

# National Disability Research and Development Agenda

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November 2011

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# Executive Summary

The National Disability Research and Development Agenda sets out national priorities, focus and direction for disability related research to improve the lives and outcomes for people with disability. The Agenda aims to facilitate the creation of a comprehensive evidence base and the foundations of robust research that will inform the policies and practices of the disability sector, governments and the mainstream community.

The Agenda recommends research and development directions and principles, details particular areas of inquiry for disability related research, and identifies approaches to further the development of national disability research.

The Agenda has been designed to assist in managing and allocating the \$10 million commitment that the Australian, State and Territory governments have made to disability research and development. This commitment was made to support the delivery of the objectives and reform priorities of the National Disability Agreement and the National Disability Strategy and, more broadly, to increase the focus in research on issues facing people with disability. Future disability reforms such as a National Disability Insurance Scheme will also benefit from this commitment.

It is not intended that all of the research directions and areas of inquiry set out in this Agenda will be resourced through this disability research and development commitment. Rather, the Agenda seeks to influence

the inclusion and direction of research relating to disability across a range of national research initiatives and sectors.

## **Directions for National Disability Research and Development**

- Australian **disability demographic profile and trend information**, including access to social and economic inclusion data.
- Disability related **social and economic inclusion** research, including research which focuses on human rights, participation in community life, access to mainstream activities and services, and broader systems change.
- Evaluations, reviews and research to contribute to the evidence base to improve **service delivery and support options**.
- Analysis of the factors that support **sector sustainability**, sector development and improved organisational capability.
- Research on the profile, experiences and issues affecting **diverse and/or disadvantaged groups of people with disability**, such as:
  - a) Aboriginal and Torres Strait Islander communities
  - b) People from culturally and linguistically diverse backgrounds
  - c) Women with disability
  - d) People in regional, rural and remote areas.

# **Foundations of National Disability Research**

- Research and development partnerships and collaborations within the disability sector, with people with disability, and with other relevant sectors and disciplines.
- Inclusion of disability issues within mainstream Australian research funding and activities, building effective participation of people with disability and the adoption of methodologies that support their involvement.
- Accessible disability related research and data and application of evidence-based findings and approaches in practice.

## **Principles for National Disability Research and Development**

The Research Principles provide a guide to the core values for disability related research and development.

Research should be:

- Inclusive and rights based
- Responsive and diverse
- Practicable and outcomes orientated
- Collaborative and cross disciplinary

- Accessible and communicated
- Efficient and targeted.

# 1 The National Disability Research and Development Agenda

## 1.1 Introduction

The Australian, State and Territory governments have made a significant commitment to improving research and development in the disability arena by contributing \$10 million for research and development over five years. This funding commitment was made specifically to support the delivery of the objectives and reform priorities of the National Disability Agreement<sup>1</sup> and National Disability Strategy<sup>2</sup> and, more broadly, to increase the focus in research on issues facing people with disability. Future disability reforms such as a National Disability Insurance Scheme will also benefit from this commitment.

The National Disability Research and Development Agenda (“the Agenda”) has been developed by the Australian, State and Territory governments and has been approved by Ministers from all jurisdictions. The Agenda articulates principles, directions and priorities applicable to disability related research in both the disability and mainstream sectors. While the Agenda has been designed to assist in managing and allocating the national funding commitment for disability research and

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<sup>1</sup> The National Disability Agreement is available at [http://www.federalfinancialrelations.gov.au/content/national\\_agreements.aspx](http://www.federalfinancialrelations.gov.au/content/national_agreements.aspx)

<sup>2</sup> The National Disability Strategy is available at <http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx>



development, it is not intended that all of the research directions and priorities set out in this Agenda will be resourced from the national funding commitment. Rather, the Agenda has a broad scope and seeks to influence the inclusion and direction of research relating to disability across a range of national research initiatives and sectors.

## **1.2 Background**

The Disability Policy and Research Working Group consisting of officials from the Australian, State and Territory governments, has responsibility for developing and implementing the National Disability Research and Development Agenda. Expert advice is provided to the Disability Policy and Research Working Group by the National Disability Research and Development Steering Committee, which includes representatives from government, academia, service providers and the community.

This Agenda has been developed following extensive engagement with a wide range of stakeholders. Consultation processes were held across the nation during August and September 2010. Each State and Territory government (except the Northern Territory) invited representatives of people with disability, academics, service providers, peak organisations and government agencies, to a “roundtable” where discussion was facilitated and opinions sought on disability research principles, directions and priorities. A total of 180 people participated in the local roundtables.

Participants of the State and Territory events were then selected to attend a national roundtable held on 9 December 2010. Fifty-seven people attended the national event which built on the local roundtable discussions by refining and further identifying the components of a research and development agenda. Detailed input was also obtained through two questionnaires distributed prior to and following the national roundtable.

Finally, feedback was sought from roundtable participants and a range of stakeholders on a draft version and incorporated into this final Agenda.

### **1.3 Purpose and Scope of the Agenda**

The purpose of this document is to set a national agenda for research into matters relating to disability for the nation. Establishing this Agenda is supported by and under the direction of Disability Services Ministers.

Specifically, the National Disability Research and Development Agenda is intended to identify research and development priorities to support the implementation of the National Disability Agreement and the National Disability Strategy.

More broadly, the Agenda also aims to:

- Focus on activities that will result in practical benefits for people with disability and support the creation of a more inclusive Australia.
- Support the continued development of robust disability research.

- Influence other research programs to better facilitate the inclusion of disability issues in mainstream data collection, research, evaluations and reviews.
- Promote partnerships and collaboration within the disability research sector and with other research sectors.

The Agenda sets out research and development principles and directions and identifies particular areas of inquiry for disability related research. It will be used to guide the allocation of the national funding commitment for disability research and development. A separate process for allocation of funding has been developed and will be managed by the Disability Policy and Research Working Group. Strategic advice will be provided by the National Disability Research and Development Steering Committee and by relevant independent experts.

The Agenda is not, however, solely concerned with management of the national funding commitment for disability research and development. It is anticipated that the directions and priorities articulated in the Agenda will also be pursued by agencies, institutions or individual researchers through other research and development opportunities.

By clearly articulating research principles and directions applicable across research sectors, research stakeholders at all levels will be able to focus their efforts on complementary research and development activities.

Historically disability research in Australia has largely focussed on the clinical treatment and medical aspects of disability. This Agenda has been designed with the intention of expanding the breadth of research activities relating to disability and to particularly target areas that have not been well resourced previously or where there has been little research to date.

A wide range of research types and methods are encouraged. Without being too prescriptive and limiting the scope for research innovation, the Agenda supports the use of:

- Pure research
- Applied research
- Action research
- Evaluations
- Surveys
- Demonstration projects
- Data linkage
- Activities that contribute to data development
- Audits of existing research
- Longitudinal studies.

Finally, it should be noted that the focus of this Agenda is on research that will lead to improved outcomes for Australians with disability. It is acknowledged that a significant proportion of people with disability live with and/or are supported by family members and carers. While not always referenced in this document, it is intended that the Agenda should be read as including, where relevant, family members and carers of people with disability within the scope of the research principles, directions and areas of inquiry described below. It is also noted that people with disability includes people in all age groups, including children with disability.

## **1.4 Current Disability Policy and Research Context**

The National Disability Agreement and the National Disability Strategy set the key disability reform priorities and policy directions relevant to this Agenda.

The broader focus of the Agenda also links to and reflects other national commitments and processes. A key commitment is the *United Nations Convention on the Rights of Persons with Disabilities*. Other related national initiatives include the National Carer Strategy, the National Health Reform Agreement and outcomes from the Productivity Commission Inquiry into the National Disability Long-term Care and Support Scheme. Further information relating to these initiatives is provided in **Appendix 1**.

Implementation of the National Disability Strategy, together with progress on already identified and new initiatives will impact on how the Agenda is used over the coming years.

Research agendas and the work of research bodies from other sectors will also be relevant to the implementation of this Agenda. Research and initiatives undertaken as part of this Agenda should consider linkages and cross-disciplinary opportunities with research bodies such as the Australian Research Council, the National Health and Medical Research Council and the Australian Housing and Urban Research Institute.

## **1.5 Directions for National Disability Research and Development**

The five Directions for National Disability Research and Development have been established to focus and guide investment in disability related research across the nation to those areas identified as of greatest priority.

The Directions are:

- Australian **disability demographic profile and trend information**, including access to social and economic inclusion data.
- Disability related **social and economic inclusion** research including research which focuses on human rights, participation in community life, access to mainstream activities and services, and broader systems change.

- Evaluations, reviews and research to contribute to the evidence base to improve **service delivery and support options**.
- Analysis of the factors that support **sector sustainability**, sector development and improved organisational capability.
- Research on the profile, experiences and issues affecting **diverse and/or disadvantaged groups of people with disability**, such as:
  - a) Aboriginal and Torres Strait Islander communities
  - b) People from culturally and linguistically diverse backgrounds
  - c) Women with disability
  - d) People in regional, rural and remote areas.

More specific Identified Areas of Inquiry, including suggested research themes, topics and questions are detailed in **Section 2**. These demonstrate the breadth of activities that could be progressed against each of the Directions.

## **1.6 Foundations of National Disability Research**

In addition to supporting the objectives of the National Disability Agreement and National Disability Strategy, the role of this Agenda is also to support the continued development of robust national disability research and to influence other research programs to better facilitate the inclusion of disability issues in mainstream data collection, research, evaluations and reviews.

This will require new strategies and approaches involving a range of stakeholders including people with disability, individual researchers, organisations undertaking research and governments.

Key Foundations for the continued development of disability research are:

- Research and development **partnerships and collaborations** within the disability sector, with people with disability, and with other relevant sectors and disciplines.
- Inclusion of disability issues within **mainstream Australian research funding and activities**, building effective participation of people with disability and the adoption of methodologies that support their involvement.
- **Accessible disability related research and data** and application of evidence-based findings and approaches in practice.

Identified activities to build these Foundations, including suggested systemic approaches for researchers, organisations undertaking research and governments, are outlined in **Section 3**.

## **1.7 Research Principles**

The Agenda Principles provide a guide to the core values for disability related research and development, consistent with the National Disability Agreement objectives and outcomes.



The Principles do not constrain the range of research projects to be pursued under the Agenda. Rather, they are designed to outline some key underpinning values of the disability sector and how this relates to research within a contemporary Australian context.

## **Inclusive and Rights Based**

Consistent with Australia's commitment to the *United Nations Convention on the Rights of Persons with Disabilities*, research should affirm the human rights of people with disability.

Genuine effort should be extended to ensure research is inclusive of people with disability, their families and carers, and representative organisations of people with disability. Research should be built on the premise that the lived experience of people with disability should influence the development, design, conduct, analysis, dissemination and application of research and evaluation. It should aim to include and engage people with disability at every level, including in research, evaluation and policy.

## **Responsive and Diverse**

People with disability have specific needs, interests, priorities and perspectives. These may reflect their specific impairment, be based on their personal circumstances and location, and/or reflective of their gender, age, sexuality, ethnic or cultural background. Research should reflect and respond to this diversity amongst people with disability.

Research should recognise that disability issues may be differently experienced and understood in Aboriginal and Torres Strait Islander

communities, as well as within culturally and linguistically diverse communities and across genders. It should also acknowledge that these communities, and those living in regional, rural or remote areas, may face different issues and challenges from broader population groups.

## **Practicable and Outcomes Orientated**

Research should contribute to the evidence base on which future systems change, policies, programs, services and support models are based. Research should focus on informing the direction and focus of disability programs and services, as well as broader inclusion strategies. It should be outcomes orientated and be able to support disability programs, as well as other social and economic inclusion processes and activities.

This focus requires both short and longer term investigations to be undertaken.

## **Collaborative and Cross Disciplinary**

Research design and implementation should aim to promote research collaborations within the disability sector and with other sectors and disciplines.

Opportunities for cross-sectoral and cross-disciplinary research should be promoted. In addition, disability information should be routinely included in other research and program data collection.

## **Accessible and Communicated**

Research activities and their outcomes should be coordinated, accessible and available for dissemination to stakeholders including other researchers, government officials, service providers, current and potential employers, people with disability and their families, carers and representative organisations. Informed choice requires access to information and this is particularly important for people with disability.

## **Efficient and Targeted**

Research activities should be efficient and make optimal use of the limited resources available.

Research should be well designed, rigorous, ethical and independent. It should primarily target issues or areas where there are identified research needs, and that are most likely to support improved outcomes for people with disability, their families and carers.

## **2 National Disability Research and Development Directions – Identified Areas of Research and Inquiry**

Priority will be given to funding research projects and initiatives that address the areas of inquiry listed below. It should be noted that this does not constitute an exhaustive list of areas of inquiry or activities that could be undertaken to pursue each Research Direction.

### **2.1 National Disability Profile and Trend Data Development**

**Research Direction: Australian disability demographic profile and trend information, including access to social and economic inclusion data.**

#### **Identified Areas of Inquiry**

2.1.1 Collection and examination of a comprehensive range of information about people with disability over time, considering issues such as:

- Life stage and transition experiences
- Social and economic inclusion and barriers
- Interventions and use of specialist services

- Access and use of mainstream services, including housing and health services.

2.1.2 a) Examination of definitions used for “person with disability” and the issues and options relating to the development of a standardised national definition.

b) Examination of issues and options for the adoption of standardised items for all mainstream data collection systems to report on disability.

## **2.2 Social and Economic Inclusion**

**Research Direction: Disability related social and economic inclusion research including research which focuses on human rights, participation in community life, access to mainstream activities and services, and broader systems change.**

### **Identified Areas of Inquiry**

2.2.1 Examine practical measures for improving social and economic inclusion of people with disability, particularly in areas of low participation rates and/or where negative social attitudes, discrimination, vilification or violence are known to be barriers.

Topics for specific focus include:

- Access to education and employment opportunities
- Economic participation and capacity to exit poverty and low socio-economic status
- Transport and infrastructure accessibility.

2.2.2 a) What are appropriate indicators of social and economic inclusion for people with disability in Australia, including indicators appropriate to different life stages and reflective of gender and Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities' perspectives?

b) What mechanisms could be used to facilitate and promote the adoption and reporting on inclusion by mainstream institutions and

organisations, including those related to education, health, housing, employment, sport and leisure, technology, arts and culture?

2.2.3 What is the scale, causes and impacts of prejudice towards people with disability including those stemming from stereotypes, assumptions and community attitudes?

Issues for initial focus include:

- The prevalence and circumstance of violence and vilification of people with disability
- Parenting and the right to parent
- Sexuality and disability/gender politics
- Sterilisation policies and practices
- How community attitudes can be influenced and changed.

2.2.4 What are the views of, and issues of interest, to people with disability and trends in issues and concerns on topics such as:

- Access to mainstream services and activities
- Barriers, discrimination and inclusion.

One approach may be a regular national survey of the views of people with disability.

- 2.2.5 What are effective consumer outcome measures relevant to people with disability that will best inform improvements in an individual's quality of life?
- 2.2.6 What contributes to the cost of living for people with disability, including the relationships between employment policies, taxation, and income support eligibility, other participation incentives and disincentives?
- 2.2.7 a) Examination of the use and impact of restrictive practices placed on people with disability in institutions such as prisons and mental health facilities and other locations where restrictive interventions are used.
- b) Identification of contemporary practice and organisational culture change strategies that lead to the safe elimination of restrictive practices.



## **2.3 Service Delivery and Support**

**Research Direction: Evaluations, reviews and research to contribute to the evidence base to improve service delivery and support.**

### **Identified Areas of Inquiry**

2.3.1 Research to enhance the evidence base for the specialist disability service system in priority areas such as:

- the measurement of need for disability services
- targeting services to more vulnerable population groups (including older carers and Aboriginal and Torres Strait Islander people with disability)
- quality assurance and the continuous improvement of disability services
- service planning
- strategies to simplify access to specialist disability services
- early intervention and prevention strategies
- aids and equipment.

Issues for consideration include the roles and processes for engaging:

- Individuals with disability, including those with a cognitive impairment
- Family members, carers, and advocates
- Service providers and funding bodies.

2.3.2 What policies, procedures and decision making models best inform person-centred planning, individualised support and self-directed funding?

2.3.3 a) How best can disability research evidence be translated into practice?

b) What elements make disability research useable in practice and how can evidence be better used to create sustainable services and systems?

## 2.4 Sector Development and Sustainability

**Research Direction: Analysis of the factors that support sector sustainability, sector development and improved organisational capability.**

### Identified Areas of Inquiry

2.4.1 Examination and analysis of factors which contribute to a sustainable disability services sector in Australia.

2.4.2 What are the sector development and workforce change implications for the disability sector in adopting person-centred planning, individualised support and self-directed funding models, in areas such as:

- Capacity
- Sector sustainability
- Client engagement and assessments
- Supported decision making
- Financial planning
- Workforce profile and development issues
- Reporting requirements
- Service marketing?

### 2.4.3 What are effective indicators to measure and report on the disability and mainstream services sectors in areas such as:

- Quality of staffing and workforce
- Service performance
- Funding allocations and levels
- Service contribution to outcomes for people with disability.

## **2.5 Diversity Issues**

Research Direction: Research on the profile, experiences and issues affecting diverse and/or disadvantaged groups of people with disability, such as:

- Aboriginal and Torres Strait Islander communities
- People from culturally and linguistically diverse backgrounds
- Women with disability
- People in regional, rural and remote areas.

### **Identified Areas of Inquiry**

2.5.1 The collection and examination of data to measure outcomes for:

- Aboriginal and Torres Strait Islander people with disability
- Culturally and linguistically diverse people with disability
- Women with disability
- People in regional, rural and remote areas.

2.5.2 What practice approaches to person-centred services and support are appropriate to:

- Aboriginal and Torres Strait Islander people with disability
- Culturally and linguistically diverse people with disability

- Women with disability

In addition to 2.5.1 and 2.5.2, many Identified Areas of Inquiry in the other Research Directions could be undertaken with a focus on diverse and/or disadvantaged groups of people with disability.

- People in regional, rural and remote areas.

# 3 Foundations of National Disability

## Research

To support the continued development of effective national disability research, activities have been identified for researchers, organisations undertaking research, as well as for governments. Priority will be given to funding research, projects and initiatives that seek to adopt one or more of the approaches identified below.

### 3.1 Disability Research Sector Partnerships and Collaborations

**Foundation: Research and development partnerships and collaborations within the disability sector, with people with disability, and with other relevant sectors and disciplines.**

#### Identified Approaches

3.1.1 Researchers and organisations undertaking disability research are encouraged to:

a) Actively pursue partnerships with business, philanthropic bodies, non government organisations and governments to sponsor specific pieces of research or host research dissemination activities.

b) Develop meaningful inclusion, collaboration and participation models involving people with disability and their representative organisations, considering:

- the skills and capacity of research staff and people with disability including those with cognitive impairment
- methodologies to support and enable meaningful collaboration and participation.

c) Develop strong relationships and information sharing with other researchers, research organisations and various disability stakeholders through partnerships and networking opportunities.

d) Promote data sharing including disaggregated data regarding diversity, impairment, gender, age, location.

e) Engage with the mainstream research community and establish co-research programs and partnerships.

3.1.2 Governments will have a role in developing and/or supporting:

a) Policies and funding systems that support and enable meaningful collaboration and participation.



b) Systematic engagement with the mainstream research community across Australia (for example, a national think-tank), and ways to influence:

- Funding systems, guidelines and inclusive decision making processes
- The establishment of co-research programs and partnerships involving disability researchers, relevant government and non-government organisations, and people with disability including people with a cognitive impairment
- The capacity of researchers to engage with and include people with disability
- Access to data and research outcomes.

## 3.2 Inclusive Mainstream Research

**Foundation: Inclusion of disability issues within other Australian research funding and activities, building effective participation of people with disability and the adoption of methodologies that support their involvement.**

### Identified Approaches

3.2.1 Organisations undertaking research are encouraged to:

- a) Ensure that people with disability are included as part of the research participant group in mainstream research activities.
- b) Develop the skills and capacity of individuals involved in research, or potentially involved in research, related to people with disability including:
  - Academics and professional researchers
  - Disability service providers (government and non-government)
  - People with disability including people with cognitive impairment
  - Families and carers.

3.2.2 Governments will have a role in encouraging national research funding bodies, in particular the National Health and Medical Research Council and the Australian Research Council, to support and fund disability related research and methodologies that:

- a) Involve people with disability, including those with cognitive impairment, as part of the research participant group.
- b) Support people with disability as researchers and co-researchers in the design and implementation of research activities.
- c) Support people with disability to acquire research training from tertiary and higher education to increase research capacity.
- d) Consider the ethical implications of not including people with disability in any human research.

Options may include:

- A presumption that people with disability and/or their representative organisations will be included in any research design involving participants
- Amending standardised research applications and ethics approvals so that they include an 'if not, why not' clause to explain why people with disability will not be included
- Additional funding being made available to facilitate inclusion of people with disability in research design and methodologies.

## 3.3 Access to Research and Data

Accessible research and the effective dissemination of research findings is critical for providing an evidence base for policy development and the achievement of improved outcomes for people with disability.

**Foundation: Accessible disability related research and data and application of evidence-based findings and approaches in practice.**

### Identified Approaches

3.3.1 Researchers and organisations undertaking research are encouraged to:

a) Consider options for communication and strategies to ensure broad accessibility and wide dissemination.

For example:

Plain English summaries that translate research findings for non-academics

Publishing research findings with a web based version and in a format accessible by screen readers.

b) Make greater use of existing open access research websites and social networking facilities, such as the Australian Government's AUSInfo for dissemination of research findings.

c) Actively pursue and utilise media and communication outlets and other opportunities to promote disability findings and research.

Opportunities for promotion may include:

- On various international days
- At conferences
- Via news outlets, including the ABC disability online site
- Via publication in mainstream journals
- Via public reports including Australia's contribution to:
  - UN Convention on the Rights of Persons with Disabilities or
  - World Report on Disability sponsored by the World Health Organisation.

d) Undertake research that is closely linked to practice and industry.

3.3.2 Organisations undertaking research are encouraged to develop:

a) Mechanisms for different groups of stakeholders to exchange information and form partnerships and alliances related to research.

b) Systems to effectively disseminate research findings.

Options may include:

- A national disability research website, with capacity for chat rooms and specialist links.
- A national clearinghouse for disability related research and data that is accessible online in easy-to-access formats.

The holding of conferences to share research findings and developments. To maximise access to information, conference presentations and discussions should be made available in multiple formats, such as pod casts and online publications.

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- The holding of conferences to share research findings and developments. To maximise access to information, conference presentations and discussions should be made available in multiple formats, such as pod casts and online publications.

3.3.3 Governments will have a role in supporting national initiatives, such as a national research website or national disability research conferences.

## 4 Conclusion

### 4.1 Implementation

To support the effective implementation of the Agenda Directions and Foundations, a range of research activities will be needed. The national funding commitment for disability research and development will be allocated over five years to:

- Research and evaluation projects
- Research ventures/partnerships
- Research capacity building, collaboration and dissemination initiatives.

#### 4.1.1 Research and evaluation projects

Funds will be allocated through competitive funding rounds and other processes for research, evaluation and data development activities which address areas identified in the Agenda Directions and Foundations.

Research projects may vary in duration from a few weeks to a few years and may range from research essays on emerging policy issues to systematic reviews of disability research, evaluations and significant primary data collection initiatives. Research briefs may be used to commission particular research projects to target research areas that are not addressed through competitive



funding rounds.

#### 4.1.2 Research ventures/partnerships

Funding over a number of years will be considered for a limited number of research ventures or partnerships. These projects would be designed to answer research questions that are complex and/or longitudinal in nature and for which a longer-term funding commitment is required, and may include funding for the inclusion of disability items in mainstream research, surveys and data collections.

#### 4.1.3 Research capacity building

Initiatives which develop the skills and resources of the disability and mainstream research community will also be considered for funding. This may include support for undergraduate and/or postgraduate research, training to support research participation by and collaboration with people with disability, and funding to service providers to support participation in research (for example, through the Australian Research Council Linkage Grants).

#### 4.1.4 Research collaboration

Funding will be available for research activities which promote partnerships and collaborations within the disability sector, with people with disability, and with other relevant sectors and disciplines. These may include collaboration roundtables between mainstream and disability researchers and organisations

undertaking research, and the development of a network or networks for disability researchers.

#### 4.1.5 Research dissemination

As a key Agenda Foundation, funding will also be available to support activities which contribute to the accessibility and dissemination of disability related research and data. This may include a clearinghouse or research archive, plain English summaries of research findings, and seminars and conferences.

## 4.2 Conclusion

The National Disability Agreement and the National Disability Strategy represent the commitment of all Australian Governments to significant reform in disability services. The Productivity Commission Inquiry into a National Disability Long-Term Care and Support Scheme has the potential to result in further significant changes to the way services are funded and provided to people with disability.

In this environment of substantial reform, robust research and development will be central to supporting and sustaining the reform process. Building a sound evidence base is critical for informed decision-making and policy development. This Agenda seeks to focus the direction of disability research and development activity so that it will provide good evidence for future policy and practice decisions that will ultimately lead to improved outcomes for Australians with disability.

# Appendix 1

## Current Disability Policy and Research Context

### 1 National Disability Agreement

The National Disability Agreement between the Australian, State and Territory governments came into effect in January 2009. The Agreement was established to affirm the commitment of all governments to work in partnership, and with stakeholders including people with disability, their families and carers, to improve outcomes for people with disability and to clarify roles and responsibilities.

A key objective of the National Disability Agreement is to progress reforms which place people with disability, their families and carers at the centre of services across the country. All aspects of the National Disability Agreement contribute to, or measure progress towards:

*“People with disability and their carers have an enhanced quality of life and participate as valued members of the community.”*

The National Disability Agreement seeks to contribute to the following outcomes:

- people with disability achieve economic participation and social inclusion

- people with disability enjoy choice, wellbeing and the opportunity to live as independently as possible
- families and carers are well supported.

The Parties to the National Disability Agreement have agreed to concentrate initial national efforts in several identified priority areas to underpin the policy directions and achieve reforms in the disability service system. The priority areas, as outlined in the National Disability Agreement, are:

**a) Better Measurement of Need:** A national model to estimate demand will be developed by mid 2010; data collected through the Survey of Disability, Ageing and Carers (SDAC) will be improved providing a stronger basis for demand estimates; improvements in the quality of data reported under the National Minimum Data Set and jurisdiction-level unmet demand data.

**b) Population Benchmarking for Disability Services**

A National Population Benchmarking Framework will be developed and initial population benchmarking of disability services, based on information available, will be achieved by mid 2010 and improve the evidence base to assist in policy, service and planning decisions.

### **c) Making Older Carers a Priority**

The National Disability Priorities Framework will assist governments to target services to more vulnerable population groups based on relative need (including older carers and Indigenous people with disability).

### **d) Quality Improvement Systems based on Disability Standards**

A National Disability Quality Framework with a National Quality Assurance system for disability services will be developed to introduce a national approach to quality assurance and the continuous improvement of disability services by mid 2010.

### **e) Service Planning and Strategies to Simplify Access**

The National Framework for Service Planning and Access will be developed, focussing on providing a person centred approach to service delivery and to simplify access to specialist disability services.

### **f) Early Intervention and Prevention, Lifelong Planning and Increasing Independence and Social Participation Strategies**

Early Intervention and Prevention Framework will be developed to increase governments' ability to be effective with early intervention and prevention strategies and ensure that clients receive the most appropriate and timely support by mid 2011.

### **g) Increased Workforce Capacity**

A national workforce strategy will be developed to address qualifications, training and cross sector career mapping issues and establishing the disability sector as an 'industry of choice' by the end of 2010.

### **h) Increased Access for Indigenous Australians**

National Indigenous Access Framework will ensure that the needs of Indigenous Australians with disability are addressed through appropriate service delivery arrangements.

### **i) Access to Aids and Equipment**

More consistent access to aids and equipment by the end of 2012.

### **j) Improved Access to Disability Care**

Systems that improve access to disability care and ensure people are referred to the most appropriate disability services and supports, including consideration of single access points and national consistent assessment processes in line with nationally agreed principles by the end of 2011.

As part of the COAG review of the performance frameworks of National Agreements under the IGAFRR, the NDA will be considered in the second half of 2011.

## 2 National Disability Strategy

The National Disability Agreement recognised that improved outcomes for people with disability, their families and carers are also contingent upon effective coordination of efforts across all areas of government and therefore committed jurisdictions to the development of a National Disability Strategy to complement the reform work in the specialist disability service systems.

The National Disability Strategy sets out a ten year national plan for improving life for Australians with disability, their families and carers.

The purpose of the Strategy is to:

- Establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy.
- Drive improved performance of mainstream services in delivering outcomes for people with disability.
- Give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability.
- Provide national leadership toward greater inclusion of people with disability.



The Strategy will play an important role in protecting, promoting and fulfilling the human rights of people with disability. It will help ensure that the principles underpinning the *United Nations Convention on the Rights of Persons with Disabilities* are incorporated into policies and programs that have implications for people with disability, their families and carers. It will contribute to Australia's reporting responsibilities under the Convention.

The National Disability Strategy covers six policy areas:

- **Inclusive and accessible communities:** the physical environment including public transport, parks, buildings and housing, digital information and communications technologies, civic life including social, sporting, recreational and cultural life.
- **Rights protection, justice and legislation:** statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems.
- **Economic security:** jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.
- **Personal and community support:** inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services, informal care and support.

- **Learning and skills:** early childhood education and care, schools, further education, vocational education, transitions from education to employment, life-long learning.
- **Health and wellbeing:** health services, health promotion and the interaction between health and disability systems, wellbeing and enjoyment of life.

The Australian, State and Territory governments have developed the Strategy in partnership and with assistance from the Australian Local Government Association. The Strategy aims to drive improved performance of mainstream services in delivering outcomes for people with disability, and to give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability.

The emphasis on mainstream services and public policy continues the growing recognition that people with disability should be able to access mainstream services in their community and that these services should cater for all Australians.

### **3 Other National and International Initiatives**

#### **United Nations (UN) Convention on the Rights of Persons with Disabilities**

*The UN Convention on the Rights of Persons with Disabilities* (the Convention) was ratified by Australia on 17 July 2008. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity.

Signatories to the Convention commit themselves to develop and carry out policies, laws and administrative measures for securing the rights recognised in the Convention, and abolish laws, regulations, customs and practices that constitute discrimination.

The Convention contains fifty Articles which express varying levels of obligations on participating countries. Some of the obligations in the Convention are immediately applicable according to international law. Other obligations that stem from economic, social and cultural rights can be implemented progressively, taking into account available resources.

While the Convention does not give any guidance as to the timeframes for implementing the obligations that arise from economic, social and cultural rights, the primary requirement is to implement the purpose and aims of the Convention in good faith.

Commonwealth, State and Territory legislation, policies and programs currently comply with all immediately applicable obligations, and substantially achieve implementation of the progressively realisable obligations in the Convention.

## **National Carer Strategy**

The Australian Government in consultation with State and Territory Governments has developed a National Carer Recognition Framework, comprising of legislation and a National Carer Strategy, to better recognise and support carers.

On 18 November 2010, the Carer Recognition Act 2010 came into effect to nationally acknowledge the vital social and economic contribution that carers make to Australian society.

The National Carer Strategy was released on 3 August 2011 and outlines the Australian Government's long-term commitment to ensure that carers have rights, choices, opportunities and capabilities to participate in work, community and family life. It will also complement reforms occurring, or being considered across aged care, disability, mental health, palliative care, hospitals and community care systems.

The National Carer Strategy is supported by a \$60 million package of measures, which will improve the financial security of carers and raise public awareness of the role and contribution of carers through a national and targeted campaign.

The National Carer Strategy contains six priority areas of action. These priority areas are: recognition and respect; information and access; economic security; services for carers; education and training; and health and wellbeing.

Over the next year, the Australian Government will develop an implementation plan outlining how the Strategy's priorities and ideas for future action will be put into place. The Australian Government will work in collaboration with state and territory governments, carers and their representatives to develop this implementation plan.

## **Productivity Commission Inquiry into National Disability Long-term Care and Support Scheme**

The Australian Government requested the Productivity Commission to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry is to assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- Provides long-term essential care and support for eligible people with severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime.
- Is intended to cover people with disability not acquired as part of the natural process of ageing.
- Calculates and manages the costs of long-term care and support for people with severe and profound disability.

- Replaces the existing system funding for the eligible population.
- Ensures a range of support options is available, including individualised approaches.
- Includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime.
- Assists the person with disability to make decisions about their support.
- Provides support for people to participate in employment where possible.

The Productivity Commission was asked to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries.

The final report, *Disability Care and Support*, was publically released on 10 August 2011. The Productivity Commission report recommends significant changes to the way services are funded and provided to people with disability in Australia. Government consideration of the recommendations of the Productivity Commission inquiry will influence how this Agenda is further developed and actioned in the future.

# **The National Health Reform Agreement**

The Council of Australian governments (COAG) has agreed, out-of-session in August 2011, the National Health Reform Agreement which will deliver major reforms to the organisation, funding and delivery of health and aged care. The Agreement sets out the shared intention of the Commonwealth, State and Territory governments to work in partnership to improve health outcomes for all Australians and ensure the sustainability of the Australian health system. The reforms will achieve better access to services, improved local accountability and transparency, greater responsiveness to local communities and provide a stronger financial basis for the health system into the future through increased Commonwealth funding. The reforms will result in funding and program responsibility changes between the Australian Government and States and Territories (with the exception of Victoria and Western Australia) in aged care, community care and specialist disability services.