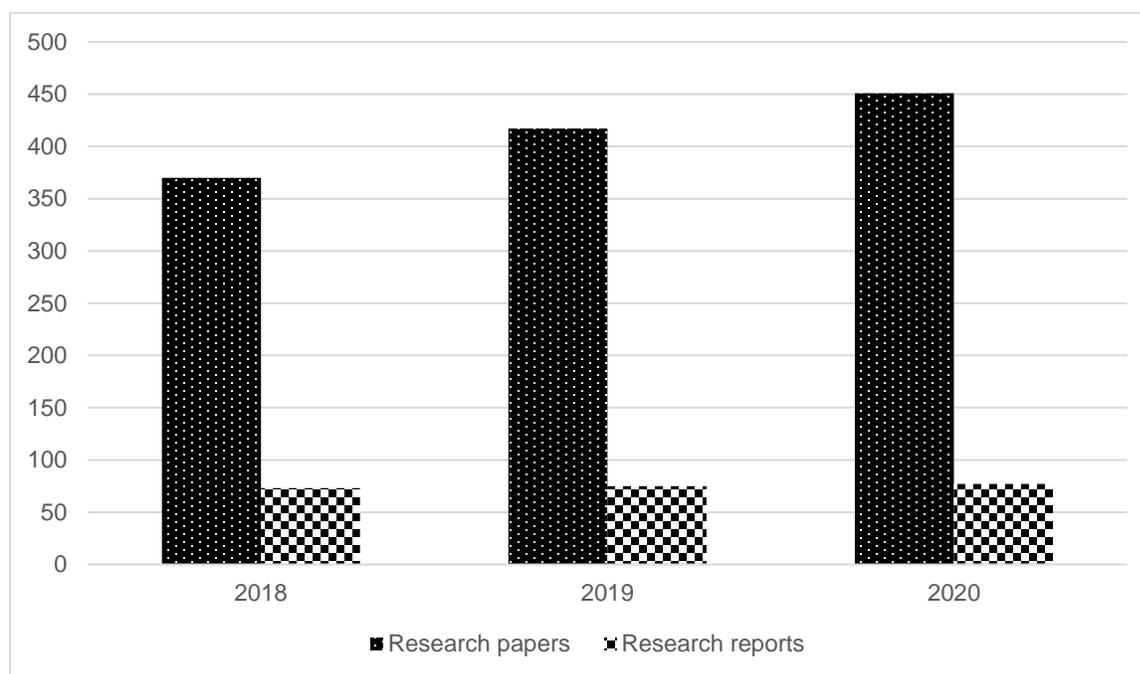
The 2014 Audit covered the period 2000-2013 and identified 1658 items (research papers and research reports) (118/year). The 2017 Audit Update covered the period 2014-2017 and identified 939 items (234/year). The growth in numbers of publications will be impacted by both an increased level of activity as well as the expanded search strategies discussed in the methods section above[5].

Aboriginal and Torres Strait Islander people with disability

Papers were examined for focus on Aboriginal and Torres Strait Islander people with disability where the aims or conclusions referenced Aboriginal and Torres Strait Islander people or issues, rather than just mentioning their needs in passing (e.g., in a background section). In total, 75 research papers (6%) and 15

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[5] Please note that although the criteria for research papers covers the period 2011-2020 this report only addresses the data from the 2018-2020 period, which is the target of this phase of work.

research reports (6.6%) focused on Aboriginal and Torres Strait Islander people with disability. These results are discussed further in the narrative synthesis, below.

Culturally and linguistically diverse communities
We also specifically identified papers that focused on people with disability from culturally and linguistically diverse communities. We found only 17 research papers (1.4%) and 8 research reports (3.5%) with this focus. The narrative analysis provides a detailed description of these papers.

People with disability who are LGBTIQA+
There were only two papers (0.16%) which specifically focused on people with disability who are LGBTIQA+.

Disability group focus
All papers were classified according to status of participant as person with disability or relationship to person/ people with disability, as well as primary disability type reported for the participants with disability. The four main groups discussed were people with disability, family members (including siblings, parents, and unpaid carers) disability workforce , and 'other', which includes papers focusing on multiple groups or the general public. The numbers of papers in each of these groups is provided in table 2, below.

The vast majority of papers focused on people with disability as the main group being discussed (67.4% of research papers and 74.1% of research reports). There were a smaller number of papers focusing on family members, supporters and unpaid carers (11.5% and 18.1% respectively) and the disability workforce broadly understood (6.2%) (e.g., teachers working in mainstream education with children with disability in this group).

The 'other' category included research papers and reports where two groups were discussed equally, those which focused on the general public or community (n = 10) and papers and reports focusing on the functioning of a policy or administrative body, such as the NDIS or Administrative Appeals Tribunal without discussing people with disability or workforce. Other papers focused on the workforce in areas outside of the disability sector or whose practice did not focus solely on disability, such as people working in universal design or policy makers.

Table 2: Numbers of research papers and reports by group

Group	Research papers	Percentage	Research reports	Percentage
People with disability	811	67.4	143	74.1
Family members, allies, supporters and unpaid/informal carers	138	11.5	35	18.1
Workforce and staffing	164	13.6	12	6.2

Others* community/general public n=10, disability services n=2, disability policy n=2, NDS organisations n=2, both people with disability and family members, supporters or unpaid carers (n=5), policy makers n=3, coaches, employers, all of the categories, health care providers combination or two or more categories, teachers.	91	7.6	3	1.6
Total*	**1204**	**100**	**193**	**100**

* Not all papers and reports focused on a particular group but rather reported about disability generally.

We also analysed research papers and reports by their professed focus on particular general or specific types of disability or impairment. We used disability types as identified in the papers. Around a third of the research papers (33.7%) focused on people with disability generally rather than a specific type of disability. The next biggest groups of papers were those that focused on people with intellectual or cognitive disability (17%), autism (13.1%) and mental illness (12.4%). This accounts for more than half of the papers (61.1%). Research reports also mainly focused on disability generally (53.5%), mental illness[6] (15%), autism (12.2%) and intellectual disability (7%). These figures are presented in the table below. If a paper spoke about two or more main types of disability (30 research papers did this) then these were included separately.

Table 3: Numbers of research papers by disability category

Disability focus	Number research papers	Number research reports
General discussion of disability	417	114
Intellectual/cognitive disability	226	18
Autism	168	26
Mental illness	157	32
Brain injury	47	2
Deaf/deaf, hearing loss or impairment	37	1
Spinal cord injury	32	1
Fetal Alcohol Spectrum Disorder (FASD)	26	0
Communication disability	21	0
Visual impairment, visual loss, blind.	20	8
Cerebral Palsy	18	2
Physical mobility impairment	15	1
Down Syndrome	14	0

[6] Mental illness was only included where it was serious and continuing, used the phrase 'psychosocial disability' or used in the context of disability (e.g., discussion of the NDIS, the National Disability Strategy).

Developmental	6	3
ADHD	6	4
Other	75 includes:, MS=10, Genetic n=10,	2 Includes: developmental coordination disorder, neurotrauma,

Age group

We identified papers based on the age groups discussed in the papers. As they were defined by papers, the age groups are not mutually exclusive and sometimes described broad age groups such as 'children', 'adolescents' or 'adults'. A majority of studies did not specify the age of the target group or could potentially apply to all ages. This was followed by studies focusing on adults of any age.

Table 4: Number of papers and reports by age group.

Age group	Research papers	Percentage	Research reports	Percentage
People of all ages/ age not specified	498	40.1	149	66.2
Adults of any age	406	32.7	32	14.5
Children (5 < 18 years)	101	8.1	9	4
Children of any age	89	7.2	14	6.2
Young adults (18 < 30)	61	4.9	8	3.5
Infants and early childhood (<5)	36	2.9	0	0
Adolescents*	23	1.9	4	1.7
Older age (65+)	18	1.5	0	0
Others: Children and adolescents or young people (n=4), other age groups: 0-25 years, 12-30 years, 12-25 years, <25 years (n=4).	12	1.0	8	3.5
Total	**1241**	**100**	**225**	**100**

* This term is used where papers have referred to populations as being adolescents, but this term is not used universally to connote a particular age range.

Domains and topics

The main topics identified in the research papers and research reports are displayed in tables 5 and 6 below. Each paper was allocated up to 3 topics, so the data do not add up to the total number of papers in the mapping exercise. For a list of the papers we categorised against the domains in the original Audit reports please see Appendix 4.

Table 5: Research topics: journal articles.

Research topics	Research papers	Percentage
Health and Wellbeing	378	19.4
Education	197	10.1
Lived experiences of disability	153	7.9
Policy	119	6.1
Service development and evaluation	95	4.9
Workforce development and leadership	93	4.8
Law, criminal justice and rights	85	4.4
Employment, volunteering, work experience	70	3.6
Disability accommodations and adjustments (see below)	65	3.3
Social and community involvement. Leisure, sport and physical activity	65	3.3
Safety, security, discrimination, violence and abuse	48	2.5
Quality of Life	47	2.4
NDIS	44	2.3
Technology	40	2.1
Disability research and research methods	35	1.8
Social care	33	1.7
Housing and the Built Environment	33	1.7
Community and Civic Participation	32	1.6
Economic security and social security payments	29	1.5
Intersectional approaches (e.g., race and disability, gender and disability)	25	1.3
Public attitudes to people with disability	23	1.2
Self-determination, choice and control	20	1.0
Communication	17	0.9
Prevalence studies	17	0.9
Economic Cost	15	0.8
Transport	14	0.7
Critical theory, philosophy and religious consideration of disability	12	0.6
Sexuality and reproductive rights	12	0.6
The arts, culture and literature	12	0.6
Retirement, ageing, aged care, end of life	10	0.5
Behaviour support	9	0.5
Media - traditional and social	9	0.5

	119	6.1
Other		
Total	**1945**	**100.0**

*Can choose more than one category

Table 6: Research topics: research reports.

Research topics*	Research reports	Percentage
Service development and evaluation	51	15.8
Health and wellbeing	45	13.9
Policy	43	13.3
Workforce Development and leadership	23	7.1
Education	22	6.8
Lived experience of disability	18	5.6
Employment-volunteering-work experience	15	4.6
Prevalence studies	12	3.7
Self-determination choice and control	12	3.7
Social care	10	3.1
Law-criminal justice and rights	9	2.8
Technology and transport	9	2.8
Disability accommodation and communication (see below)	7	2.2
Housing	5	1.5
Intersectional approaches e.g., ethnicity and disability	5	1.5
Safety, security, violence, discrimination and abuse	5	1.5
Economic security and social security payments	4	1.2
Public attitudes to people with disability	3	0.9
Quality of life	3	0.9
Social and community involvement, leisure and sport	2	0.6
The arts	2	0.6
Other	18	5.6
Total	**323**	**100**

*Can choose more than one category

Study design/ type of investigation

The most frequently occurring study types were qualitative studies (40%) and quantitative studies (37%). Because of the highly variable and often limited description or methods in research reports we have not described their methods.

Table 7: Number of research papers by methodology used.

Study design/ type of investigation	Research papers
Qualitative research	493
Quantitative research	458
Mixed method	71
Systematic review	61
Narrative, scoping reviews	62
Expert discussion*	49
First person accounts/autoethnographies	10
Other: e.g. website analysis, critical theoretical discussion, readability analysis, network analysis.	37
Total	**1241**

* expert discussion includes papers where a topic is discussed (e.g. a philosophical or legal discussion) but without a particular methodology being utilised. Does not include opinion pieces.

Fifty papers were first-person auto-ethnographies (n = 10) or took a participatory action (n = 17), or co-research/ inclusive research approach (n = 23).

Co-research or inclusive research

Papers using a co-research or inclusive research approach did so with a range of purposes. Most papers focused on explaining how co-research or inclusive research has been or should be carried out (Arnold et al., 2019; Arstein-Kerslake, Gooding, Mercer, Raymond, & McSherry, 2019; Clifton, Fortune, Llewellyn, Stancliffe, & Williamson, 2020; Dee-Price, 2020b; Jenkin, Wilson, Campain, & Clarke, 2020; Kendall et al., 2019; Purcal, Fisher, Robinson, Meltzer, & Bevan, 2019; Ramcharan, David, & Marx, 2020). There were several papers that had a co-research and inclusive research design and reported results (e.g. Collings, Strnadová, Loblinzk, & Danker, 2020; Pellicano et al., 2020; Skinner, 2018). It should be noted that this number is likely an under-representation of the amount of inclusive or co-research taking place as some papers will not have discussed the co-research design as part of the project.

Narrative Analysis

We conducted a focused analysis of the focus areas from the previous Audit reports, along with a discussion of research areas that the research mapping team identified as important. The narrative analyses are presented in the following order:

- Aboriginal and Torres Strait Islander research
- Culturally and linguistically diverse (CALD) communities
- Policy analysis research
- Rights-based approaches
- Research utilising secondary analysis of large data sets
- Children and young people
- Funding sources of research papers and research reports published 2018-2020

In reporting these results we provide examples of papers to illustrate points made, or to show the dimensions of the field being described. The papers cited in text are examples only and do not represent all of the research being conducted in the field.

Aboriginal and Torres Strait Islander people with disability

Our mapping of existing disability research over the period since the 2017 Audit Update located 75 research papers and 15 research reports relating to Aboriginal or Torres Strait Islander people with disability. All papers and reports included referred to Aboriginal and Torres Strait Islander people with disability either in the research aims or the study conclusions, so this analysis may miss some relevant research that mentions Aboriginal and Torres Strait Islander people with disability or the topics relevant to them as a more minor aspect of the research. The 2017 Audit Update, which covered a larger period of time of five years (2013-2017), located only 28 papers that focused on Aboriginal and Torres Strait Islander people with disability (3%), where this review located more than double that number over 3 years, at 6% of all research papers identified.

Most of the research papers (n = 58) and research reports (n = 12) focused on Aboriginal or Torres Strait Islander people with disability as the primary focus of the research. Six papers and 1 report focused on

family members, supporters, allies and unpaid/informal caregivers[7], 4 papers focused on the paid workforce, and 9 'others' including a paper focusing on legislation, 2 papers and 2 reports on the general public and 2 research papers on people working outside of disability services (sports coaches and youth justice custodial staff)[8]. A summary of the types of disability covered in the papers is included in the table below.

Table 8: Number of papers by disability type.

Disability focus	Research papers	Research reports
General discussion of disability	33	10
Fetal Alcohol Spectrum Disorder (FASD)	14	0
Brain injury	7	0
Hearing impairment	5	0
Intellectual and cognitive disability	5	0
Autism	3	1
Developmental disability	2	0
Mental ill-health	2	4
Neurological disability	2	0
Communication disability	1	0
Spinal cord injury	1	0
Total	**75**	**15**

There were 5 research papers that focused on Aboriginal and Torres Strait Islander people with hearing-related disability, but none that focused on visual impairment and only one paper focused on communication disability. The 2017 Audit Update reported a lack of literature focusing on acquired disability in the literature relating to Aboriginal and Torres Strait Islander people with disability. There is an increased number of papers focusing on acquired brain injury and physical disability in Aboriginal and Torres Strait Islander people. The variations in numbers of papers, for example in acquired brain injury, between the 2017 Audit Update (n=1) and the current review (n=7) may be a result of major projects receiving funding at a particular time. This highlights the importance of funding bodies supporting specific strands of work in areas of need rather than researchers identifying a need and producing related research. A good example of funding driving research is the large number of research papers which focus on Fetal Alcohol Spectrum Disorder (FASD) which were funded (11/14). Three of these papers were

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[7] This phrase is used to capture people in the families and communities surrounding an individual with disability, who have an interest in their care and support. The language chosen to align with the NDRP principles. **https://www.ndrp.org.au/principles**

[8] Some papers had more than one topic group.

funded through the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (Hamilton, Reibel, et al., 2020; Hamilton, Maslen, et al., 2020; Hamilton et al., 2019). Other FASD funding came from the NHMRC FASD Research Australia Centre of Research Excellence (Bower et al., 2018; Symons, Pedruzzi, Bruce, & Milne, 2018) and through grants from the mining company BHP (Fitzpatrick et al., 2020; Symons et al., 2018).

Three papers and 2 reports specifically stated that they took a decolonising approach to data collection and analysis. One of these focused on research methodology in the context of a large disability project (Gilroy et al., 2018) and another was an expert discussion of disability research and decolonising practices in comparison with Indigenous disability research in other countries (Gilroy et al 2018b). One book examined intersectional inequality in relation to Aboriginal and Torres Strait Islander people with disability (Avery, 2018). Two papers from one study focused on acquired communication disability in people with brain injury, including participant experiences (Armstrong, Coffin, Hersh, et al., 2019) and the training and employment of Aboriginal research staff on the project to conduct qualitative interviews on the experience of communication disabilities in acquired brain injury (Armstrong, Coffin, McAllister, et al., 2019). I Twenty-seven research papers were qualitative in approach, with many of these focusing on the experiences of Aboriginal people accessing services or living with disability. For example, there were several papers focusing on how family members of a person with disability experienced supporting someone with disability or receiving a diagnosis (Fitts et al., 2019; Gilroy et al., 2020; Hamilton, Maslen, et al., 2020; McRae et al., 2019).

Eight research papers were based on secondary data analysis of existing data sets. Most studies used linked data from administrative data sets including education, youth justice, education child protection, hospital and mortality data sets (e.g. He et al., 2020; Katzenellenbogen et al., 2018; Maclean, Taylor, & O'Donnell, 2020; Su, Guthridge, He, Howard, & Leach, 2020; Su et al., 2019). Other data sets used were the Australian Early Development Census (Simpson, Šarkić, Enticott, Richardson, & Buck, 2020) and the National Aboriginal and Torres Strait Islander Social Survey (Temple, Wong, et al., 2020a, 2020b).

The 2017 Audit Update drew attention to the large number of systematic reviews and policy commentaries in the literature (11/28 – 40% of studies) and the low number of studies that engaged in direct fieldwork or other empirical data collection. In this Mapping Report, the percentage of reviews, policy commentaries and expert analyses (defined above) was (17/75 – 23% of studies).

Papers focusing on culturally and linguistically diverse communities.

There were only 17 research papers and 8 research reports that focused on people from culturally and linguistically diverse communities. Of the research papers 13 focused on people with disability, 2 on workforce and 2 on family members, , supporters, allies and unpaid/informal caregivers. All research reports focused on people with disability. The majority or research papers (n = 9) and all research reports focused on people of all ages or did not specify an age group, 3 research papers were specifically about adults, including one about older adults (aged 50-90) and 5 about children and young people. In terms of disability types, most (n = 10) research papers and research reports (n = 7) discussed disability generally, with the rest focusing on developmental disability (2 research papers) mental illness (1 research paper, 1 research report) and brain injury, intellectual disability, cerebral palsy, and visual disability (1 research paper each). Thirteen research papers reported on culturally and linguistically diverse people as a group only. Only 1 research paper and 1 research report focused on a specific cultural or linguistic group. A research paper examined Greek and Italian migrant families in a study focusing on caring for a family member with intellectual disability into old age (Walker, Belperio, Gordon, Hutchinson, & Rillotta, 2020). A research report focused on Australian Chinese people speaking Mandarin or Cantonese and their needs and preferences in relation to the NDIS (Fang and Fisher, 2019).

The large proportion of papers with a general focus on disability or culture without a specific age or cultural group focus, demonstrates that much of the literature is high-level, rather than exploring the experiences of disability and disability services for people from culturally and linguistically diverse backgrounds. This is borne out when examining the topics covered in the papers, most of which focused on policy, critical theory and large data set analysis. Only 5 papers focused on health and wellbeing or quality of life (e.g. Jones et al, 2020). The research reports were empirical , most focusing on either service evaluation (n = 5) or lived experience of disability (n = 2). Three research papers and 2 research reports took an intersectional or critical theoretical approach to their analysis (e.g. Abdullahi et al, 2020).

There was no clear dominant methodological approach taken in this subset of papers. There were 2 systematic reviews, 3 qualitative studies, including an in-depth case study of one person's experience of assessment in higher education (Olave-Encina, 2019), two expert discussion papers, a policy analysis paper and a service evaluation paper. The rest of the papers were quantitative, including two that were secondary analysis of data sets: Soldatic et al's (2019) study using Census data linked with the Federal Department of Immigration and Border Protection's Settlement Reporting Facility and data from the Department of Human Services for information on Centrelink and other social security payments; and Woolfenden et al's (2019) study using the Cerebral Palsy Register. Notably absent from the research

papers was work on lived experiences of disability (1 paper only) and research focusing on the needs of people with disability from culturally and linguistically diverse communities in relation to services. Nine of the research papers acknowledged a funding source. Four of these were category one funding (NHMRC – 3, ARC – 1). The rest received funding from NGOs, government and university sources. Of the research reports 3 acknowledged funding, though others were likely to have been funded by services given that they were service evaluations. Acknowledged funding came from 2 government and one NGO source.

Policy focused papers

Policy papers were those where policy was identified as a key topic in the data extraction. There was a significant increase in the number of policy-related papers identified and included in the current review in comparison with the 2017 Audit Update, which included 56 policy papers (5.9% of overall papers) compared to 119 papers identified for the current three-year period (2018-2020) (9.6% of overall papers). There were 43 research reports (20% of research reports) focusing on policy. The majority of research papers (n = 70) and research reports (n = 28) focused on people with disability. Ten research papers and 9 research reports focused on the interests and experiences of workforce in relation to policy. The rest of the papers and reports mainly referred to disability policy broadly without discussing a specific group. Eighty-one papers spoke about policy considering people with disability as a general group, with 17 focusing specifically on policy in relation to intellectual or cognitive disability and 12 in relation to mental illness. Other disabilities focused on were autism, brain injury and communication disorders. For research reports 31 focused on disability generally, 10 on mental illness and one on autism. Ten research papers and 3 research reports focused on policy relating specifically to children, including one paper that focused specifically on children under 5. There were 5 research papers that focused on young adults. All the rest of the research papers and research reports focused on adults or people with disability of no specific/all ages. The NDIS was a focus of 44 of the research papers and 17 research reports. Other key topics were education policy (n = 20 research papers, 3 research reports), economic security and social security payments (n = 13 research papers), employment policy (n = 5 research papers; n = 1 research reports) and social and community development (n = 5 research papers).

Three papers had a focus on housing policy (e.g. Callaway & Tregloan, 2018;) and 2 research papers and 5 research reports focused on policy in relation to people with disability, health and wellbeing. The limited papers in these areas are a significant gap considering the problems in integrating health and social care for people with disability and the significant problems related to safe, secure and stable housing, particularly for people with psychosocial disability. Both of the papers that focused on health and wellbeing in relation to policy focused on intellectual disability and mental health policy and were by members of the same research team (e.g. Dew, Dowse, Athanassiou, & Trollor, 2018;). Three papers and

one report examined the implementation of disability policy from the position of lived experience of disability (Collings, Dew, & Dowse, 2019;). As discussed in the previous Audit reports, these papers are important because they seek to bring lived experience to policy. There were no papers that discussed the involvement of people with lived experience directly in policy design. This remains a significant gap because it is important to know the impact of lived experience in policy decision making. There was one paper examining the implementation of policy into practice that had been co-designed and carried out with people with lived experience of disability. This paper discussed community action and the implementation of a co-designed project in the context of the NDIS-related policy changes (Ramcharan et al., 2020).

There were three research papers and three research reports focusing on policy related to people from culturally and linguistically diverse people with disability. All three research papers and one report focused on refugee and migration policies (e.g. St Guillaume & Finlay, 2018). While this is an improvement on the 2017 Audit Update, where none were identified, this number remains low. There is a need for papers that look beyond immigration and refugee policy to consider people from culturally and linguistically diverse communities in disability-related policy more broadly. Two research reports focused on culturally and linguistically diverse people with disability and the NDIS. Only 5 research papers focused on policy in relation to an aspect of security, safety, discrimination or abuse of people with disability. This included papers on protections under human rights and consumer protection law (e.g. Chesterman, 2019), institutional violence against people with disability in relation to law and policy (Cadwallader, et al, 2018), one on chemical restraint (Edwards, King, Williams, & Hair, 2020) and one on mental health law and stigma and discrimination in workplaces (Mellifont, 2019).

Several research papers focused on policy implementation, including the impact of policy on services (n = 9) and the role of the policy and service workforce in designing and implementing policy (n = 5). This includes how government bureaucrats design policy (e.g. Nevile et al., 2018) and how members of the social care workforce implement policy (mainly the NDIS) in local areas (Malbon & Carey, 2020). Seventeen research reports focused on service development and evaluation. Papers and reports were largely qualitative in approach relying on interviews with key actors or content analysis of policy documents.

Six papers and one report focused on people with disability, their families, supporters and allies living in regional, remote and rural areas. These included 2 papers on the implementation of NDIS policy in regional, remote or rural areas of Australia (e.g. Ramcharan et al., 2020), another on the impact of reforms to the Disability Support Pension and their impact on Indigenous Australians with disability (Soldatic, 2018). Two others focused on policy in relation to experiences and attitudes towards specific

types of disability in these locations: multiple sclerosis (Ahmad et al., 2020), autism (Lilley, Sedgwick, & Pellicano, 2020) and intellectual disability (Garnham, Bryant, Ramcharan, Nilan, & Adams, 2019). The lack of papers and reports focusing on the implementation of policy in rural and remote areas remains a gap in current research. This needs to be addressed because of continued problems of policy implementation in these areas, and the lack of data and policy solutions in relation to these populations. While the majority of people with disability live in cities and regional areas, many of our policy approaches do effectively work for people in these areas (e.g. disability employment strategies, elements of the NDIS) which means that policy often doesn't meet the interests of people who are already at increased marginalisation or risk of poverty. This example points to the overall gap in the literature with regards to the extent to which particular sub-groups of the population (e.g. LGBTIQA+, people with complex needs) are addressed in mainstream policy approaches.

The 2017 Audit Update drew attention to gaps in relation to policy related to Aboriginal and Torres Strait Islander people, rural and remote, culturally and linguistically diverse communities, policy evaluation, multi-disciplinary approaches and approaches inclusive of consumer knowledge. The discussion here shows that disability policy research has grown significantly as a field in Australia, with several new areas of work emerging in relation to the NDIS (e.g. Carey, Dickinson, Malbon, & Reeders, 2018), markets and service impact of policy change (e.g. Carey, Weier, Malbon, Duff, & Dickinson, 2020), and critical policy studies (Soldatic & Fitts, 2020; Soldatic et al., 2019). However, the findings also show that disability policy research is patchy and sometimes barely touched those areas where we are facing the biggest policy implementation challenges including, for example:

- People with complex needs
- People with disability in rural and remote areas
- Integrated systems approaches
- Housing
- Employment
- Safety, discrimination and abuse.

Large data sets

We drew attention to data sets in our analysis to understand how they are currently being utilised to provide generalisable data. We identified 101 research papers accessing large data sets which were either 1) government general administrative data 2) government health and disability specific data sets 3) other dedicated population data sets. The data sets being utilised by researchers were:

- *The Household Income and Labour-Dynamics in Australia (HILDA)* survey, which is a household panel survey hosted by the Melbourne Institute. It was used in 15 papers (e.g. Milner, Aitken, Byars, Butterworth, & Kavanagh, 2020; Patton, Ware, McPherson, Emerson, & Lennox, 2018; Vu, Khanam, Rahman, & Nghiem, 2020)

- *Growing up in Australia: the Longitudinal Study of Australian Children (LSAC)* which is administered as a partnership between the Department of Social Services, the Australian Institute of Family Studies and the Australian Bureau of Statistics. Six papers analysed data from this survey. It was used, for example, in the epidemiology of hearing loss in children aged 11-12 over the past 25 years (Wang et al., 2018), for linking with pharmacy dispensing data from the Australian Government Pharmaceutical Benefits Scheme to understand psychotropic medication provision to children with autism (Rasmussen, Pratt, Roughead, & Moffat, 2019) and to understand psychological distress in fathers of children with autism and associated personal risks (Seymour, Giallo, & Wood, 2018).

- The ABS *Survey of Disability, Ageing and Carers (SDAC)* was used in 20 studies. The SDAC provides a population data collected by the ABS on the prevalence of disability and the demographic characteristics of people with disability, older people and carers. This included economic analyses of disability related care (e.g. Schofield et al, 2019), prevalence estimates (e.g. Coleman et al 2018) and profile of carers for different disability types (e.g. Diminic et al 2019).

- The ABS *Household Expenditure Survey* was used to examine food insecurity for people on disability support pension compared to other types of income support payments (Temple, Booth, & Pollard, 2019).

- The ABS *Australian National Health Survey* was used in one study to examine the link between the impact of disability, health service usage and mental illness (Zhou, Li, & Du, 2020).

- The ABS *General Social Survey* was used in one study to understand reports of discrimination in older Australians who have a disability (Temple, Kelaher, Brooke, Utomo, & Williams, 2020).

- The ABS *National Aboriginal and Torres Strait Islander Social Survey* was utilised to understand levels of interpersonal racism and avoidance towards Aboriginal and Torres Strait Islander people with disability (Temple, Wong, et al., 2020a) and to measure physical violence, threats exposure and disability (Temple, Wong, et al., 2020b).

- The AIHW *Australian Child and Adolescent Survey of Mental Health and Wellbeing* was used to describe attendance at school of children with mental disorders (Lawrence, Dawson, Houghton, Goodsell, & Sawyer, 2019).

- The *Australian Early Development Census (AEDC)* which is a collaboration between the Federal Government the Centre for Community Child Health, Royal Children's Hospital, Melbourne, and the Telethon Kids Institute. It was used in two studies to examine the development of children with hearing loss (Simpson et al., 2020; Su et al., 2020) and in a study of school readiness in children with a parent hospitalised with mental illness (Bell, Bayliss, Glauert, Harrison, & Ohan, 2019).

- *Australian Longitudinal Study on Male Health ('Ten to Men')*, funded by the Australian Government and hosted by the Australian Institute of Family Studies and the Social Research Centre (SRC). It was used in three studies, for example to examine the connection between self-report disability and suicidal thoughts (Milner, Bollier, Emerson, & Kavanagh, 2019) and to compare aspects of sexual function between disabled and nondisabled men using a representative sample (Bollier, King, Shakespeare, Hocking, & Kavanagh, 2019).

- The *Bettering the Evaluation and Care of Health* (BEACH) GP dataset was used in two studies. For example, it was used to understand prescribing by GPs for people with intellectual disability compared to people who do not have intellectual disability (Salomon, Britt, Pollack, Biomed, & Trollor, 2018).

- The Global Burden of Disease Study 2015 was used to examine burden due to mental and substance use disorders in Australia (Ciobanu et al., 2018).

- The AIHW *National Aged Care Data Clearinghouse* was used to evaluate trends in rates of young people entering and leaving residential aged care from 2008 to 2018 (Brown, Bishop, Winkler, & Douglas, 2020).

- The *National Coronial Information System* was used to understand rates of child drowning and included conclusions related to intellectual disability (Chang & Ozanne-Smith, 2020).

- The *Royal Life Saving National Fatal Drowning Database* was also used to understand drowning deaths in children with autism (Peden & Willcox-Pidgeon, 2020)

Disability-specific databases

- The Federal Department of Health *Australian National Survey of Psychotic Illness* was used in three studies to understand the health-related quality of life, functioning and social experiences in people with psychosis (Nevarez-Flores et al., 2020) and loneliness and psychosis (Badcock, Di Prinzio, Waterreus, Neil, & Morgan, 2020; Badcock et al., 2019).

- The *Australian Rett Syndrome Database* was used in 4 studies. For example, one study described the oral health of individuals with Rett syndrome (Lai, Wong, King, Downs, & Leonard, 2018) and another study used the Down Syndrome, Australian Rett Syndrome and International CDKL5 Disorder databases to examine parental well-being in caregivers of children with one of those disorders (Mori, Downs, Wong, Heyworth, & Leonard, 2018).

- The *Cerebral Palsy Register* was used in three studies, including to understand the comorbidity of cerebral palsy and intellectual disability (Reid, Meehan, Arnup, & Reddihough, 2018) and to understand the types of socio-economic disadvantage that are correlated with severity of cerebral palsy (Woolfenden et al., 2019).

- The *National Survey of High Impact Psychosis* was used in three studies, for example to investigate the impact of having versus not having a carer on length of hospital stay for mental illness (e.g. Hielscher, Diminic, Harris, et al., 2019).

- The *Australian Longitudinal Study of Adults with Autism* administered by the Autism CRC was used in 10 studies. For example, it was used in one study to examine participation and satisfaction by autistic adults in leisure activities (Stacey, Froude, Trollor, & Foley, 2019) and another paper which described features of the cohort and the research development (Arnold et al., 2019).

In addition to these population data sets, research teams brought together data from multiple administrative data sets and linked datasets. This included one study that used the Western Australian Monitoring of Drug Dependence Systems, Western Australian Literacy and Numeracy Assessment database, and the Midwives Notification System to look at literacy and numeracy in children with ADHD (Silva et al., 2020). Another used the Department of Human Services, Victorian Minimum Data Set and the Restrictive Intervention Data System to examine characteristics of people with disability upon whom restraint is used for neither therapeutic or legal reasons (Webber et al., 2019). Eight papers used administrative data from disability and health care providers. Four papers utilised aggregated data from different court record keeping systems: the NSW District Court (Nielssen, Yee, Dean, & Large, 2019), QLD Coroners' Court (Crissman, 2019), QLD Mental Health Court (Young et al., 2018) and Children's Courts (Baidawi & Piquero, 2020) and one drew on police system data (Hwang et al., 2020).

The papers identified in the search show that population, administrative and disability-specific data sets are being used in important ways to provide strong evidence for policy. The broad range of purposes and research questions to which these datasets are put shows that these data sources are an important resource that could potentially be better utilised. The administrative data sets hold enormous potential for understanding the impacts of policy changes and past policy changes via natural experiments. They should be understood and utilised to monitor the new National Disability Strategy where possible. The National Disability Data Asset[9] aims to utilise the data held in many of these data sets ensuring it becomes accessible for answering important disability research questions. We also, as a field, need to upskill disability researcher knowledge of the potential and contents of these data sets.

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[9] The National Disability Data Asset is a national government-led project which aims to link and promote access to disability-related data held by governments at all levels in Australia. For more information about the asset visit this webpage: **www.ndda.gov.au**

Papers that take a rights-based approach

We identified 87 research papers and 5 research reports that specifically referenced the rights of people with disability. The main topics of these papers were education (n = 14), employment (n = 4), disability accommodations (n = 7), economic security and social security payments (n = 3), health services, health and wellbeing (n = 8), criminal justice and legal systems (16), lived experiences of disability for people with disability (n = 6) and family members, supporters, allies and unpaid/informal caregivers (n = 3), policy (n = 22), safety security discrimination and abuse (n = 9), self-determination (n = 4) education (n = 2) and workforce development and leadership (n = 8). Three papers used intersectional theoretical approaches to draw attention to human rights in the context of disability and Indigeneity (e.g. Bielefeld & Beaupert, 2019) and addiction and disability (Bunn, 2019). Four had a focus on rights implications of technology including electronic health records for children (Meredith, McCarthy, & Hemsley, 2018), the concept of 'choice' in assistive technology access under the NDIS (Steel, 2019) and digital inclusion (Goggin, Ellis, & Hawkins, 2019).

Twenty-nine papers specifically referenced the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Papers focusing on the CRPD mainly had a focus on the criminal justice and legal systems (12 papers), including guardianship in the context of COVID-19 (Wilson, 2020) and the impact of the CRPD on guardianship hearing discourse and decision making (Watson, Anderson, Wilson, & Anderson, 2020), consumer law for people with cognitive disability (Maker, Arstein-Kerslake, McSherry, Paterson, & Brophy, 2018), advocacy for parents with intellectual disability engaged with the child protection system (Collings, Spencer, Dew, & Dowse, 2018) and right to access to private transport for people with disability and their families, supporters and carers (Darcy & Burke, 2018). Several papers focused on human rights in the context of Australian laws or treatment practices which allow treatment that is compulsory or involves seclusion and restraint (e.g. Gill, Allan, Clark, & Rosen, 2020;). Amongst others were papers focusing on bringing a human rights approach to operationalising support for people with intellectual disability (Didi, Dowse, & Smith, 2018) and a paper that took an intersectional approach and focused on human rights in the context of both disability and Indigeneity (Harpur & Stein, 2018). Six papers focused on the CRPD in relation to education. These focused on either the use of restraints (e.g. Poed, Cologon, & Jackson, 2020) or inclusion (e.g. Cologon, 2020).

Research focusing on children, youth and young adults

This section considered papers that focused on children and young people up to the age of 30 years. The rationale for selecting this age range is that defining an adolescent period by age group is complex, that many studies consider a broader age range once they include older teenagers and we wished to be inclusive, and importantly, we wished to consider the critical period of transition to adulthood[10].

There were 318 research papers (25.6% of the total number of papers) and 36 research reports (16%) which focused on children and young people. This section will include some overlap with narrative summaries above where they have reported on children, youth and young people. In this set of papers, the majority focused directly on children and young people with disability. The remaining research papers focused on the families, supporters or unpaid carers of children and young people with disability or focused on workforce and staffing. A small number of papers focused on multiple groups of participants (e.g., children and their teachers) and several others focused on regulation or policy. We used a range of age groupings to categorise the ages of children and young people in the papers and Covidence extractors were also able to add their own categories under 'other'. The results of these groupings are in table 9.

Table 9: Number of papers focusing on children, adolescents and young people by age group.

Age grouping	Research papers	Research reports
Children (5 < 18)	101	9
Children of any age	89	14
Young adults (18 < 30)	61	8
Infants and early childhood (<5)	36	0
Adolescents	23	4
Children and adolescents or young people (n=4), other age groups: 0-25 years, 12-30 years, 12-25 years, <25 years (n=4),	8	0
Total	**318**	**36**

The types of disability discussed as a focus of the papers are listed in the table below.

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[10] Sawyer et al (2018) writing in the Lancet Child and Adolescent Health suggest a definition of adolescence using an age range of 10-24. People doing studies do not cleanly choose a year-based cut off – or they all choose something different for various reasons and we did not want to unnecessarily exclude studies on this basis. Based on discussions in our team, we extended the category of young people age up to 30 years because many people with child-onset disability will experience delays in development – thus it is not an unreasonable extension on the contemporary notion of adolescence-related development (social and physical), and also because we wanted to capture the period of young adulthood.

Table 10: Number of papers focusing children and young people by disability type.

Disability focus of paper	Research papers*	Research reports
General discussion of disability	87	12
Autism	88	16
Intellectual disability	42	2
Hearing impairment/ Deaf	25	0
Mental illness	12	1
Cerebral palsy	12	0
Foetal Alcohol Spectrum Disorder	11	0
Vision impairment	11	0
Communication disability	6	0
Developmental disability	6	4
ADHD#	5	1
Neurodevelopmental disability	4	0
Behavioural	3	0
Brain Injury	3	0
Other: e.g. spinal cord injury (1), Down syndrome (4), mobility impairments (2), physical disability (1), spinal muscular atrophy (1)	9	0
Total	**325***	**36**

It is a limitation of this study that we will have missed papers where a particular diagnostic category is not aligned with the disability literature and we did not specifically search for the particular diagnostic category (see search terms included in the Appendix 1). In the case that the paper does not talk about disability in its title or abstract then it would likely have been missed from the analysis.

* Some papers equally focused on 2 or 3 main types of disability, so numbers will not add up to the total number of papers

Table 10 shows a large number of papers focusing on children with autism with the next biggest group being papers generally focusing on children with disability.

Education was the most frequent focus with 132 research papers and 17 research reports focusing on education. Of research papers that specified an education phase, papers focused on early childhood education (n = 16), primary school (n = 25), secondary school (n = 22), both primary and secondary (n = 7), higher education (n = 11) and transitions between levels or types of education (n = 10). The specific focus of education papers is listed in the table below.

Table 11: Number of papers focusing on education and children and young people by focus area.

Education papers focus	Research papers	Research reports
Student experiences	23	6
Inclusion	21	1
Student outcomes	20	0
Teacher experiences	17	1
Parent experiences	10	1
Disability accommodations	6	2
Teacher training and workforce development	5	4
Education policy and regulation	5	2
Student participation*	3	0
Student attendance	3	0
Pedagogy/ curriculum	2	0
Other (includes also papers that focused on more than one area)	17	0
Total	**132**	**17**

* Student participation refers to in-class participation and student attendance refers to school attendance

As demonstrated in Table 11, above, of the 21 research papers and one research report focused on **educational inclusion**, most were in the secondary school context (n = 7) with a further eight papers and one report not specifying an age group or education level. Three papers focused on higher education (e.g. Maxwell, 2019), two on both primary and early childhood education (e.g. Gigante & Gilmore, 2020) and one paper focused on inclusion when transitioning between schooling levels. Issues explored included the interaction between children and educators (Faragher & Clarke, 2020); attitudes of students and parents toward social inclusion; the legal context of inclusion and safety for students with disabilities (Robinson, 2018); inclusive education policy analyses (Slee, 2018); funding mechanisms (Sharma, Furlonger, & Forlin, 2019); current practices and barriers in Australia; and inclusive education needs and practices for children with autism or vision-related disability (e.g. Jessup et al., 2018),. Almost half of the research papers focusing on inclusion did not focus on a type of disability (n = 10). Five papers focused on inclusion of children with autism and 4 focused on inclusion of children with visual impairments. Only three of the papers that explored inclusive education also had a focus on children from culturally and linguistically diverse communities or Aboriginal and Torres Strait Islander communities.

Educational experiences from varied perspectives were explored in 53 research papers and 8 research reports- 29 from the student's perspective, 11 from a parent's perspective, 18 from a teacher's perspective and two from a combination. Seven of the papers and reports were focused on primary

school, 4 in secondary school, 4 on higher and vocational education, 12 across both primary and secondary or no specific level, and 4 in relation to transition between schools or levels. The focal groups included in this body of work were autism (almost half of these papers), intellectual disability, general disability and hearing loss. There were no papers focused on children and youth from culturally and linguistically diverse communities or Aboriginal and Torres Strait Islander communities. Topics explored included the following: experiences of schooling and inclusive education including transition between schooling levels and from mainstream to special school (Chen et al., 2020); experiences supporting students with disabilities in school; provision of specialised programs and assessment models to guide education (Olave-Encina, 2019); barriers and facilitators to inclusive education (Munchan & Agbenyega, 2020); literacy and learning outcomes (Moni, Jobling, & Baffour, 2018); changes experienced since the NDIS rollout (Marchbank, 2019) and COVID-19 (Yates, Dickinson, Smith, & Tani, 2020); relationships between school readiness and parental mental illness (Bell, Bayliss, Glauert, Harrison, & Ohan, 2019); experiences with eLearning (Kent, Ellis, & Giles, 2018); experiences of abuse (Robinson, 2018); rural and regional education; inclusive mathematics (Barr & Mavropoulou, 2019); effectiveness of early education; motivations to pursue higher education and training (Hatfield, Ciccarelli, Falkmer, & Falkmer, 2018).

Health, wellbeing and quality of life papers comprised the next largest group (n=43 research papers, n=4 research reports). Health services research was the largest subgroup and examples of issues addressed include: use of telehealth services to reach rural/remote children and youth (Hines, Bulkeley, Dudley, Cameron, & Lincoln, 2019), exploring impact on identification of disability in relation to difficulty in achieving neonatal follow up at age 8 years (Doyle et al., 2018), impact of having a disability (as a marginalised group) on navigating health care systems (Robards, Kang, Usherwood, & Sanci, 2018), nursing care of youth with intellectual disability (Lewis, Wilson, Jaques, O'Reilly, & Wiese, 2019), extent of unmet need of youth with mental disorders in Australia (Johnson, Lawrence, Sawyer, & Zubrick, 2018) and extent of care provided to young people with mental illness (Hielscher, Diminic, Kealton, et al., 2019).

Health services research involving children and youth with autism explored reasons for general practice encounters for children with autism (Foley, Pollack, Britt, Lennox, & Trollor, 2018), quality of care provided by GP and paediatricians in autism (Churruca et al., 2019) factors that optimise care of children with autism during hospitalisations (Taghizadeh, Heard, Davidson, Williams, & Story, 2019), need for schools, universities and employers to understand diversity of strengths and needs in young people with autism (Pillay, Brownlow, & March, 2020), feasibility of telehealth delivery of speech and language services to children with autism (Sutherland, Trembath, Hodge, Rose, & Roberts, 2019), review of assessment practices for children with autism who are minimally verbal (Trembath & Tager-Flsuber, 2019), and use of canine-assisted therapy in autism (Hill, Ziviani, & Driscoll, 2020). Other papers reported the impact of mental disorders on school attendance (Lawrence et al., 2019), presence of multiple risk factors for cardiovascular

disease in young people with psychosis (Hahn et al., 2018), poorer mental health outcomes associated with disability or borderline intellectual impairment (King et al., 2019), the risk of traumatic injury associated with intellectual impairment (White, McPherson, Lennox, & Ware, 2018), mitigating the impacts of COVID-19 on children and youth with disability (Jones et al., 2020), behavioural profiles of children with autism (Adams, 2019), and social capital in hearing impaired youth (Wong, Ching, Whitfield, & Duncan, 2018).

Health services research involving Aboriginal and Torres Strait Islander children and young people included exploration of the relationship between hearing impairment and child-protection notifications in Aboriginal children (He et al., 2020), experiences of system interactions and access to meaningful care (Green et al., 2020) and an exploration of service coordination needs to influence access and use of early intervention in Aboriginal and Torres Strait Islander children (Green 2020). Intersectional work included a study on the risk of hospitalization of disabled children in Indigenous and migrant families (Abdullahi et al., 2020).

Health impacts on parents and families were also researched including: mental health needs of mothers of children with disability (Gilson, Davis, Johnson, et al., 2018), developing a resource for mental wellbeing for parents (Gilson, Davis, Corr, et al., 2018), supporting families of children with rare conditions (Gilmore, 2018), impact on families of caring for a child with spinal muscular atrophy (Farrar, Carey, Paguinto, Chambers, & Kasparian, 2018), supporting key workers to support parental mental wellbeing (Davis et al., 2019), exploring family quality of life (Bhopti, Lentin, & Brown, 2020) and sibling adjustment in presence of paediatric brain injury (Bursnall & Degeneffe, 2018) and maternal stress in presence of autism (Zheng, Grove, & Eapen, 2019).

Quality of life research (n=11 research papers, n=1 research report) has focused on wellbeing in relation to children with autism (Danker, Strnadová, & Cumming, 2019), impact of anxiety on quality of life (Adams, Clark, & Keen, 2019), quality of life profiles in children/youth with ADHD and autism (Thomas, Sciberras, Lycett, Papadopoulos, & Rinehart, 2018), and of parents/families with children with autism (Willet, Dorstyn, Due, & Li, 2018), Down's syndrome (Haddad, Bourke, Wong, & Leonard, 2018; Shields et al., 2018) and specific language impairment (Nicola & Watter, 2018). Several studies also focused on quality of life instruments for children/youth (e.g. Downs et al., 2019). One report conducted in partnership with the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council focused on what makes a good life for Aboriginal children with disabilities and their families in Central Australia (Gilroy et al, 2018).

Lived experience of disability was considered in 27 research papers and 3 research reports addressing child and/or youth lived experience of disability. Of the research papers, 15 reported on experiences of children and youth with disability. Issues related to service provision and participation in decision making

for those with profound impairments (King, 2020), complex support needs (Ellem, Smith, Baidawi, McGhee, & Dowse, 2020), higher education (Datta, Halder, Talukdar, & Aspland, 2019), bullying (Kavanagh et al, 2018), isolation (Merrells, Buchanan, & Waters, 2019), wellbeing and quality of life (e.g. Anderson, Carter, & Stephenson, 2020). The three reports include two which focus on the desire of adolescent and young adults with disability to be included in decision making of relevance to them (e.g. Office of the Advocate for Children and Young People in Australia, 2020).

Twelve research papers focused on family (parents or siblings) and, using varied methods, sought to understand parent wellbeing (Mori, Downs, Wong, & Leonard, 2019), supports required, practical assistance and positive personal interactions (Mizzi, Honey, Scanlan, & Hancock, 2020), need for disability-specific information (Steward & Spurgeon, 2020), experience of diagnosis and access to services generally (Aitken et al., 2019; Bent, Barbaro, & Dissanayake, 2020), or in rural/remote areas (Dee-Price, 2020a), or the NDIS (Barr, Dally, & Duncan, 2020). One paper (Ellem, 2018) explored lived experience of other support-persons in the criminal justice system. Four research reports focused on parent experiences of disability, supports and systems (e.g. Parents of ADHD Advocacy Australia, 2019).

Usefulness of mentors was explored in three papers, including in navigating the transition to further education for children and young people with autism (e.g. Ashburner, Bobir, & van Dooren, 2018).

Service development and evaluation; service access, workforce development and leadership in relation to children and young people were considered in 20 papers; 14 service development, 3 workforce development, 2 NDIS, 1 service access. Issues considered included: contextual factors that impact wellbeing in the context of accessing NDIS (Loadsman & Donelly, 2020), impact of social inequities on transition to NDIS (Boaden, Purcal, Fisher, & Meltzer, 2020), service provider understanding of Aboriginal and Torres Strait Islander children and young peoples' access to services, the need to remove the silo approach to mental and physical health care needs (Son, Debono, Leitner, Lenroot, & Johnson, 2019) and service gaps (quality and frequency) in rural, regional and remote communities (Barr, Duncan, & Dally, 2018). Evaluation studies focused on, for example, service design approaches in autism (Thompson-Hodgetts & Magill-Evans, 2018) In relation to family-centred care, implementation issues for family centred approaches (e.g. 2020; Ellem, Chenoweth, & Edwards, 2019), use of the Canadian Occupational Performance Measure for person-centred goal setting (Mathews, Mozolic-Staunton, Jefford, & Salehi, 2020), effect of specific interventions for parents or from parent perspectives (Brown & Gillon, 2019; Hines, Bundy, Haertsch, & Wallen, 2019), and importance of relationships in service provision (Robinson et al., 2020) were studied. Other service and system-focused papers identified included a lack of autism research and services in Aboriginal and Torres Strait Islander communities (Lilley, Sedgewick and

Pellicano, 2019) and reviewed policy outcomes in out-of-home care (Purcal, Hill, Meltzer, Boden & Fisher 2018).

Social and community involvement, participation in arts culture and literature were considered in 19 papers relating to children and young people; 16 related to social and community involvement and 2 related to the arts, culture and literature. Topics considered included: value of music (Looi, Torppa, Prvan, & Vickers, 2019), involvement in library story time (Paynter & Westerveld, 2020), negotiating community transport and mobility (Kersten, Coxon, Lee, & Wilson, 2020), access to wild nature (Galbraith & Lancaster, 2020), role of local government in inclusive outdoor play spaces (Sterman, Naughton, Bundy, Froude, & Villeneuve, 2019), an overview of evidence based interventions for children (Novak & Honan, 2019), modifiable factors supporting community participation (Shields, Epstein, et al., 2020) and social participation for those with profound impairments (Gauthier-Boudreault, Beaudoin, Gallagher, & Couture, 2019).

Ten papers focused on physical activity participation and sport for children, youth and young adults, highlighting: the need for transformational inclusive approaches to community sports (Jeanes et al., 2018, 2019) including taking a social model of disability approach (Darcy, Ollerton, & Grabowski, 2020), opportunities afforded by accessible sports e.g. All-Play football (Howells, Sivaratnam, May, Lindor, & Rinehart, 2019) and Auskick (May et al., 2019; May & Williams, 2018). Studies also focused on systemic issues relating to participation, including access to community sports (Borland, Hu, Tonge, Einfeld, & Gray, 2020), service provider supports to enabling sports participation and lack of appropriate sports opportunities (Wright, Roberts, Bowman, & Crettenden, 2019), issues pertinent to physical activity participation in rural settings (Robinson, Wakely, Marquez, & Rae, 2018), and a framework for supporting sustained participation in physical activity (Morris, Imms, Kerr, & Adair, 2019).

Law, criminal justice and rights for children and youth were considered in 14 papers. Of these, 6 papers addressed issues for Aboriginal or Torres Strait Islander children and young people. These 6 papers explored factors associated with offending, including hearing impairment (He et al., 2019), exploration of issues related to FASD, including diagnostic assessments in detention settings (Hamilton, Reibel, et al., 2020), prevalence of FASD in young people in detention (Bower et al., 2018), models and methods to address the over-representation of youth with FASD in detention (e.g. Blagg & Tulich, 2018). Of the remaining papers, the issues addressed included role of the family court in decisions regarding growth attenuation treatment for profoundly impaired children (Lee Spyrou, 2019), examination of the extent to which the mental health tribunal operates as a rights-based model for young people with mental illness (Kotzmann et al., 2018), training needs of detectives involved with youth with ADHD (Cunial, Casey, Bell, & Kebbell, 2020), criminalization of young people with disability (Baldry, Briggs, Goldson, & Russell, 2018),

and an examination of the interaction between youth and police at the point of entry to the justice system (Richards & Ellem, 2019). Reports focused on children and youth overall to address the relationship between involvement with child protection and youth justice (AIHW 2020), and trends in involvement of children aged 10years and older in youth detention (AIHW 2020).

Safety, security, discrimination and abuse was considered in 5 papers including children/youth with various disabilities. This included three papers on various aspects of the impact of bullying (e.g. Moffat, Redmond, & Raghavendra, 2019). 2 papers focused on the need to enable children with disability to stay safe and discuss feeling unsafe (e.g. Robinson & Graham, 2019).

Of the 9 papers **focused on communication**, 4 addressed issues related to hearing loss including language development (Cupples et al., 2018), parental decision making about communication methods (Scarinci, Gehrke, Ching, Marnane, & Button, 2018) and barriers to early intervention (McLean, Ware, Heussler, Harris, & Beswick, 2019). The remaining 5 papers explored alternative and augmentative communication: barriers and facilitators to use (Donato, Spencer, & Arthur-Kelly, 2018), review of predicters and outcomes of AAC (Sievers, Trembath, & Westerveld, 2018), long term follow up of outcomes from use of picture exchange communication system use (Jurgens, Anderson, & Moore, 2019) and exploration of communication behaviours of children who are minimally verbal (Mei et al., 2020).

Technology. Nine papers addressed aspects of technology as a primary focus, 5 involved those with autism, 2 with cerebral palsy, 1 was not disability specific and 1 addressed those with hearing impairments. Of these, 2 papers focused on the use of tablets to support learning (Roberts-Yates & Silvera-Tawil, 2019) or augment therapy for children with autism (Parsons, Cordier, Lee, Falkmer, & Vaz, 2019). Two addressed use of eye-gaze technology for children with cerebral palsy (Karlsson, Allsop, Dee-Price, & Wallen, 2018; Karlsson et al., 2019). Three explored use of telehealth (e.g. Johnsson, Kerslake, & Crook, 2019).

Employment and volunteering of young people were addressed in 4 papers and 4 reports. Transition from school to employment was considered in 3 papers, for example one which investigated the effectiveness of Transition to Work service providers in achieving employment outcomes (Xu & Stancliffe, 2019). Reports included a report by the LaTrobe University Living with Disability Research Centre (Theile et al, 2018) which reviewed the literature on the experiences of school students with intellectual disability participating in work. Additional papers reported on the experience of young people with first episode mental illnesses and found that vocational interventions need to be targeted differently across diagnostic groups (Caruana et al., 2018); and another (Shields, Dimov, et al., 2020) examined the association between employment-seeking when unemployed and distress, and found that those young people with

disabilities seeking employment had increased odds of poor mental health and suggested that supporting young people to gain employment could improve mental health. When the practice of using work capacity assessments to determine capability for work was examined findings were that the current policy creates stigma and division between service users and service providers (Stafford, Marston, Beatson, Chamorro-Koc, & Drennan, 2019). This study recommended a rights and self-determined approach to supporting education to employment pathways. Employment-focused social enterprises to provide a pathway out of disadvantage were considered (Centre for Social Impact, Swinburne University, 2019) as was the effectiveness of a strengths-based program for adolescents with autism (Bankwest Curtin Economics Centre). This report identified essential components of strengths-based programs and suggested service providers need to consider facilitators, activities and environment when planning these interventions.

Within the children and youth papers and reports, there were two papers that reported **findings existing of research priority setting for children**: one from a paediatric hospital (Lopez-Vargas et al., 2019) that focused on children with chronic conditions and reported the following priorities: focus on life participation, psychosocial well-being, impact on family and quality of care. The second paper sought perspectives of parents of children with autism (Clark M, 2020). Clark reported that understanding the parent, sibling, child and family impact and stress was the highest ranked priority for home settings, teacher/staff education and support for the school setting and recognizing and supporting anxiety for the community.

Funding sources

Of the research papers identified for the 2018-2021 period, 582 (47%) of papers had one or more funding sources noted. For research reports 170 (76%) reported a funding source. A break-down of the overall funding by source is shown in table 12 and figure 3, below. Some papers reported more than one funding source. Some grant schemes (e.g. ARC Linkage Grants, NHMRC Partnership Grants) encourage funding from partner organisations. Where partner funding was noted, these were noted separately

It is important to note that these figures are necessarily limited by the information that authors chose to acknowledge or were obliged (or not) to include in research papers and research reports.

**Table 12:** Funding sources by number of papers identified.

Type of funding	Research papers	Research reports
Government funded projects (postgrad, ARC, CRC and NHMRC listed separately below and not counted here)	160	61

NGO, charity and foundation funding	99	57
Private sector	17	2
ARC schemes	109	12
NHMRC schemes	117	4
CRC schemes	54	18
University funding	112	9
Australian Government postgraduate funding	47	1
International funding	36	0
Other (unable to classify source)	13	6
Total*	**765**	**170**

* note that projects often reported more than one funding source, so the number of funding bodies does not add up to the number of papers that acknowledged a funding source.

Figure 3. Main source of disability research funding

MAIN FUNDING SOURCES: RESEARCH REPORTS
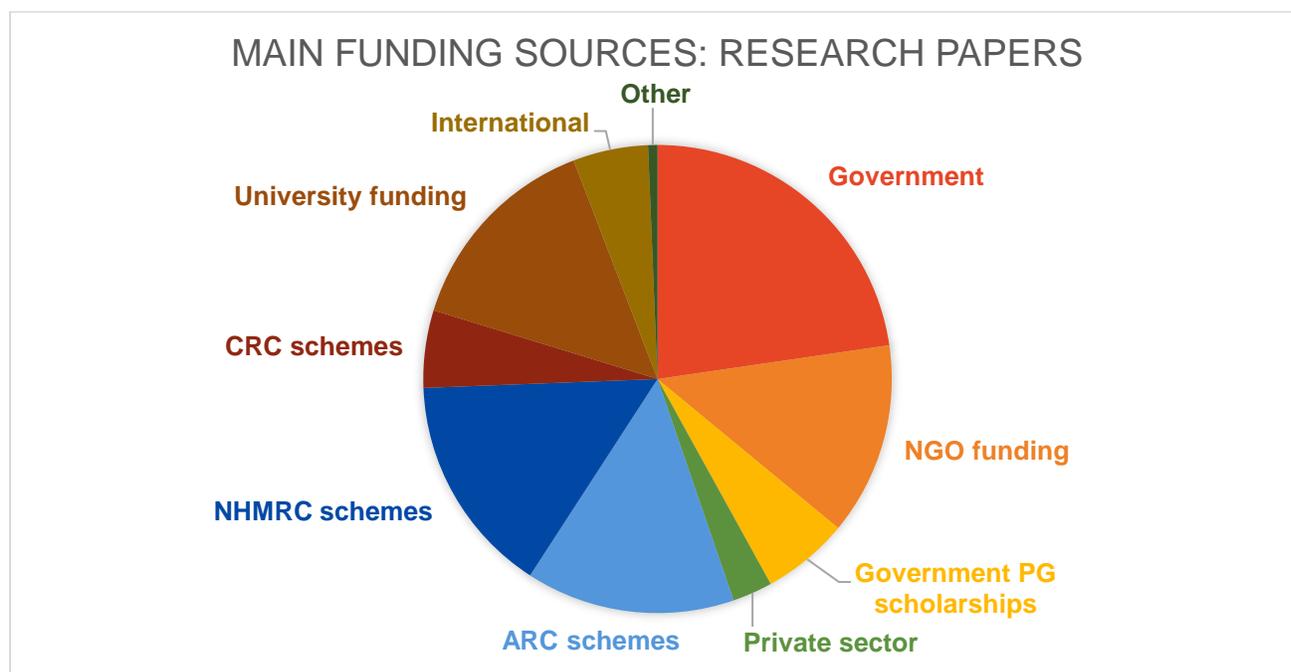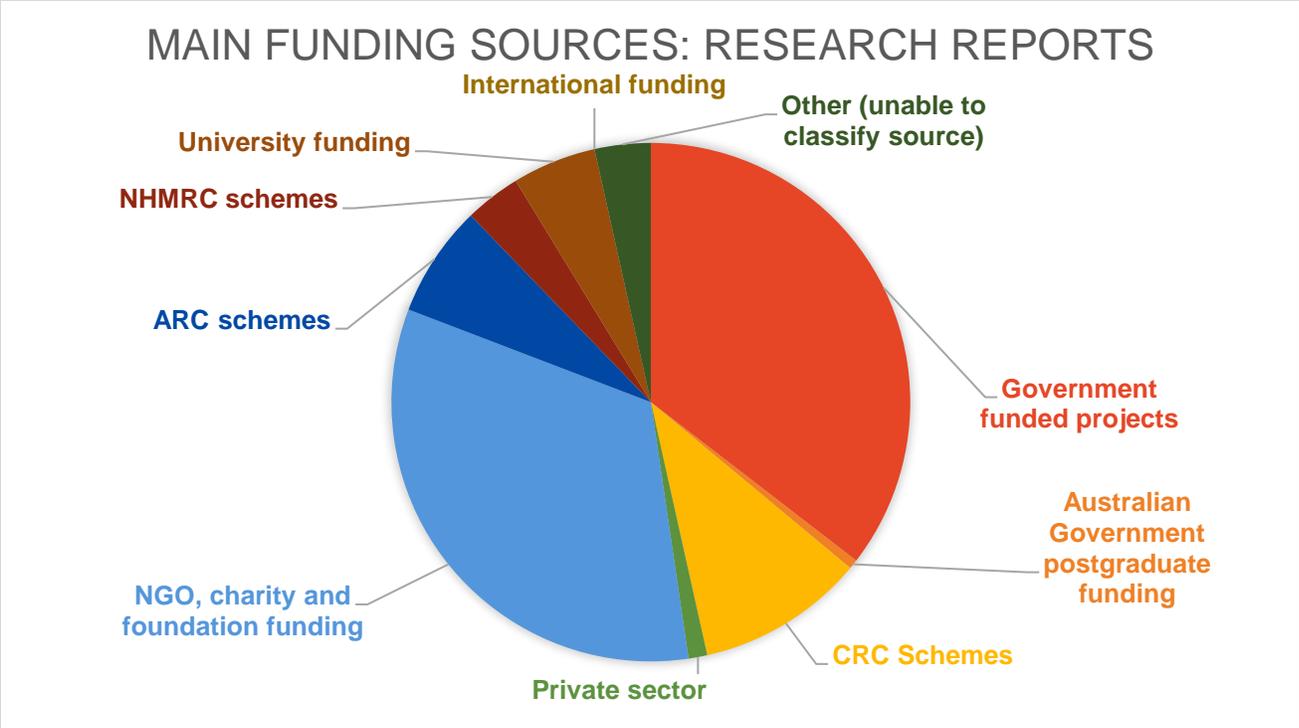
NGO, charity and foundation funding were reported in 99 research papers and 57 research reports and came from a broad range of organisations, mainly in the disability and mental health sectors, but with many working broadly across health and social care. For the research papers 38 separate foundations and charities providing funding. These are listed in the box below.

Geelong Community Foundation, auDA Foundation (2), Perth Children's Hospital Foundation, The Jack Brockhoff Foundation (2), the APEX Foundation for Research into Intellectual Disability (2), and the Royal Children's Hospital Foundation (3), Sydney Medical Foundation, Victorian Health Promotion Foundation (2), Movember Foundation, WA Foundation for Deaf Children, Deafness Foundation of Australia, Endeavour Foundation (4), Repat Foundation, Pratt Foundation, Mater Foundation (2), National Heart Foundation of Australia (2), Lishman Health Foundation (2), Lord Mayor's Charitable Foundation, Clem Jones Foundation, Financial Markets Foundation for Children, National Stroke Foundation, Pierce Armstrong Foundation, Pride Foundation Australia, Cerebral Palsy Alliance Research Foundation, Select Foundation, Minderoo Foundation, Collier Charitable Fund, Western Australian Nurses Memorial Charitable Trust, the Lorenzo and Pamela Galli Charitable Trust, GALFA (now renamed Pride Foundation Australia), Sidney Myer Fund, The University of Melbourne Humanities Foundation Board, H+L Hecht Trust, the Joanne Tubb Foundation, Law and Justice Foundation of NSW, Simons Foundation, MJD Foundation and the Roger Montgomery Family Trust.

Private funding came from BHP (3), Ferrero Group, Moose Toys (2), Hewlett Packard, Microsoft, the pharmaceutical companies AbbVie and Pfizer (3), the hearing device manufacturers Phonak, Oticon and Unitron, and several private disability and health care providers.

International funding was usually for studies that were centred in other countries that included Australian participants or Australian studies from the last 10 years, or was part of a consortium of Australian and international partners collaborating to fund research (e.g. Baldry et al., 2018).

Overall funding by Australian government bodies via direct funding, ARC, NHMRC and CRC grants and postgraduate awards made up the vast majority of funding producing research papers, with 487 mentions, followed by university-sector funding (n = 112), NGO funding (n = 99) and Private (n = 17). The share of funding is represented in figure 4, below. For research reports, governments also funded the most (n = 98), followed by the NGO sector (n = 57).

Figure 4. Disability research funding by sector, research papers.

Funding source by sector

Government 64%
University 14%
NGO 13%
Private sector 2%
International 5%
Other 2%
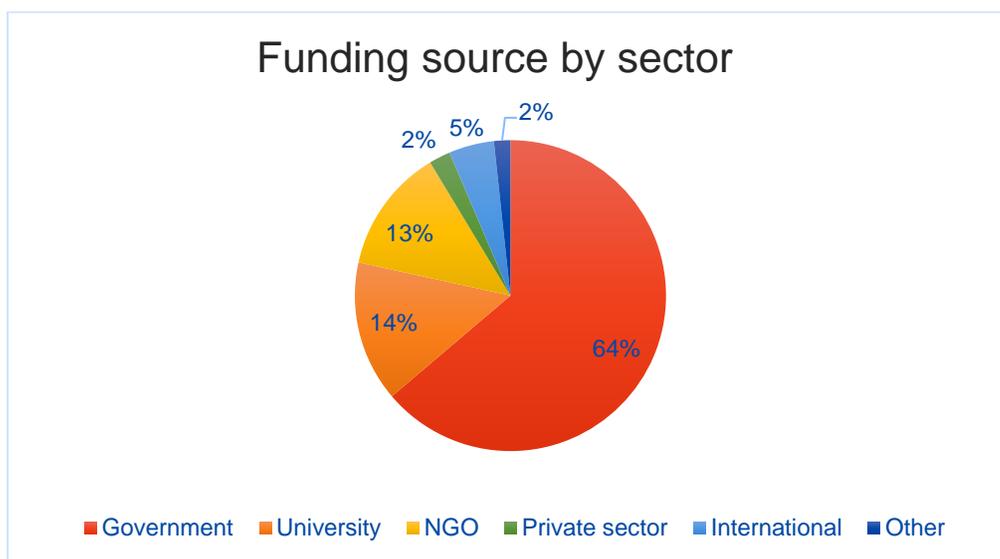
Government funding

Excluding government funding via the NHMRC, ARC, CRC and postgraduate training award programs, Australian Federal, territory and state governments were acknowledged as funding 160 research papers and 61 reports. The breakdown of funding provided by government is listed in table 13. The data show that the federal government funded most research through its departments and agencies, followed by the state governments of NSW (32) and Victoria (30). The ACT and Tasmania were not referenced as funding any research papers or research reports. Four of the Australian government funded grants were provided

through state-based primary health networks (PHNs). Most of these grants were to Partners in Recovery evaluation projects, which is likely as a result of the funding for independent evaluation that was provided via block funding to PHNs.

Table 13: Funding sources by type of government and number of papers identified

Government	Research papers funded	Research reports funded
Australian Federal government#	59	29
New South Wales	35	13
Victoria	34	7
Queensland	16	2
South Australia	6	0
Western Australia	7	2
Northern Territory	2	1
Australian Capital Territory	0	1
Tasmania	0	1
Cross-government collaboration (federal government and multiple states and territories.	3	5
Total*	**162**	**61**

Competitive grants funded under the ARC, NHMRC and CRC schemes are not listed here

* Some papers were funded by multiple governments

National Health and Medical Research Council (NHMRC) grant funding

One hundred and seventeen research papers and 4 research reports mentioned NHMRC funding. Twenty-six papers or reports mentioned NHMRC funding generally (no details or grant details not obtainable) but the rest reported specific funding schemes or identification numbers from which we were able to determine grant types. These are listed in table 14, below.

Table 14: NHMRC grant types by number of papers and reports.

NHMRC Grant type	Number of papers and reports referencing grant type	
Centre for Research Excellence (CRE)	34	34
Early Career Research Postdoctoral Fellowship	19	
Research Fellowship (level not specified)	11	
Career Development Fellowship	6	

Senior Research Fellowship	11	
Postgraduate Scholarship	3	
NHMRC-ARC Dementia Fellowship	2	
Capacity Building Fellowship	1	53
Partnership grant	14	14
Project grant	25	25
Program grant	6	6
Targeted Call for Research in FASD in Indigenous populations	1	1
General (grant type not specified)	26	26
Total		**159**[*]

* Some papers and reports mentioned more than one type of NHMRC funding.

From these data the most successful NHMRC schemes in terms of publication outputs were the fellowship schemes, CRE schemes, Project and Partnership grants. There were 53 fellowship grants referenced.

The funding for Centres for Research Excellence referenced most were: Disability and Health (n = 16), Foetal Alcohol Spectrum Disorder (8) and Recovering the Effects of Antenatal Alcohol on Child Health (n = 3).

Australian Research Council (ARC) funding

Of the papers and reports that mentioned ARC funding there were 125 funding grants referenced. These are listed in table 15 below.

Table 15: Number of papers and reports by ARC grant type

ARC Grant type	Number of papers and reports referencing grant type	Total
Linkage grant	61	61
Discovery grant	23	23
Future Fellowship	10	
Discovery Early Career Research Award (DECRA)	14	
NHMRC-ARC Dementia Fellowship	2	28
Postgraduate Scholarship	2	

Centre for Excellence in Population Ageing Research (CEPAR)	9	9
Generally referenced without details	5	4
Total		**125**[*]

* Some papers mentioned more than one type of ARC funding.

Three mentioned the ARC only generally in funding acknowledgements but the remaining papers reported specific schemes. Most non-fellowship funding came via the partnership-based Linkage grant scheme (61 articles) and the Discovery grant scheme (n = 23). The Discovery grant scheme has three types of fellowships. Of these, papers and reports referenced Future Fellowships (n = 10) and Discovery Early Career Fellowships (DECRA) (n = 14). There were no references to the third scheme – the Australian Laureate Fellowships. One Centre for Excellence was mentioned – the Centre for Excellence in Population Ageing Research (CEPAR). All 9 of the papers funded by CEPAR had the same lead author (e.g. Temple & Kelaher, 2018; Temple, Kelaher, Utomo, Williams, & Brooke, 2020). These papers used population data sets (Survey of Disability Ageing and Carers, National Aboriginal and Torres Strait Islander Social Survey, Household Expenditure Survey, General Social Survey) to mainly understand disability and discrimination.

Cooperative Research Centre (CRC) funding

Of the 54 research papers which were funded under the Australian Government's Cooperative Research Centre program, 44 were funded through the Autism CRC, 6 by the Hearing CRC, two by the Mental Health CRC, one by the Young and Well CRC and one by the CRC for Contamination Assessment and Remediation of the Environment. 18 research reports were also funded by the Autism CRC. Several of these reports reported research that was also reported in the research papers.

The University Sector

The university sector funded research in 112 research papers and 9 research reports. The funding was spread across a large number of organisations as shown in table 16.

Table 16: Number of research papers and reports funded through university funding, by university.

Griffith	18	University of Queensland	6
University of WA	5	Curtin	7
University of New England	2	RMIT	3
Deakin	4	Bond	1
Avondale	1	Queensland University of Technology	2
University of Adelaide	2	La Trobe	8
University of Western Sydney	3	Newcastle	2

University of Sydney	6	Tasmania	2
Wollongong	2	Flinders	5
Australian Catholic University	1	Swinburne	1
UNSW	10	University of Southern Queensland	1
University of Technology Sydney	3	University of Sunshine Coast	1
University of Melbourne	5	University not specified, or multiple	5

Of the university-based funding, much was provided by internal research centres such as the Hopkins Centre at Griffith University. While most funding types were not described, where it was, funding provided included PhD scholarships or top-up scholarships (10), seed funding (4), start up funding for new staff (4) and fellowships (4).

Conclusions

The mapping has shown that there is a significant amount of disability research taking place in Australia. There are growing amounts of research in some key areas including disability research by and with Aboriginal and Torres Strait Islander people, research into some groups, particularly those of people with autism and intellectual disability and their families, supporters, and allies, disability-focused education research and the policy context of the NDIS. Much of this is research associated with funding sources such as the Australian Government's schemes including the NHMRC Centres of Research Excellence and Cooperative Research Centres as evidenced in the large numbers of publications emerging from the collaborations that these schemes bring together.

It is important that research agenda is aligned where possible with the needs of the new National Disability Strategy so that research is able to both support the implementation of the strategy through creating new knowledge in areas of national importance, but also to monitor the implementation of the strategy. This mapping has shown that Australia has significant data sources in administrative and population data sets.

This report is phase one of a project funded by the National Disability Research Partnership whose overall aim is to inform the development of the research agenda for the NDRP. This first phase of this task has determined what disability research currently exists in Australia. This mapping phase will be built on by two subsequent phases. The second phase is a national consultation on disability research priority areas as identified by the disability community and the third is an exercise to determine key areas that must be addressed in Australian disability research.

Limitations

The research included in this mapping of disability research in Australia is limited by methodological and resource constraints. It was necessary to create a strict inclusion and exclusion criteria to make the project manageable and deliverable. In line with the previous Audit reports methods, we used words associated with Australia, states and territories as a limiter for the search. This may have meant that we inadvertently excluded some papers that did not mention where the study was carried out in the title or abstract. We will have missed papers where research that focuses on a particular diagnostic category focuses mainly on lab-based, diagnosis and treatment studies which were excluded from this review. If the paper or report did not talk about disability in its title or abstract, then they may have been missed because the databases

used do not have the capacity to search the full-text of research papers. The mapping results should be read in relation to the search terms used and the inclusion and exclusion criteria we applied.

In relation to the funding data, it is very likely that further funding was provided in relation to the research contained in the papers, but funder details were not included in the publication and we did not have the resources to go back to the paper authors to check. Some grants may also have produced papers which were not included in our review because they are not within its remit (e.g., papers that are treatment focused). Grants most active before and during the time frame (2018-2020) are more likely to be represented rather than grants that were just starting up during this time period. With respect to funding there may be an under-estimation of funding provided by government, private and NGO partner organisations on CRC, ARC Linkage and NHMRC Partnership grants where funders were not mentioned by name.

The report focuses on only the most prominent themes that we identified across the literature and cannot possibly do justice to all the important areas of research covered (and not covered) in the papers that we identified over the 2018-2020 period.

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Note: this reference list contains only the papers and reports that have been cited in this mapping report and is not a full list of the papers included in the mapping exercise. A full list of the papers is available in a supplement to the report.

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Appendix1. Databases and search terms used

Database	Searched Terms

AMED	1	disabilit*.mp. (30980)
	2	Handicap/ or handicap*.mp. (2505)
	3	"mental* retard*".mp. or Mental disorders/ (7874)
	4	"development* disabilit*".mp. (1202)
	5	Learning disorders/ or "learning disorder*".mp. (1126)
	6	"hearing impair*".mp. or Hearing disorders/ (878)
	7	Vision disorders/ or "vision disorder*".mp. (1080)
	8	Speech disorders/ or Deafness/ or "hearing disorder*".mp. (2201)
	9	"special needs".mp. or Learning disability/ or Disabled/ or Education special/ (5882)
	10	"cognitive disability*".mp. or Brain injuries/ or Cognition disorders/ or Psychotic disorders/ (7090)
	11	Communicative disorders/ or Cognition disorders/ or "communication disorder*".mp. (2641)
	12	Speech disorders/ or "communication disability*".mp. or Communicative disorders/ (1213)
	13	"neurological disorder*".mp. or Neurologic manifestations/ (740)
	14	Brain injuries/ or "brain injury".mp. (5101)
	15	"congenital disorder*".mp. (12)
	16	autism.mp. (1698)
	17	Chromosome abnormalities/ or Mental retardation/ or Language disorders/ or "fragile x".mp. (3500)
	18	"genetic disorder*".mp. (68)
	19	Cerebral palsy/ or "cerebral palsy".mp. (3345)
	20	Spina bifida occulta/ or "Spina bifida".mp. (236)
	21	down syndrome/ or "down syndrome".mp. (739)
	22	Fragile X Syndrome/ or "Fragile X syndrome".mp. (97)
	23	Fetal disease/ or Substance related disorders/ or "prenatal alcohol exposure".mp. (384)
	24	Rett syndrome/ or "Rett Syndrome".mp. (80)
	25	Psychosexual disorders/ or "psycho* disorder*".mp. or Mental disorders/ (7323)
	26	blind.mp. (3658)
	27	Vision disorders/ or "vision impair*".mp. (1087)
	28	"low vision".mp. (190)
	29	Hearing disorders/ or "hearing loss".mp. (897)
	30	*mute/ or deaf*.mp. [mp=abstract, heading words, title] (810)
	31	Learning disability/ or Sign language/ or sign language.mp. (3336)
	32	Mental handicap/ or "special education*".mp. (1538)
	33	"hard of hearing".mp. (137)
	34	Australia/ or australia.mp. (3011)
	35	Australasia/ or "new south wales".mp. (329)
	36	"northern territory".mp. (21)
	37	"australian capital territory".mp. (14)
	38	queensland*.mp. (180)
	39	Tasmania.mp. (15)
	40	Victoria.mp. (164)
	41	NSW.mp. (66)
	42	ACT.mp. (2074)
	43	NT.mp. (97)
	44	SA.mp. (262)
	45	WA.mp. (65)
	46	or/1-34 (59655)
	47	or/34-45 (5721)

	48 46 and 47 (3818) 49 limit 48 to yr="2011 -Current" (1358)
AVERY	S1 disab* OR handicap* OR "mental* retard*" " OR development* disabilit*" OR "intellectual disabilit*" S2 "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" S3 "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" S4 "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" S5 "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "Fragile X syndrome" S6 "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR blind S7 "vis* impair*" OR "low vision" OR "hearing loss" OR (*mute OR deaf*) OR "sign language" S8 Auslan OR "special education" OR "hard of hearing" S9 austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "Australian capital territory" OR "queensland* OR Tasmania OR Victoria S10 NSW OR ACT OR NT OR SA OR WA S11 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 S12 S9 OR S10 S13 S11 AND S12 S14 S11 AND S12
CINAHL	TI (disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" OR "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR mute OR deaf* OR "sign language" OR Auslan OR "special education*" OR "hard of hearing ") OR AB (disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" OR "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR mute OR deaf* OR "sign language" OR Auslan OR "special education*" OR "hard of hearing ") AND TI (austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria) OR AB (austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria)

Compendex	((((((((((autis*) WN ALL) OR (("fragile x") WN ALL)) OR (("genetic disorder*") WN ALL)) OR (("Cerebral palsy")WN ALL)) OR (("Spina bifida") WN ALL)) OR (("neurodivers*") WN ALL)) OR (("down syndrome") WN ALL)) OR(("Fragile X syndrome") WN ALL)) AND ((austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR"northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria) WN ALL))
	(((((((((("hearing disorder*") WN ALL) OR (("special needs") WN ALL)) OR (("cognitive* disability") WN ALL))OR (("communication disorder*") WN ALL)) OR (("communication disability*") WN ALL)) OR (("neurological disorder*")WN ALL)) OR (("brain injury") WN ALL)) OR (("congenital disorder*") WN ALL)) AND ((austral* OR "new south wales"OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* ORTasmania OR Victoria) WN ALL))
	(((((((("hearing loss") WN ALL) OR ((*mute OR deaf*) WN ALL)) OR (("sign language") WN ALL)) OR ((Auslan)WN ALL)) OR (("special education") WN ALL)) OR (("hard of hearing") WN ALL)) AND ((austral* OR "new south wales"OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian captial territory" OR queensland* ORTasmania OR Victoria) WN ALL))
	(((((((("F*tal Alcohol") WN ALL) OR (("prenatal alcohol exposure") WN ALL)) OR (("Rett Syndrome") WNALL)) OR (("psych* disorder*") WN ALL)) OR (("psych* disab*") WN ALL)) OR ((blind) WN ALL)) OR (("vis* impair")WN ALL)) OR (("low vision") WN ALL)) AND ((austral* OR "new south wales" OR "south austral*" OR "west* austral*"OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria) WN ALL))
	((((((((((disab*) WN ALL) OR ((handicap*) WN ALL)) OR (("mental* retard*") WN ALL)) OR (("development*disabilit*") WN ALL)) OR (("intellectual disabilit*") WN ALL)) OR (("learning disabilit*") WN ALL)) OR (("learningdisorder*") WN ALL)) OR (("hearing impair*") WN ALL)) OR (("vision disorder*") WN ALL)) AND ((austral* OR "newsouth wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queeslandOR Tasmania OR Victoria) WN ALL)) AND (English WN LA)
EMBASE	((disab* or handicap* or mental* retard* or development* disabilit* or intellectual disabilit* or learning disabilit* or learning disorder or cognitive* or (disability or hearing impair* or hearing loss* or hearing disorder*) or (vision impair* or vision disorder* blind or vis* impair* or low vision)).mp. or ((special needs or communication disorder* or communication disability*).mp. or *mute/ or deaf*.mp. or sign language.mp. or Auslan.mp.) or (neurological disorder* or brain injur* or congenital disorder* or autis* or FragileX syndrome or genetic disorder*).mp. or (Cerebral palsy or Spina bifida or neurodivers* or down syndrome or F*tal Alcohol or prenatal alcohol exposure or Rett Syndrome).mp. or (psych* disorder* or psych* disab* or special education*).mp.) and (australia/ or australian capital territory/ or new south wales/ or northern territory/ or queensland/ or south australia/ or tasmania/ or victoria/ or western australia/) [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word] yr="2011 - 2021"
ERIC	1 exp Disabilities/ or exp Welfare Recipients/ or disab*.mp. or exp Multiple Disabilities/ (169595) 2 exp Disabilities/ or exp Physical Disabilities/ or handicap*.mp. (162012) 3 "mental* retard*".mp. or exp Genetic Disorders/ (11174) 4 exp Attention Deficit Disorders/ or exp Learning Disabilities/ or exp Dyslexia/ or "learning disorder*".mp. or exp Learning Problems/ (28776)

5   "hearing impair*".mp. (8578)
6   exp Visual Impairments/ or "vision disorder*".mp. (7284)
7   exp Communication Disorders/ or exp Hearing Impairments/ or "hearing disorder*".mp. (14337)
8   exp Special Needs Students/ or exp Special Education/ or "special needs".mp. (34917)
9   "cognitive* disability*".mp. (46)
10   exp Communication Disorders/ or exp Language Impairments/ or "communication disorder*".mp. (8957)
11   "communication disability*".mp. (26)
12   exp Neurological Impairments/ or "neurological disorder*".mp. (7554)
13   exp Head Injuries/ or exp Neurological Impairments/ or "brain injury".mp. (7951)
14   exp Congenital Impairments/ or "congenital disorder*".mp. (3692)
15   exp Pervasive Developmental Disorders/ or exp Asperger Syndrome/ or exp Autism/ or autist*.mp. (16002)
16   "fragile x".mp. (447)
17   "genetic disorder".mp. or exp Genetic Disorders/ (1150)
18   "Cerebral palsy".mp. or exp Cerebral Palsy/ (1391)
19   exp Developmental Disabilities/ or "Spina bifida".mp. (5395)
20   "neurodiverse*".mp. (14)
21   "down syndrome".mp. or exp Down Syndrome/ (1878)
22   "Fragile X syndrome".mp. (407)
23   exp Fetal Alcohol Syndrome/ or "Fetal Alcohol".mp. (361)
24   "prenatal alcohol exposure".mp. (58)
25   "Rett Syndrome".mp. (116)
26   "psych* disorder*".mp. (1400)
27   exp Visual Impairments/ or exp Deaf Blind/ or blind.mp. or exp Blindness/ (10417)
28   exp Partial Vision/ or exp Visual Impairments/ or "low vision".mp. or exp Multiple Disabilities/ or exp Blindness/ (9918)
29   exp Hearing Impairments/ or "hearing loss".mp. or exp Deafness/ (13075)
30   *mute/ (0)
31   exp Deaf Blind/ or deaf*.mp. (10632)
32   "sign language".mp. or exp Sign Language/ (3227)
33   exp Deaf Interpreting/ or Auslan.mp. (461)
34   exp Special Education/ or "special education*".mp. (39968)
35   "hard of hearing".mp. (1777)
36   austral*.mp. (36010)
37   "new south wales".mp. (1473)
38   "south austral*".mp. (831)
39   "northern territory".mp. (242)
40   "australian capital territory".mp. (93)
41   queensland*.mp. (1704)
42   Tasmania.mp. (411)
43   Victoria.mp. (2020)
44   NSW.mp. (411)
45   ACT.mp. (57547)
46   NT.mp. (141)
47   SA.mp. (1722)
48   WA.mp. (984)
49   or/1-35 (205559)
50   or/36-48 (96528)
51   49 and 50 (16557)

	52 limit 51 to yr="2011 - 2021" (3836)
Informit	(disabil* OR handicap* OR “mental* retard*" OR "development* disability*" OR "intellectual disability*" OR "learning disability*" OR "learning disorder*) OR (disability or “hearing impair*” or “hearing loss*” or “hearing disorder*” OR “vision impair*” or “vision disorder*” blind or vis* impair* or “low vision” OR “special needs” or “communication disorder*” or communication disability* or *mute or deaf* or sign language or Auslan) OR (neurological disorder* or brain injur* or congenital disorder* or autis* or “Fragile X syndrome” or genetic disorder* OR cerebral palsy or spina bifida or neurodivers* or down syndrome or F@tal Alcohol or prenatal alcohol exposure or “Rett Syndrome”) OR (psych* disorder* or psych* disab* or special education*) AND (austral* OR “new south wales” OR south* austral* OR west* austral*OR “northern territory” OR “australian capital territory” OR queensland* OR tasmania OR victoria) py:2011-2021
Global Health	(disab* or handicap* or "mental* retard*" or "development* disabilit*" or "intellectual disabilit*" or "learning disabilit*" or "learning disorder*" or "hearing impair*" or "vision disorder*" or "hearing disorder*" or "special needs" or "cognitive* disability*" or "communication disorder*" or "communication disability*" or "neurological disorder*" or "brain injury" or "congenital disorder*" or autis* or "fragile x" or "genetic disorder*" or "Cerebral palsy" or "Spina bifida" or "neurodivers*" or "down syndrome" or "FragileX syndrome" or "F*tal Alcohol" or "prenatal alcohol exposure" or "Rett Syndrome" or "psych* disorder*" or "psych* disab*" or blind or "vis* impair*" or "low vision" or "hearing loss" or mute or deaf* or "sign language" or Auslan or "special education*" or "hard of hearing").ab. or (disab* or handicap* or "mental* retard*" or "development* disabilit*" or "intellectual disabilit*" or "learning disabilit*" or "learning disorder*" or "hearing impair*" or "vision disorder*" or "hearing disorder*" or "special needs" or "cognitive* disability*" or "communication disorder*" or "communication disability*" or "neurological disorder*" or "brain injury" or "congenital disorder*" or autis* or "fragile x" or "genetic disorder*" or "Cerebral palsy" or "Spina bifida" or "neurodivers*" or "down syndrome" or "FragileX syndrome" or "F*tal Alcohol" or "prenatal alcohol exposure" or "Rett Syndrome" or "psych* disorder*" or "psych* disab*" or blind or "vis* impair*" or "low vision" or "hearing loss" or mute or deaf* or "sign language" or Auslan or "special education*" or "hard of hearing").ti. or (disab* or handicap* or "mental* retard*" or "development* disabilit*" or "intellectual disabilit*" or "learning disabilit*" or "learning disorder*" or "hearing impair*" or "vision disorder*" or "hearing disorder*" or "special needs" or "cognitive* disability*" or "communication disorder*" or "communication disability*" or "neurological disorder*" or "brain injury" or "congenital disorder*" or autis* or "fragile x" or "genetic disorder*" or "Cerebral palsy" or "Spina bifida" or "neurodivers*" or "down syndrome" or "FragileX syndrome" or "F*tal Alcohol" or "prenatal alcohol exposure" or "Rett Syndrome" or "psych* disorder*" or "psych* disab*" or blind or "vis* impair*" or "low vision" or "hearing loss" or mute or deaf* or "sign language" or Auslan or "special education*" or "hard of hearing").hw. limit 8 to yr="2011 -Current" (austral* or "new south wales" or "south austral*" or "west* austral*" or "northern territory" or "australian capital territory" or queensland* or Tasmania or Victoria).ab. or (austral* or "new south wales" or "south austral*" or "west* austral*"

	or "northern territory" or "australian capital territory" or queensland* or Tasmania or Victoria).hw. or (austral* or "new south wales" or "south austral*" or "west* austral*" or "northern territory" or "australian capital territory" or queensland* or Tasmania or Victoria).ti.
Medline	Disabled Persons/ or disab*.mp. or handicap*.mp. or mental* retard*.mp. or development* disabilit*.mp. or intellectual disabilit*.mp. or learning disabilit*.mp. or learning disorder.mp. or cognitive*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
Hearing Disorders/ or disability.mp. or hearing impair*.mp. or hearing loss*.mp. or hearing disorder*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
Vision Disorders/ or vision impair*.mp. or vision disorder* blind.mp. or low vision.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
(language development disorders or speech disorders or communication disorder* or communication disability* or mutism or deaf* or sign language or Auslan).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
(neurological disorder* or brain injur* or congenital disorder* or autis*).mp. or Mental Retardation, X-Linked/ or genetic disorder*.mp. or "Congenital, Hereditary, and Neonatal Diseases and Abnormalities"/ [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
Cerebral palsy/ or Spina bifida/ or neurodivers*.mp. or down syndrome.mp. or F*tal Alcohol.mp. or prenatal alcohol exposure.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
Mental Disorders/ or psych* disorder*.mp. or psych* disab*.mp. or Education, Special/ [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
Mental Disorders/ or psych* disorder*.mp. or psych* disab*.mp. or Education, Special/[mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
AND
australia/ or australian capital territory/ or new south wales/ or northern territory/ or queensland/ or south australia/ or tasmania/ or victoria/ or western australia/

PsycINFO	(disab* or handicap* or mental* retard* or development* disabilit* or intellectual disabilit* or learning disabilit* or learning disorder or cognitive* or (disability or hearing impair* or hearing loss* or hearing disorder*) or (vision impair* or vision disorder* blind or vis* impair* or low vision)).mp. or ((special needs or communication disorder* or communication disability*).mp. or *mute/ or deaf*.mp. or sign language.mp. or Auslan.mp.) or (neurological disorder* or brain injur* or congenital disorder* or autis* or FragileX syndrome or genetic disorder*).mp. or (Cerebral palsy or Spina bifida or neurodivers* or down syndrome or Foetal Alcohol or prenatal alcohol exposure or Rett Syndrome).mp. or (psych* disorder* or psych* disab* or special education*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh] AND (Australia* or new south wales or western australia or australian capital territory or south australia or Tasmania or Northern territory or Queensland or Victoria).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
Sociological Abstracts	noft(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" OR "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR mute OR deaf* OR "sign language" OR Auslan OR "special education*" OR "hard of hearing ") AND noft(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria)
Scopus	(TITLE-ABS-KEY(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs")OR TITLE-ABS-KEY("cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*")OR TITLE-ABS-KEY("Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome")OR TITLE-ABS-KEY("psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR *mute OR deaf* OR "sign language" OR Auslan OR "special education*" OR "hard of hearing ")AND TITLE-ABS-KEY(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria))
Sociological Abstracts	noft(disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" OR "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR mute OR deaf* OR "sign language" OR Auslan OR "special

	education*" OR "hard of hearing ") AND noft(austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria)
Web of science	TS = (disab* OR handicap* OR "mental* retard*" OR "development* disabilit*" OR "intellectual disabilit*" OR "learning disabilit*" OR "learning disorder*" OR "hearing impair*" OR "vision disorder*" OR "hearing disorder*" OR "special needs" OR "cognitive* disability*" OR "communication disorder*" OR "communication disability*" OR "neurological disorder*" OR "brain injury" OR "congenital disorder*" OR autis* OR "fragile x" OR "genetic disorder*" OR "Cerebral palsy" OR "Spina bifida" OR "neurodivers*" OR "down syndrome" OR "FragileX syndrome" OR "F*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome" OR "psych* disorder*" OR "psych* disab*" OR blind OR "vis* impair*" OR "low vision" OR "hearing loss" OR *mute OR deaf* OR "sign language" OR Auslan OR "special education*" OR "hard of hearing" AND TS = (austral* OR "new south wales" OR "south austral*" OR "west* austral*" OR "northern territory" OR "australian capital territory" OR queensland* OR Tasmania OR Victoria)

Appendix 2. Research Reports Search Strategy

Exclusion:
- Annual reports
- Government policy documents
- 'How to' Guidelines
- Explanations about NDIS etc
- Resources
- Submissions eg. Submission to NDS Consultation Paper, Submission to NSW Ageing and Disability Commission, Submission to Disability Royal Commission, Submission to AHRC
- Compendium

Part 1 search:
- Google.com.au
- 2018-2020

Search String (Google.com.au)	Google pages
Australian disability research filetype:pdf	14
Australian mental illness research filetype:pdf	14
Australian special education research filetype:pdf	15
Australian autism research filetype:pdf	11
Australian down syndrome research filetype:pdf	14
Australian cerebral palsy research filetype:pdf	7
Australian vision impairment research filetype:pdf	12
Australian psychosocial disability research filetype:pdf	12
Australian cognitive disability research filetype:pdf	14
Australian communication disorders research filetype:pdf	13
Australian ADHD research filetype:pdf	13
Australian intellectual disability research filetype:pdf	12
Australian hearing impairment research filetype:pdf	12
Total documents downloaded	**n-188**

Part 2 search: Web search of partner organisations and key websites > reports & publications and resources pages

Appendix 3. Data extraction tool

This data extraction tool was developed in order to extract data from papers that were included in the review after full text was reviewed. The topic areas identified were based on the areas that we were interested in and as a short cut because they represent the topics that the reviewer team had determined, based on the reviews of abstracts and full text, where there were likely to be large numbers of papers.

General information
Title Copy and paste title of paper.
Year of publication
Abstract Copy and paste abstract.

Study population
Aboriginal and Torres Strait Islander people - focused study
Does the research focus on Aboriginal and Torres Strait Islander people in either the overall research topic or conclusions (i.e. not just mentioned in passing)?

- Yes
- No

Culturally and linguistically diverse. If Yes state which groups if mentioned
Leave blank if not a focus.
Focal group of study
Who is the group that is the focus of the paper? If there is no specific focus group (e.g. just talking about disability generally, then leave blank).

- People with disability (provide further details below)
- Family and informal carers
- Siblings and children of people with disability
- Workforce and staffing (provide further details below)
- Other

Main type of disability being discussed
What is the main type of disability being discussed?

- General discussion of disability
- Intellectual disability
- Developmental disability
- Brain injury
- Mental illness
- Spinal cord injury
- Autism
- ADHD
- Cerebral Palsy
- Other
- Age group
- Please select the most relevant age group for the study.
- Infants and early childhood (<5)
- Children (5 < 18)

- Adolescents
- Children of any age
- Young adults (18 < 30)
- Adults of any age
- Older age (65+)
- People of all ages/ age not specified
- Other

Topic of study

Aim of paper

Provide a very brief description of the aim of the paper (e.g. aim is to discuss the implications of using the ICF for measuring functioning of people with disability in employment).

Topic descriptive text

Provide a very brief description of the overarching topic (e.g. teacher attitudes towards inclusion of students with disability in early education).

Primary focus topic

Provide the primary focus of the study (not just topics mentioned in passing). Pick only one primary focus from the list. You can provide a secondary focus topic in the next section. If you need more than two focus topics, please put it in the notes at the bottom of the data extraction template.

- Education (see below to provide more detail) Any type of education – so can include school, home schooling, higher ed, vocational education
- Self-determination, choice and control Study focus is on the extent to which people can make their own decisions or are empowered to make their own decisions.
- Employment, volunteering, work experience Any employment related to people with disability and family/carers. Workforce issues related to disability workers not included here. This is included below.
- Retirement, ageing, aged care, end of life.
- Economic security and social security payments. Includes research related to welfare and social security, poverty.
- Service development and evaluation. Where the focus of the study is on any service providing support to people with disability, family, carers (e.g. health, allied health, disability services etc.)
- Workforce development and leadership Focus is on the workforce providing services to people with disability e.g. training of disability support workers, medical practitioners, workforce shortages etc.
- Disability accommodations (see below) Accommodations provided to people with disability, including interpretation.
- Communication needs
- Policy Includes NDIS, NDS, education policy relating to disability, housing policy related to disability etc.
- Technology Includes apps, wearable devices, ipads, computers
- Transport
- Housing Includes studies focusing on types of accommodation and homelessness.
- Quality of Life

- Lived experiences of disability: Personal experiences of people with disability and family members, supporters, allies and unpaid/informal caregivers.
- Social and community involvement, Leisure, sport and physical activity
- Health and wellbeing Includes the health and wellbeing needs of people with disability and their interactions with health care systems. Includes pharmacology.
- Social care (see below for further details)
- Epidemiology Studies which are primarily focused on prevalence of disability or a particular phenomenon in a population.
- Public attitudes to people with disability Attitudes to disability, stigma, disability confidence.
- Sexuality and reproductive rights
- Behaviour support
- Safety, security, discrimination and abuse
- Law, criminal justice and rights Includes the legal system, discussion of the UN CRPD, human rights, restraint and seclusion etc.
- Media - traditional and social
- The arts, culture and literature
- Critical theory, philosophy and religion
- Intersectional approaches (e.g. race and disability, gender and disability)
- Disability Research and research methods Includes papers that are about disability research and research methods as the primary topic. E.g. review of disability research, analysis of inclusive research practices.
- Other

Secondary focus topic (Only use this topic if there is a second main topic).

- Education (see below to provide more detail)
- Self-determination, choice and control
- Employment, volunteering, work experience
- Retirement and ageing
- Economic security and social security payments
- Service development and evaluation
- Workforce development and leadership
- Disability accommodations and communication (see below)
- Policy
- Technology and transport
- Housing
- Quality of life
- Lived experiences of disability
- Social and community involvement, leisure and sport
- Health and wellbeing (see below for further details))
- Social care (see below for further details)
- Epidemiology
- Public attitudes to people with disability
- Sexuality
- Safety, security, discrimination and abuse

- Law, criminal justice and rights
- Media - traditional and social
- The arts, cultural and literature
- Critical theory, philosophy and religion
- Intersectional approaches (e.g. race and disability, gender and disability)
- Other

Study design
- Randomised controlled trial
- Systematic review
- Narrative, scoping reviews
- Service evaluation
- Qualitative research
- Prevalence study
- Case report
- Policy analysis
- Co-research, inclusive research
- Participatory action research
- Economic evaluation
- Other

More specific details

Education - further details 1

Choose the main level of education being discussed.
- Early childhood
- Primary school
- Secondary school
- higher education
- vocational education
- transitions between education levels
- All/ no specific levels
- Other

Education - further details 2

Provide further information about the area of education research. Pick main topic. If more than one then put the second topic in the 'other' box.
- Inclusion
- Teacher experiences
- Student experiences
- Parent experiences
- Teacher/ teacher assistant training
- Education policy
- accommodations and technology
- behaviour
- Other

Health and Social Care - further details.

What type of health or social care services are being discussed.
- Acute hospital based care
- Community mental health care
- Primary care (including GPs)
- Pharmacy
- Dentistry
- Allied Health
- Rehabilitation
- Supported accommodation
- Long-term care facilities
- Respite
- Supported employment
- Other

Workforce - further details
- disability support workers
- nurses
- doctors
- allied health (OT, Physios etc)
- dentists
- educators
- psychologists
- social workers
- Other

Accommodations - further details
- augmentative and alternative communication
- braille
- Auslan
- Wheelchairs, mobility aids
- accessible housing
- accessible transport
- work accommodations
- education accommodations
- Wearable and implantable technology (e.g. microswitches)
- Computers and ipad related technology
- Other

Study funding sources (as noted in paper)

Notes, including other important data not captured in the above.
Please include here anything not captured above.

Appendix 4. Additional analysis tables

Further data on types of disability accommodations, health and social care contexts and workforce areas are displayed in Appendix 4.

Table 17: Types of accommodations and technology discussed in research included in review

Accommodation and technology discussed	Research papers	Research reports
Education accommodations	27	5
Augmentative and alternative communication	20	2
Accessible housing	11	2
Accessible transport	6	1
Assistive technology	5	0
Work accommodations	5	1
Wearable and implantable technology e.g. Micro switches	5	0
Assistance dogs	2	0
Computers, ipad related technology	3	0
Home environments	2	0
Auslan	1	0
Braille	1	0
Wheelchairs, mobility aids	1	0
Other	16	5
Total	**105**	**16**

Table 18: Workforce roles (where this was a paper focus)

Workforce role	Research papers	Research reports
Educators	43	8
Disability support workers	45	9
Allied health (OT, Physios etc)	32	1
Nurses	16	0
Doctors	9	0
Psychologists	6	1
Audiologists	4	0
Health professionals	4	0
Psychiatrist	4	0

Disability employment provider staff	3	0
Peer support	3	0
Social workers	3	0
Dentists	1	0
Pharmacists	1	0
Other	58	5
Total	**209**	**24**

Table 19: Types of health, social care and institutional settings where discussed as a main focus of papers and reports

Types of disability and social care services discussed	Research papers	Research reports
Disability employment service	3	0
Early intervention services	6	0
Juvenile and youth justice	6	0
Health services not otherwise specified	2	0
Acute hospital-based care	19	0
Allied Health	21	0
Mental Health	44	1
Dentistry	10	0
Disability services	12	0
Genetic screening	1	0
Hearing services	4	0
Long-term care facilities	1	0
Palliative care	1	0
Pharmacy	3	0
Primary care (including GPs)	21	2
Psychiatrist	1	0
Rehabilitation	18	0
NDIS-funded services	19	0
Respite	2	0
Supported accommodation	12	1
Supported employment	9	1
Other	80	2
Total	**289**	**7**