

Disability Policy: Sources for Evidence

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Disability Policy – Sources for Evidence

Social Policy Research Centre

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Summary

The aim of this report is to inform and enhance the disability policy development and implementation process in NSW. It is a compilation of the key information and evidence sources in the disability policy area. The report contains information on key journals, publications, research and academic bodies undertaking evidence based research, key data sources, listing of selected peak bodies, and listing of government disability agencies.

Section 1 provides background about current concepts and definitions in disability policy in the Australian context. Section 2 contains a listing of the key academic journals which contain contemporary articles on a wide range of policy and practice issues of relevance to the disability sector. The journals listed are: Journal of Disability Policy Studies, Disability and Society, Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual and Developmental Disability, and the Journal of Intellectual Disability Research. In addition two major UK Social Policy journals are included, Social Policy and Society and the Journal of Social Policy. These journals contain a wide range of articles on all social policy areas, including disability.

Section 3 contains a selected listing of key publications, including the newly ratified United Nations Convention on the Rights of Persons with Disabilities. It includes key research and evidenced based documents prepared by the Australian Bureau of Statistics (ABS), Australian Institute of Health and Welfare (AIHW) and the Productivity Commission.

Section 4 contains information about research and academic bodies undertaking evidence-based research in the disability area. These include the National Disability Administrators, Disability Policy and Research Working Group, Social Policy Research Centre, Disability Studies and Research Centre, Centre for Developmental Disability Studies and the Australian Family and Disability Studies Research Collaboration.

Section 5 contains information about key data sources, including the AIHW, ABS and the CSTDA National Minimum Dataset. Section 6 contains additional sources of evidence based practice, including the web-sites of selected peak bodies; a listing of Commonwealth, State and Territory disability agency websites; and two regular e-mail lists to consider subscribing to.

The information is current as at June 2008.

1 Background

This short paper provides information about evidence sources in disability policy research. It aims to be of use to policy makers, academics, researchers, government and nongovernment organisations, people with disability and their advocates. The report contains information on key journals, publications, research and academic bodies undertaking evidence based research, key data sources, listing of selected peak bodies, and listing of the Australian State and Territory disability agencies. The information is current as at June 2008.

The social perspective of disability locates the experience of disability in the social environment, with the action implication of dismantling the social and physical barriers to participation and inclusion of people with disability. The social perspective is distinguished from the historically dominant, medical and welfare models of disability, which locate the problem of disability in the person's impairment, with the action implication that the person must change in order to fit into society.

Social perspectives of disability distinguish between the terms 'impairment' and 'disability'. Impairment refers to the physical, sensory, psychiatric, intellectual or behavioural conditions people experience. These may be present from birth or acquired at any time; they may be sustained or intermittent; and may or may not equate with medically diagnosed conditions. Disability refers to the social experience of people as a result of their impairments. In this understanding, disability is a social experience based on difference in the same way sexism and racism are understood. The experience results from the way social organisation fails to take account of support and access needs. This results in people with impairments facing physical, social, organisational, attitudinal and economic barriers to their participation in social, economic, political and cultural life. The experience of disability is also likely to be intensified when experienced in combination with other social difference based on gender, Indigenous background, culturally and linguistically diverse backgrounds, age, sexuality and economic disadvantage.

Support needs refer to need related to impairments that people have for support to participate as other members of the public. The support needs can be addressed through informal support from social networks, families and caregivers or from formal support from mainstream services, such as health, education, housing and employment services; and specialist services, depending on the person's particular needs, such as disability and mental health services. People who provide support include informal carers, such as friends and family members and paid support workers.

Traditionally, disability support agencies were government or nongovernment organisations funded through government block funding and donations, which they rationed over the number of people needing services. More recently, government funding has also extended to individual funding, allocated to NGOs, private service agencies and sometimes to the person with disability or someone on their behalf such as a family member.

2 Journals

Journal of Disability Policy Studies

This journal addresses ethics, policy, and law related to people with disability. A major focus is quantitative and qualitative policy research. Articles have implications in fields such as education, law, sociology, public health, family studies, medicine, social work, and public administration. Occasional special series discuss current problems or areas needing more in-depth research, for example disability and ageing, policy concerning families of children with disabilities, oppression and disability, school violence policies and interventions, and systems change in supporting individuals with disabilities.

Examples of articles published recently include:

Crane, J. & A. Winster (2008), 'Early autism detection: implications for pediatric practice and public policy', *Journal of Disability Policy Studies*, 18, 245-253.

Putnam, M. (2005), 'Conceptualising disability: developing a framework for political disability identity' *Journal of Disability Policy Studies*, 16, 188-198.

Rubaii-Barrett, N. & L. R. Wise (2008), 'Disability access and e-government: an empirical analysis of state practices' *Journal of Disability Policy Studies*, 19, 52-64.

<http://dps.sagepub.com/>

Disability & Society

This journal provides a focus for debate around issues including human rights, discrimination, definitions, policy and practices, set against a background of change in the ways in which disability is viewed and responded to. The Journal publishes articles that represent a wide range of perspectives, prioritizing the voices of people with disability.

Examples of articles published recently include:

Hughes, B. (2007), 'Being disabled: towards a critical social ontology for disability studies', *Disability & Society*, 22(7), 673-684.

Hutchison, P., S. Arai, A. Pedlar, J. Lord & F. Yuen (2007), 'Role of Canadian user-led disability organisations in the non-profit sector', *Disability & Society*, 22(7), 701-716.

<http://www.tandf.co.uk/Journals/titles/09687599.asp>

Journal of Applied Research in Intellectual Disabilities

JARID is an international journal which presents findings from original applied research in intellectual disabilities, aimed at an international, multi-disciplinary readership. Topics covered include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health and service provision. The journal is a forum for the

dissemination of ideas to promote valued lifestyles for people with intellectual disabilities.

Examples of articles published recently include:

Beadle-Brown, J., A. Hutchinson & J. Mansell (2008), 'Care standards in homes for people with intellectual disability', *Journal of Applied Research in Intellectual Disabilities*, 21(3), 210-218.

Clegg, J., E. Murphy, K. Almack & A. Harvey (2008), 'Tensions around inclusion: reframing the moral horizon', *Journal of Applied Research in Intellectual Disabilities*, 21(1), 81-94.

Lundeby, H. & J. Tøssebro (2008), 'Family structure in Norwegian families of children with disabilities', *Journal of Applied Research in Intellectual Disabilities*, 21(3), 246-256.

<http://www.blackwellpublishing.com/journal.asp?ref=1360-2322&site=1>

Journal of Intellectual and Developmental Disability

This journal of the Australasian Society for the Study of Intellectual Disability (ASSID) is an international, multidisciplinary journal in the field of intellectual and developmental disability. The journal publishes original qualitative and quantitative research papers, literature reviews, conceptual articles, book reviews, opinions and perspectives.

Examples of articles published recently include:

Bigby, C. (2008), 'Beset by obstacles: a review of Australian policy development to support ageing in place for people with intellectual disability', *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.

Yueh-Ching Chou, Ping-Yi Tzou, Cheng-Yun Pu, Teppo Kroger & Wan-Ping Lee (2008), 'Respite care as a community care service: Factors associated with the effects on family carers of adults with intellectual disability in Taiwan', *Journal of Intellectual and Developmental Disability*, 33(1), 12-21.

De, S., J. Small & L. Baur (2008), 'Overweight and obesity among children with developmental disabilities', *Journal of Intellectual and Developmental Disability*, 33(1), 43-47.

<http://www.tandf.co.uk/journals/titles/13668250.html>

Journal of Intellectual Disability Research

This journal focuses on the study of intellectual disability, and includes research relating to biological, educational, genetic, medical, psychiatric, psychological and sociological studies, which increase knowledge on the treatment of intellectual disability and associated impairments, and/or inform public policy and practice.

Examples of articles published recently include:

Mulroy, S, L. Robertson, K. Aiberti, H. Leonard & C. Bower (2008), 'The impact of having a sibling with an intellectual disability: parental perspectives in two disorders', *Journal of Intellectual Disability Research*, 52(3), 175-274.

Tenneij, N. & H. Koot (2008), 'Incidence, types and characteristics of aggressive behaviour in treatment facilities for adults with mild intellectual disability and severe challenging behaviour', *Journal of Intellectual Disability Research*, 52(2), 95-173.

<http://www.blackwellpublishing.com/journal.asp?ref=0964-2633&site=1>

Social Policy & Society

This is an international academic journal sponsored by the UK Social Policy Association. The journal contains articles that draw upon contemporary policy-related research and associated developments in the social sciences. Each issue contains peer reviewed articles reflecting topical debates and issues within social policy, and a themed section edited by guest editors. Themed sections include an introductory piece, a set of peer reviewed articles, a selected review of key literature, and a guide to key sources in the area. Articles are accessible to a wide readership which includes policymakers, academics and students within and beyond the United Kingdom.

Examples of articles published recently include:

Bochel, C., H. Bochel, P. Somerville & C. Worley 'Marginalised or enabled voices? User participation in policy and practice' (2008), *Social Policy & Society*, 7(2), 201-210.

Dean, H., 'Social Policy and Human Rights: Rethinking the engagement' (2008), *Social Policy & Society*, 7(1), 1-12.

<http://journals.cambridge.org/action/displayJournal?jid=SPS>

Journal of Social Policy

This journal carries high quality articles on all aspects of social policy in an international context. It places particular emphasis upon articles which seek to contribute to debates on the future direction of social policy, present new empirical data, advance theories, or analyse issues in the making and implementation of social policies.

Examples of recent articles include:

Barnes, M. & K. Morris (2008), 'Strategies for the prevention of social exclusion: an analysis of the Children's Fund', *Journal of Social Policy*, 37(2), 251-270.

Taylor-Gooby, P. (2008), 'Choice and Values: Individualised Rational Action and Social Goals', *Journal of Social Policy* 37(2), 167-185.

<http://journals.cambridge.org/action/displayJournal?jid=JSP>

3 Publications

Government Policy and Services to Support and Include People with Disabilities

Lenny Roth, NSW Parliamentary Library Service, 2007

This is an informative resource which covers the following topics: theoretical perspectives on disability; historical overview of major developments in disability policy; Federal/State responsibilities including the Commonwealth State/Territory Disability Agreement (CSTDA) and the Home and Community Care (HAAC) Agreement; Disability Services legislation; Federal and NSW Government disability support services.

www.parliament.nsw.gov.au/prod/parlment/publications.nsf/key/GovernmentPolicyandServicestoSupportandIncludePeoplewithDisabilities

UN Convention on the Rights of Persons with Disabilities

Australia signed the convention in March 2008. It came into force in May 2008. Federal parliament is debating ratification. The purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disability 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.

www.un.org/disabilities/

Survey of Disability, Ageing and Carers 2003 (SDAC), Summary of findings

Australian Bureau of Statistics (ABS)

The report presents a summary of results from the SDAC conducted by the ABS across Australia in 2003. The primary objective of the survey was to collect information about people with disability, older people and carers.

www.abs.gov.au/ausstats/ABS@.nsf/7d12b0f6763c78caca257061001cc588/c258c88a7aa5a87eca2568a9001393e8!OpenDocument

Current and future demand for specialist disability services

Australian Institute of Health and Welfare (AIHW), June 2007

This report addresses the following key issues: profile of current CSTDA-funded service users; unmet demand for accommodation and respite, community access and employment services; factors affecting levels of demand and how demand is expected to change over coming years; interface with other service sectors and how these affect demand for disability services.

www.aihw.gov.au/publications/dis/cafdfsds/cafdfsds-c00

Report on Government Services 2008

Australian Government Productivity Commission

Chapter 14, 'Services for people with a disability', includes a profile of specialist disability services, information on indigenous people with disability, framework of performance indicators and key results and future directions in performance reporting.

www.pc.gov.au/gsp/reports/rogs/2008/communityservices

Carers' perspectives on caring: A qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index survey 2007

Carers Australia and University of Canberra, 2008

This report explores issues for carers of people with disability, and includes a review of literature, the impact of caring on health and well-being, an understanding of the carers role, and the needs of carers for respite and supported accommodation.

www.carersaustralia.com.au

4 Research and Academic Bodies

National Disability Administrators (NDA)

The National Disability Administrators (NDA) is the key national representative body for government agencies in the Commonwealth, States and Territories responsible for the delivery of specialist disability support services to people with disabilities. The NDA website, www.nda.gov.au, contains information about the work of the National Disability Administrators, and provides a forum for sharing information and publications about important issues in the disability sector.

The Disability Policy and Research Working Group is a working party to the Community and Disability Services Ministers' Advisory Council (CDSMAC), which examines significant disability policy issues relevant to the provision of specialist disability services. The last CSTDA included contract research funding. Under the CSTDA governments contribute to a research and development trust fund for research into disability issues of national significance. The Disability Policy and Research Working Group is responsible for selecting research projects on the basis that they have a joint State/Territory and Australian Government focus and seek to address national disability issues. Current research projects recently completed or underway include the following. Information on each of these projects is available from the website.

- Effectiveness of Supported Living in Relation to Shared Accommodation;
- Disability and Ageing;
- Employment Innovation for High Support Needs Clients;
- Monitoring Employment and Day Options Reforms;
- Support Needs and Service Models for Younger People with High Clinical Needs;
- Children and Young People with a Disability;
- Building Culturally Secure Services for Indigenous Australians with a Disability.

Social Policy Research Centre (UNSW)

The Social Policy Research Centre, established in 1980, is located in the Faculty of Arts and Social Sciences at UNSW. The SPRC conducts research and fosters discussion on all aspects of social policy in Australia. Disability is one of the main topics of inquiry; other areas include economic and social inequality, poverty and social exclusion, employment and labour market policies and programs, families and children, older people, evaluation of health and community service policies and programs, and comparative social policy and welfare state studies. Further information on current and past disability projects, and resulting publications, can be found on the SPRC website, www.sprc.unsw.edu.au

Disability Studies and Research Centre (DSARC), UNSW

The Disability Studies and Research Centre (DSARC) is an inter-disciplinary national research centre at the University of New South Wales. Its research projects engage with the lived experience of people with disability. DSARC promotes the social perspective of disability in education and research to maximise Australia's capacity to ensure an equitable, participatory and accessible society for people with disability.

DSARC is developing a research program, an education program and a mentoring program, particularly for researchers with disability. As well as undertaking and managing research, DSARC assists UNSW faculties to develop and deliver educational programs and improve research funding outcomes by identifying opportunities for collaborative research programs. It is aligned with the Social Policy Research Centre, the Faculty of Arts and Social Sciences and the Faculty of Law. The Acting Director is Rosemary Kayess, email dsarc@unsw.edu.au

Centre for Developmental Disability Studies (CDDS)

The Centre is a non-profit organization affiliated to the faculty of Medicine at the University of Sydney. It designs and develops research, teaching and clinical practice to inform policy and practice which have an impact on people with developmental disabilities. Its research publications, and information on current and past projects, can be found at www.cdds.med.usyd.edu.au

Australian Family and Disability Research Collaboration (AFDSRC)

The Australian Family and Disability Studies Research Collaboration is part of the Faculty of Health Sciences, University of Sydney. The AFDSRC Team is comprised of professionals from a range of disciplines - occupational therapy, psychology, social work - all of whom are committed to identifying, promoting and addressing the issues faced by families of parents or children with disability. The broad aim of AFDSRC is to actively promote the full participation of these families in the life of their respective communities. Information about current and past research projects, covering families with children with disabilities and parents with intellectual disability, is available on its website, www.afdsrc.org

5 Data Sources

Commonwealth State and Territory Disability Agreement National Minimum Dataset

Commonwealth and State/Territory Disability Agreement National Minimum Dataset (CSTDA-NMDS) contains annually updated administrative records on specialist support services for people with disability that are funded by Commonwealth and State/Territory governments. The data are collated centrally by the Australian Institute of Health and Welfare (AIHW) after transfer from the State and Territory government. NSW data are held by DADHC. The information is collected by service providers for State and Territory governments about service users of each service they provide – their sex, age, indigenous status, living arrangements (for example whether they live alone or with family members), residential setting (including if they live in boarding houses or hostels for homeless people), primary disability type, support needs, and actual support provided.

CSTDA data are only about people who actually receive at least one disability-related service, a subset of all people with disability, and of people with service needs. The information on family arrangements in the CSTDA is sparse.

Australian Institute of Health and Welfare (AIHW)

The AIHW publishes a range of reports on disability. Their datasets include the CSTDA-NMDS and analysis of ABS datasets.

Recent reports include:

Australian Institute of Health & Welfare (2007), *Disability support services 2005 – 06: National data on services provided under the Commonwealth State/Territory Disability Agreement*, Australian Government.

www.aihw.gov.au/publications/index.cfm/title/10488

Australian Institute of Health & Welfare (2003), *Disability prevalence and trends*, Australian Government.

www.aihw.gov.au/publications/index.cfm/title/9671

Other reports are available at www.aihw.gov.au/publications

Australian Bureau of Statistics (ABS)

The ABS publishes a wide range of quantitative data and analysis on Australia's population groups, including people with disability. The most relevant dataset is the Survey of Disability, Ageing and Carers (SDAC) 2003 listed above in key publications. SDAC is a nationally representative household survey conducted by the ABS every five years. The most recent survey (2003) included information on 41,233 people, and a limited dataset for the survey (a Confidentialised Unit Record File) has been available to researchers for analysis. In the survey, respondents were for the most part asked to self-identify as having a disability or long term health condition, although in some cases, other responsible people in the household were asked to identify household members with disability. Adults who were identified as having a

disability were personally interviewed, or another household member was interviewed on their behalf if for example their disability prevented them from easily communicating with the interviewer. While detailed information of a wide range of disabilities was collected in the survey, this analysis only uses highly summarized information on major classes of disability and health restrictions. It is a good dataset for estimating support needs. The SDAC is for the most part a household survey (of people who live in private households). However, the sample also included people with other living arrangements, including short-term caravan parks, non-private dwellings such as hotels, motels, boarding houses, and self-care components of retirement villages.

ABS reports are available at www.abs.gov.au

6 Other Sources of Evidence Based Practice

6.1 Disability Peak Bodies

Australian Federation of Disability Organisations www.afdo.org.au – national peak body of people with disability groups

People With Disability Australia (PWD) www.pwd.org.au – organisation of people with disability

Women With Disabilities Australia www.wwda.org.au – organisation of people with disability

NSW Council for Intellectual Disability www.nswcid.org.au – organisation of people with disability

Aboriginal Disability Network www.pwd.org.au/adnsw – organisation of people with disability

Multicultural Disability Advocacy Association of NSW www.mdaa.org.au – organisation of people with disability

Carers NSW www.carersaustralia.com.au – organisation of people who support people with disability

National Disability Services (NDS) www.nds.org.au – organisation of disability service providers

Other disability organisations are listed at [/www.wwda.org.au/portdisa.htm](http://www.wwda.org.au/portdisa.htm)

6.2 Government Disability Agencies

Australian Government Department of Families, Housing, Community Services and Indigenous Affairs www.facsia.gov.au

New South Wales Department of Ageing, Disability and Home Care (DADHC) www.dadhc.nsw.gov.au

Victoria Disability Services Division (Victorian Department of Human Services) www.dhs.vic.gov.au/disability

Queensland Disability Services Queensland www.disability.qld.gov.au

Western Australia Disabilities Services Commission www.disability.wa.gov.au

South Australia Department for Families and Communities - Disability Services www.dfc.sa.gov.au/disability-services

Tasmania Disability Services Program (Tasmanian Department of Health & Human Services) www.dhhs.tas.gov.au

ACT Disability ACT (Department of Disability, Housing & Community Services, Australian Capital Territory) www.dhcs.act.gov.au/disability_act

Northern Territory Aged and Disability Program (Northern Territory Department of Health and Community Services) www.nt.gov.au/health/

National Disability Administrators, national body of disability government agencies (Section 4) www.nda.gov.au,

6.3 International Resources

Disability Studies Net – international links to main research organisations, journals and conferences www.disabilitystudies.net/index.php?content=5

Centre for Disability Studies www.leeds.ac.uk/disability-studies/

6.4 Mailing Lists Relevant to Policy Change

FaHCSIA Disability e-news: disability.eneews@nationalmailing.com.au

The e-news is a regular sector update to keep people informed about FaHCSIA disability issues.

CommunityNet e-news: communitynet@tricomm.org.au

This weekly e-newsletter produced by TRI Community Exchange Inc. contains the latest on community sector news, including information on disability.

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