Australian Disability Research Agenda Collaboration (ADRAC)

For comment and discussion at the Disability Research Session, Australian Social Policy Conference, UNSW, 8-10 July 2009

1 Introduction

A number of Australian disability research, policy, political and advocacy activities are contributing to establishing an Australian disability research agenda. These activities include the National Disability Strategy (NDS) process; the Disability Investment Group; statements by the Parliamentary Secretary for Disability, Bill Shorten, and in COAG; UN Convention on the Rights of Persons with Disabilities (CRPD); and discussions in disability research and community meetings and conferences. For example, in March COAG announced $10 million for disability research over 5 years.

Disability researchers attended a workshop on 2 April 2009 and a session at the Disability Studies Conference, Australia (DSCA), ‘Towards a National Disability Studies Agenda’ 27 June 2009 to discuss how to contribute to facilitating the development of a national disability research agenda. Other researchers who could not attend also expressed an interest in being involved.

The sessions resolved to participate in an inclusive collaboration of anyone interested in disability research to develop a national agenda – the Australian Disability Research Agenda Collaboration (ADRAC). The Disability Studies and Research Centre (DSRC) offered to coordinate the collaboration. DSRC is a national disability studies centre based at the University of New South Wales.\(^1\) DSRC’s role is only that of initial facilitator until the directions for a national research agenda are clearer.

This document summarises the discussions and comments received so far. The document is a way of seeking comment from other people who wish to be involved. The summary has suggestions about

- the process to establish an Australian disability research agenda
- questions about possible research agenda content, principles for research, research activities and organising disability researchers
- opportunities to participate in establishing a research agenda.

\(^1\) DSRC applies a critical social perspective to disability studies and research across disciplines. DSRC supports disability studies in Australia and the Asia Pacific to inform an equitable, participatory and accessible society for people with disabilities.
2 Australian disability research agenda process

The Australian disability research agenda process is inclusive of anyone with an interest in disability research from a social perspective. Examples are researchers, disability community organisations and other people with disabilities. The collaboration encourages diverse participation, in terms of disability, discipline and research experience. Other people and organisations may be interested in remaining informed about how the agenda is progressing and choose not to become actively involved. The aim is to develop a research agenda representing national and local perspectives.

The process is public, such as distributing written materials for consultation, inviting participation to meetings and events, and seeking comment on progress towards a research agenda.

The goal of the process is to reach broad agreement on directions for the content, process and governance of an Australian disability research agenda. The preliminary steps towards that goal are:

- National and local meetings of interested people
- Distribution of written materials for comment from interested people
- Engagement with government over steps to implement the broadly agreed directions for a research agenda.

The timeframe is to conclude the preliminary steps in 2009.

Primary communication about the process, steps and progress is through the ADRAC website [http://dsrc.arts.unsw.edu.au/adrac.html](http://dsrc.arts.unsw.edu.au/adrac.html). DSRC will coordinate the activities until the directions for a research agenda are settled.

The DSCA participants emphasised that the process should be national, with local input. This requires technology, local meetings and resources to facilitate communication and participation. A suggestion was to ask people to take responsibility for facilitating local participation.
3  Research agenda content

The goal of an Australian disability research agenda is to develop an Australian body of knowledge on disability theory, methodology and practice to improve the social experiences of people with disabilities.

A research agenda would set priorities for research. Priorities would have indicative timeframes linked to disability community preferences for prioritised research evidence. Decisions about research priorities would be informed by the gap between what we would aim to develop in an Australian body of knowledge and where we are now.

For example, the NDS process included national community consultations. It identified the priorities from community members for content in a NDS, including priorities for an Australian response to its obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The NDS consultations could be one source of priorities for national and international research projects. More specifically, COAG has raised mental health as a key national concern with funding available to develop a national strategy.

Challenges to establishing a research agenda include the cross-disciplinary nature of disability research, the small Australian disability research base, the small pool of disability researchers with experience of rigorous research and the urgent demands for an Australian body of knowledge and for research training.

Research areas that could be prioritised in an agenda include

- meanings of the lived experiences of disability, national survey of disability, life course, interests, Indigenous, population groups, location, commonalities and differences in experiences
- methods, participation and control of disability research
- human rights, citizenship, entitlement and compliance with the CRPD
- social inclusion, participation and economic independence
- cultural, historical and humanities research
- the role of disability organisations including the role of peak bodies
- applied research, such as social interventions, families, policies and practices, body and health
- comparative and collaborative research in Asia Pacific.

The DSCA participants suggested a balance between prioritising strategic research areas to influence policy and practice and remaining open to new research directions that emerge from the community. They said the content should be set by the community and priority areas would need to be broad and flexible to include marginal and new areas of research.
Questions about research agenda content

3.1 What do you think are the priorities for the content of a disability research agenda in 1, 5, and 10 year timeframes?

3.2 Do you agree with the broad research areas above? What is missing? Which parts have a higher or lower priority?

3.3 How should the priorities be established? Examples are to

- ask a small group of researchers and other people with disabilities to draft a list of priorities for anyone to comment and
- ask researchers and other people with disabilities to submit requests for seed grants (see Section 5)
4 Principles for disability research

The purpose of principles for disability research is so that the research empowers and does not cause harm to people with disabilities. Principles address questions about who should participate in the research and how it should be designed, conducted, analysed, published and applied.

Australia does not have a set of principles for disability research. Principles exist in other places such as Canada and disability research commissioned in the UK. Australia has similar principles for other groups such as Indigenous research and research with children and young people. A research activity of ADRAC would be to encourage research bodies such as the Australian Research Council to adopt the principles.

Workshop and DSCA participants suggested that disability research project management and the research agenda should include people with disabilities. They can be represented by consumer representatives, researchers with disabilities, disability peak bodies and people in smaller community organisations so that their views inform research questions and that disability research is not dominated by people with power or people who are not disabled.

People also suggested that research needs to support the participation of groups such as people with intellectual disabilities, high support needs, or other cognitive disabilities to ensure their meaningful participation. Resources will be needed to support their participation. They also emphasised the need for deliberate efforts to engage with disability NGOs and self advocacy groups so that research and practice can inform each other.

Challenges to designing principles for disability research are that Australia does not have an extensive history of inclusive disability research practice, such as people with disabilities experienced in research practice, other researchers with the experience of meaningfully engaging with people with disabilities in all stages of research projects or research funding structures that support the development of that capacity in research and disability communities.

The DSCA participants agreed that we need a set of principles for disability research practice, dissemination and application. The principles could be applied as criteria for public funded research and be publicised to encourage good practice. They cautioned that principles need to be broad enough to encompass mixed methods. They thought the priority is to inform policy with people first research.

<table>
<thead>
<tr>
<th>Questions about principles for disability research</th>
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<tr>
<td>4.1 What should the role of people with disabilities be in research projects and the research agenda? Roles include choosing priorities, designing and conducting research and disseminating and applying findings?</td>
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<td>4.2 Similarly, what is the role of disability community organisations?</td>
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<td>4.3 How would we bridge the gap between goals and capacity in principles for good quality disability research?</td>
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<tr>
<td>4.4 How should the principles be drafted? For example ask a small group of researchers and other people with disabilities to draft the principles for anyone to comment.</td>
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5 Disability research activities

A disability research agenda process must make decisions about how to attract and spend research funds to maximise the prioritised research content and capacity building. Options are to spread any research funding widely to stimulate larger research funds from other sources or prioritise fewer projects. Research funds could also be prioritised for research resources, training and capacity building so that researchers have good research practice that attracts other research funds.

The agenda process could develop a database of research in progress and researchers for potential collaborations. It must use accessible formats. It should also develop good practice models for inclusive research.

The DSRC participants agreed that all the activities below were important, particularly seed funding, networks, clearinghouse and training.

Questions about disability research activities

5.1 What should research agenda funding be spent on? For example

- Seed funding to scope larger projects that would be funded from other sources, such as ARC, NHMRC, government, competitive and commissioned research, NGOs, business? Or a smaller number of larger projects fully funded by the agenda
- Baseline datasets about experience of disability on which to build for future research agendas
- Clearinghouse of national and international research proposed, in progress and complete from and for researchers, students, community and funders
- Resources for disability researchers in the community and academia (researchers and students) – web resources, partnerships, journal, knowledge management, accessible formats, accessible dissemination for application in policy and practice
- International opportunities for collaboration
- Disability research training – education, training, mentoring, internships, students, scholarships, fellowships, professional development, research employment
6 Organising disability researchers

Some national research agendas are organised as a new organisation to encourage independent processes for prioritising research topics, collaboration between researchers and good research practice. Examples of these organisations are described below.

Reasons for forming a disability research agenda organisation include mechanisms for encouraging participation of people with disabilities and disability community organisations. These mechanisms might be necessary to actively facilitate consultations and partnerships with people who are normally disadvantaged in research processes.

Functions could include clearinghouse and database of disability research; linking researchers with organisations needing research and with potential funders; developing research themes; and attracting and distributing research funds. At the most basic level, an email network of disability researchers should be set up (DSRC agreed to play an interim role in arranging this).

Reasons for not having a research organisation are that some disability researchers already work in loose collaborations or research centres; it is unlikely that researchers will agree on competing research priorities; and another organisation requires resources that could otherwise be spent on researching.

Examples of research agenda organisations are:

- Australian Research Alliance for Children and Youth (ARACY) addresses similar needs as ADRAC. It is a national, non-profit alliance with a large number of member organisations and individuals. It builds and supports collaborations of researchers, policy makers and practitioners across disciplines. It has an executive director, a CEO, staff and a board of directors. It also has a research advisory committee to ensure that funds provided from the ARACY research fund are given in compliance with the ARACY constitution. ARACY is funded by federal and state governments, philanthropic organisations and the corporate sector and has charitable tax status. [http://www.aracy.org.au/](http://www.aracy.org.au/)

- Australian Housing and Urban Research Institute (AHURI) is an NGO with membership from government and universities. It receives funding for housing and urban research from federal and state governments and distributes the funding on a competitive basis to member universities. [http://www.ahuri.edu.au/](http://www.ahuri.edu.au/)

- Regnet is a group that brings together research on regulation for researchers and policy makers [http://regnet.anu.edu.au/](http://regnet.anu.edu.au/)

The DSCA participants agreed it was important for researchers, community and policy makers to have a way of knowing about each other’s interests and expertise to contribute to increasing research capacity and policy change. They thought structured dialogue and funding from government was important for policy impact.
## Questions about organising disability researchers

6.1 Does a research agenda require an organisation to design, set prioritise and implement disability research? If so, what governance structure is necessary to maintain rigorous research processes? Are governance structures such as ARACY or AHURI suitable?

6.2 Should a national network of disability researchers be established to implement or inform a research agenda? For example, do we need an Australasian disability studies society or association? What would its purpose be? How would it relate to other discipline specific networks?

6.3 How do we ensure local participation in a research agenda to build the local research capacity of people with disabilities, disability community organisations, disability researchers and other people who conduct or apply the research? How do we set priorities given the wide range of interests and views within the disability sector?

6.4 Does a research agenda require government funding or other sources of funding? How would the funding be allocated to researchers?

6.5 What should the relationship be between a disability research organisation and government? Can it be funded and endorsed by government but retain research independence? Should it have a structured dialogue between researchers and policy makers?
7 Opportunities to participate in ADRAC

Information about ADRAC is available at http://dsrc.arts.unsw.edu.au/adrac.html.

To register your interest or add your comments, events or for more information visit the website or contact dsrc@unsw.edu.au

We encourage you to

- Comment on this paper and any other material about a research agenda
- Let other people who might be interested know about ADRAC so that they can participate
- Organise your own meetings about ADRAC or the research agenda. Please let us know so that we can publicise it on the website to other people in your area and share the outcomes from the events.

8 Abbreviations

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<tbody>
<tr>
<td>AHURI</td>
<td>Australian Housing and Urban Research Institute</td>
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<td>ARACY</td>
<td>Australian Research Alliance of Children and Youth</td>
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<td>CRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<td>COAG</td>
<td>Council of Australian Governments</td>
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<td>DIG</td>
<td>Disability Investment Group</td>
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<td>DSRC</td>
<td>Disability Studies and Research Centre</td>
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<td>FAHCSIA</td>
<td>Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (responsible for disability policy)</td>
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<td>NDA</td>
<td>National Disability Agreement</td>
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<td>NDS</td>
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