Making Mental Health Policy Inclusive of People with Intellectual Disability
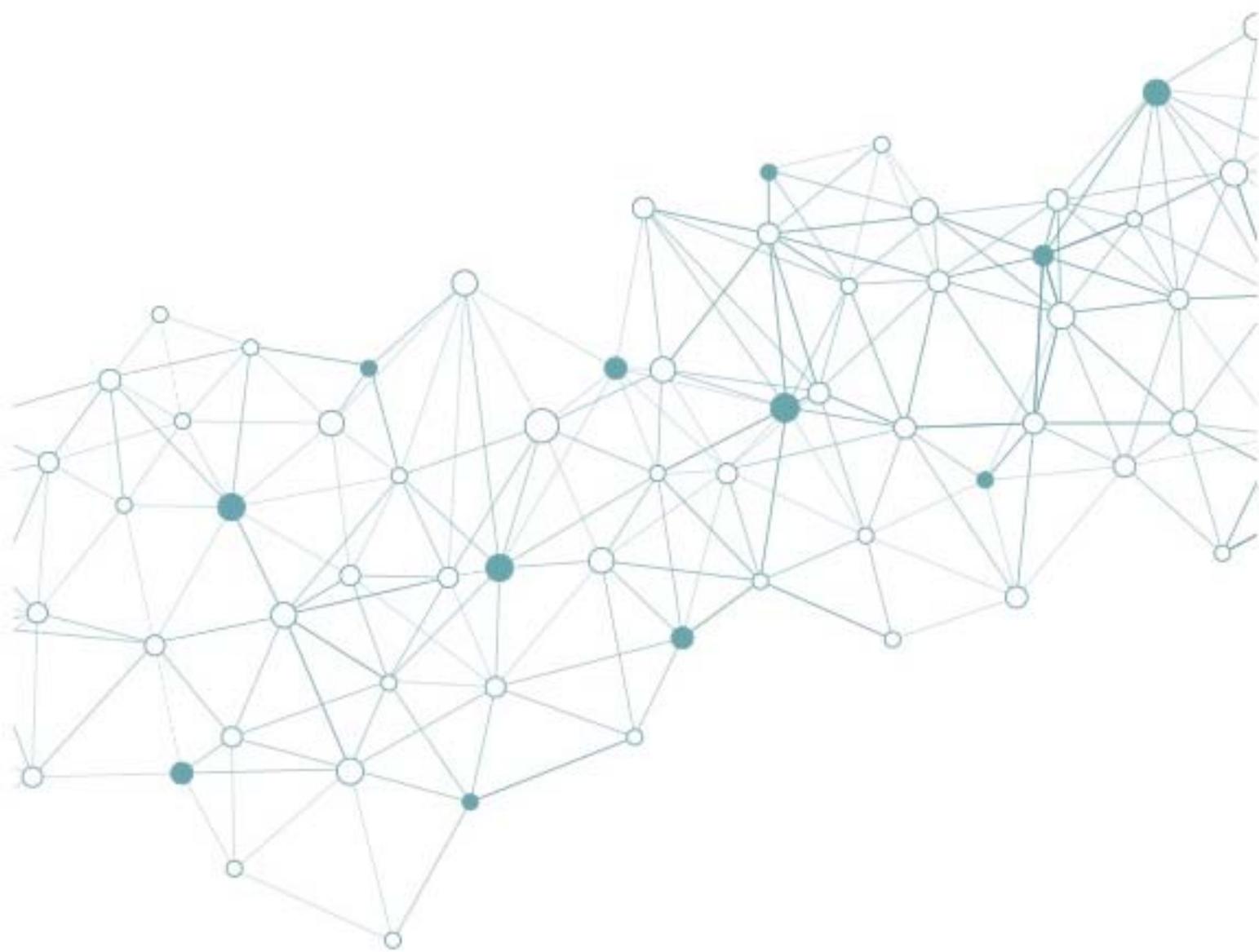
Report prepared by:

Dr Angela Dew, Senior Research Fellow[1]

Associate Professor Leanne Dowse, Chair IDBS, Project Lead[1]

Ms Ulrika Athanassiou, Research Assistant[1]

Professor Julian Trollor, Chair IDMH, Chief Investigator[2]

Dr Simone Reppermund, Senior Research Fellow[2]

[1] Intellectual Disability and Behaviour Support (IDBS) Program, School of Social Sciences, Arts and Social Sciences, UNSW Sydney

[2] Intellectual Disability Mental Health (IDMH), Department of Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Sydney

Contact

Department of Developmental
Disability Neuropsychiatry
School of Psychiatry | UNSW Medicine
34 Botany Street, UNSW Sydney NSW 2052
AUSTRALIA

P   +61 2 9931 9160
E   dddn@unsw.edu.au
W   3dn.unsw.edu.au

@3DN_UNSW

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Executive Summary

It is estimated that 1 – 2% of Australians have an intellectual disability with 57% of these estimated to have a mental disorder. This report addresses one aim of a National Health and Medical Research Council 'Partnerships for Better Health' Grant: *Improving the Mental Health Outcomes of People with Intellectual Disability*, funded from 2015 to 2018, and focussing on the inclusion of people with intellectual disability in mental health policy in Australia.

Project Overview

In order to address the individual, structural and social concerns that result from poor recognition and response to mental illness among people with intellectual disability, the project reported here maps the current policy landscape in relation to intellectual disability mental health. It takes as its primary form of evidence policy documents across the three key policy domains of health, mental health and disability. Sixty one Australian Commonwealth, State and Territory mental health and health and five key Commonwealth disability policy documents were analysed to determine the extent to which the specific needs of people with intellectual disability who also have mental ill-health are represented. An analysis framework was developed to identify the strengths/facilitators and gaps/barriers in each policy document related to the inclusion of people with intellectual disability. Thirty eight documents were mental health specific policy and related documents. Twenty three documents were general health policy and related documents that included mention of mental health. Nineteen of the documents included mention of people with 'intellectual disability' and/or associated terms, of these 16 were mental health specific documents.

Key Findings

Overall there is a lack of recognition of people with intellectual disability as a group at high risk of experiencing mental ill-health in current health, mental health and disability policy in Australia. The key weaknesses identified in the policy documents related to the lack of explicit identification or inclusion of people with intellectual disability as a group at high risk of mental ill-health and a general lack of recognition of their specific needs for expertise, modifications and adaptations in order to be well supported in mental health and health services. Five general strengths common to the mental health and health policy documents analysed were identified which potentially provide the foundations for greater recognition and inclusion of people with intellectual disability and mental illness including: a values-based approach, recognition of diversity, a life-course approach, focus on workforce development, and building in service outcome checks and balances such as monitoring, evaluation and research.

Two documents provided positive exemplars of inclusion of the mental health of people with intellectual disability in policy. The New South Wales *Living Well, A Strategic Plan for. Mental Health in NSW* and the Victorian *Because Mental Health Matters* both identify the need for dedicated strategies to ensure appropriate and accessible services for this group.
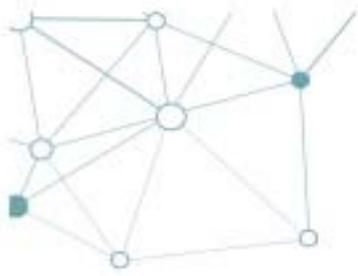
Recommendations Arising

The values underpinning all policy documents indicate a consistent platform of rights-based, consumer and strengths focussed principles. These provide a foundation to enable policy that is inclusive of the specific requirements and needs of people with intellectual disability and mental illness. The report points to a clear need for a comprehensive policy framework which recognises people with intellectual disability as a group at high risk of mental ill-health, that is inclusive of their specific needs and in line with Australia's obligations under the UNCRPD.

In designing inclusive intellectual disability mental health policy two key principles were identified from the review. First, there is a need for a comprehensive understanding of the context within which policy is developed in line with the UNCRPD, consistent with the NDIS and mental health sector interface principles, built on the evidence of the incidence and prevalence of mental illness among people with intellectual disability, and taking as its starting point a shared set of values across the mental health and disability sectors. Second, the inclusion of key stakeholders including people with intellectual disability who have mental illness and their family and carers along with policy makers, disability and mental health providers and professionals, and the broader community is key to tailoring the process of developing inclusive policy and content to the needs of people with intellectual disability and mental illness.

The development of inclusive policy requires a human rights framework which engages whole of government, cross-sector approaches and includes workforce training and professional development that recognises the need for specialist input from both disability and mental health sectors. Policy content must be informed by a sound evidence base regarding the mental health needs of people with intellectual disability, be inclusive of the diversity of issues arising across the life course, include measurable actions and targets, and detail strategies for inclusive and accessible services.

A knowledge translation approach is required to ensure that policy is informed by best evidence and practice and, that end users are engaged throughout the policy process. An inclusive approach to the development and implementation of intellectual disability mental health policy will address the current lack of attention, as highlighted in this report, to the important area of how to best meet the mental health needs of individuals with intellectual disability.
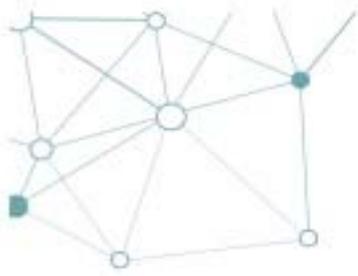
1. Context of the Report

1.1 National Health and Medical Research Council (NHMRC) Grant 2014-18

In order to address the poor inclusion of people with intellectual disability in mental health policy and practice in Australia, a team of investigators and partner organisations (see Appendix A for full list of partnership members) received funding from the National Health and Medical Research Council (NHMRC) to collaborate with key mental health, disability, education, justice and consumer agencies. The *Improving the Mental Health Outcomes of People with Intellectual Disability* project is a translational research program conducted from 2015-2018 which has four main aims:

- *Aim 1:* Create an annualised linkage of administrative minimum datasets of partner organisations to enable a detailed examination of mental health profiles and service utilisation, patterns of cross-sector service provision including specific gaps, the impact of recent service initiatives for people with intellectual disabilities, and to enable comprehensive development of intellectual disability mental health services in NSW.

- *Aim 2:* **Analyse Commonwealth and State and Territory mental health policy to determine the current representation of people with intellectual disabilities and to establish strategies which will enhance intellectual disability mental health policy.**

- *Aim 3:* Engage with stakeholders including consumers and support persons (including family and non-family carers), to inform improved recognition of mental ill health, accessibility of mental health services and mental health policy for people with intellectual disabilities across the lifespan.

- *Aim 4:* Progress to maturity a partnership which develops and applies an evidence-based approach to intellectual disability mental health service development, policy and reform across the lifespan.

1.2. About this Report

This report addresses Aim 2 of the *Improving the Mental Health Outcomes of People with Intellectual Disability* project. The report presents an interrogation of Australian Commonwealth, State and Territory mental health, health and disability policy documents to determine the extent to which the specific needs of people with intellectual disability who also have mental ill-health are represented
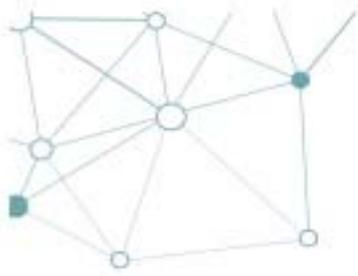
The report addresses the following research questions:

1. What is the current representation of people with intellectual disability in mental health policy, what factors have given rise to the current level of representation, and what potential impacts does this have on service delivery?

2. What research, advocacy and policy development strategies could enhance the representation of people with intellectual disability in mental health policy?

2. Background

2.1. Intellectual Disability and Mental Health

2.1.1 Definitions

Intellectual disability (also known as Intellectual Developmental Disorder) is a condition involving impairment of general mental abilities that is first apparent during the developmental period (i.e., before the age of 18), and impacts significantly on the person's adaptive functioning. The diagnosis is usually based on standardised assessment of deficits in adaptive functioning, intellectual abilities or both. The severity of intellectual disability can usually be described as mild, moderate, severe or profound (American Psychiatric Association, 2013, p. 33).

Mental illness describes a clinically significant disturbance of mood or thought that can affect behaviour and cause distress for the person or those around them. Mental illness may impact the person's ability to function normally and can interfere with a person's cognitive, emotional and social abilities (Department of Developmental Disability Neuropsychiatry, 2014, p. 42). One in five Australians will suffer a mental illness in any given year (Australian Government Department of Health and Ageing, 2007). Psychosocial disability is the term used to describe the experience of people with impairments and participation restrictions related to mental illness (UNCRPD, 2006).

2.1.2 Prevalence

Reported prevalence rates of intellectual disability range from 1 – 2% of the population (ABS, 2014; Maulik et al., 2011) with 57% of people with intellectual disability estimated to have a mental illness (ABS, 2010; Trollor, 2014). Health surveys have revealed that compared to the general population, people with intellectual disability experience very poor
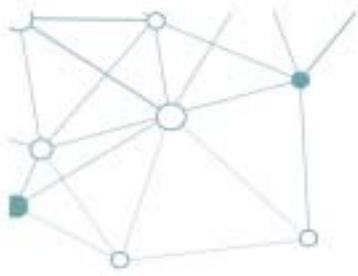
health status, characterised by higher mortality (Bittles et al. 2002; Patja et al. 2000) and elevated rates of common mental disorders such as schizophrenia (Borthwick-Duffy 1994), affective and anxiety disorders (Cooper 1997; Cooper & Holland 2007; Strydom et al. 2007, 2009), and dementia that are 2-3 times higher than the general population (Cooper et al., 2007; Einfeld et al., 2006, 2011; Smiley et al., 2007; Emerson & Hatton, 2007). People with intellectual disability with schizophrenia experience early onset of the disease, underscoring a specific vulnerability to mental illness and the importance of timely access to psychiatric services (Morgan et al. 2008).

People with intellectual disability in Australia are a minority group who experience poor mental health status, major barriers in access to mental health services and treatments, and an impoverished service system characterised by poor cross-sector coordination and poor preparedness of staff to meet mental health support needs (Trollor, 2014; Evans et al., 2012). Australian intellectual disability mental health policy and service standards fall short of its obligations under the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD) and lags behind leading international standards in intellectual disability health policy and services. In a review of the literature related to the state of mental health services for people with intellectual disability in Australia, Evans et al., (2012, p. 1102) stated that "In the area of ID mental health, Australia's policies remain vague, and mental health targets are illdefined". Australia is not alone in this regard with Chaplin and Taggart (2012) in the United Kingdom (UK) and Gough and Morris (2012) in Canada also identifying that the mental health needs of people with intellectual disability were not well recognised or reflected in policy.

2.2 Defining policy and its importance

Public policy represents "what governments do, why, and with what consequences" (Fenna, 2004, p. 2). Governments set broad strategic policy directions that have implications for society as a whole. While on face value defining what policy is seems a relatively straightforward exercise, the ways in which issues move on to the policy agenda has been recognised as a process of mediation and contestation (Hoppe, 1999). For some, policy is seen as the end product of a succession of steps deliberately taken to reach an authorised decision (Althaus, Bridgman & Davis, 2007). Others understand policy to emerge as a result of a collective process whereby participants negotiate with one another on behalf of various organisations and interest groups to identify and pursue goals (Colebatch, Hoppe & Noordegraaf, 2010). In either interpretation, policy making is a complex interplay between facts (what 'is') and values (what 'ought to be'). These less definitive conceptualisations of policy are important because they allow for an understanding that behind policy formation there are a range of social and structural processes (van Toorn and Dowse 2014). This recognition of complexity helps to account for why some issues are taken up as policy priorities and others remain less prominent.
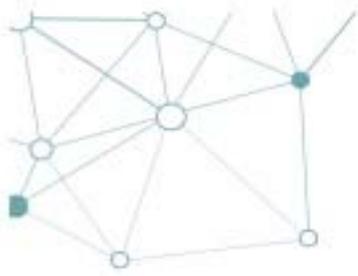
In Australia, policy is made by governments at the Commonwealth and State/Territory levels. Policies are implemented at various levels: micro (individual), meso (user groups) and macro (whole population). These three layers are equally important in interrogating policy responses to any given issue, since they provide a framework for understanding the individual, structural and social dimensions of actions designed to address a particular issue. In examining Australia's current capacity to address the mental health needs of people with intellectual disability these dimensions point to three different but interconnected concerns:

I.   The significant personal impact that un-addressed mental ill-health has on individuals with intellectual disability and their families and carers;

II.   The complex structural position of intellectual disability mental health as a policy issue that spans multiple policy domains – including health, mental health and disability, and

III.   The social responsibility to address issues which particularly impact on one of the most vulnerable and marginalised groups in our community and significantly impinge on their human rights.

In order to address these three interconnected concerns, the project reported here maps the current policy landscape in relation to intellectual disability mental health. It takes as its primary form of evidence policy documents across the three key policy domains of health, mental health and disability. In describing health policy, Cheug, Mirzaei and Leeder (2010, p. 406) refer to policy as "...a plan that steers the direction of investment and action designed to alleviate suffering, improve health care or prevent illness. It can be manifested as laws, bureaucratic edicts, practice guidelines, or more vaguely, simply as guiding principles." Policy for people with intellectual disability and mental ill-health is therefore considered a major driver of practice such that the inclusion or exclusion of the concerns of this group and related issues determines allocation of funding and hence service delivery priorities.

2.3 Intellectual Disability Mental Health Policy

The benefits of a strong policy framework in the area of intellectual disability and mental health are exemplified by the UK in the policy documents *Valuing People* (Department of Health UK, 2001) and *Valuing People Now* (Department of Health UK, 2009). These UK documents highlight the need for national service frameworks to enhance the understanding and appropriate treatment of the mental health needs of people with intellectual disability across the disability, mental health and mainstream service sectors.

Australia's poor record in the area is identified in the *Fourth National Mental Health Plan* which recognises that those with intellectual disability and comorbid mental disorder are "overlooked and access to appropriate treatment for both disabilities is limited"
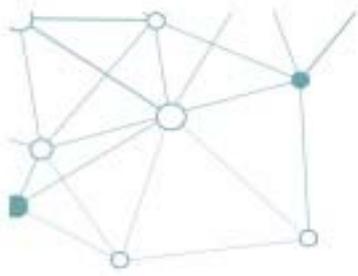
(Department of Health & Ageing 2009, p.70). The *Fourth National Mental Health Plan* highlights the urgent need to address mental disorders in this group, and to do so in an inclusive manner (see Priority Areas 1 and 2) (Department of Health & Ageing, 2009). However, the mismatch between the expectations outlined in policy and the readiness of currently available services to adopt this approach makes a more detailed evaluation of the mental health policy framework very important.

3. Methods

In order to undertake the policy analysis a three step process was undertaken as follows.

3.1. Identify and collect policy documents

Purposive and snowballing sampling techniques were used to:

I. Identify key Australian Commonwealth disability legislation and policy documents. Documents were found via searches of the Australian Commonwealth Department of Social Services, and National Disability Insurance Scheme and additional documents identified by project partner investigators.

II. Identify broad strategic Australian Commonwealth and State/Territory mental health and health legislation and policy documents with mention of mental health (see Table 3). Documents were found via searches of Australian Commonwealth and State/Territory Department of Health websites, and additional policy documents were identified by project partner investigators.

Broad strategic policy documents came in many guises with some documents identified with a 'policy' label, while others were called 'frameworks', 'strategic plans' or 'strategies'. We included documents with all these labels that were accessible on key government websites.

We took inclusion on the website as endorsement by the relevant government department. Inclusion criteria for mental health and health documents:

- Available online;
- Mental health policy documents;
- General health policy documents which included mental health;
- Spanning years 2005-2015.

In the interest of focusing on broad strategic policy directions, operational plans, protocols and guidelines related to implementation at departmental or organisational levels were excluded.

All documents were downloaded and saved as PDFs. Details of each document were entered into an Excel spreadsheet grouped by jurisdiction. Once located, each document was
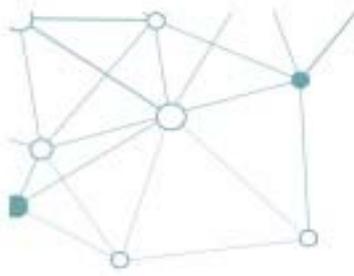
searched using the following key words: mental health, mental illness, mental disorder, mental disease; intellectual disability, intellectual impairment, learning disability, learning disorder, cognitive impairment, disability; vulnerable populations, special populations, complex needs. The presence or absence of these key words was recorded on the spreadsheet.

3.2. Develop an analysis framework

A coding analysis framework (see Appendix B) was developed to address the objective and key research questions for Aim 2. The analysis framework combined elements from:

I. The *World Health Organization (WHO) Checklist for Evaluating a Mental Health Plan* (WHO, 2007) including:
- Process issues – how policy is developed and with whose input;
- Operational issues – timeframes, indicators, targets, activities;
- Content issues – coordination and management, financing, legislation/human rights, organisation of services, promotion, prevention and rehabilitation, medication, advocacy, quality improvement, information, human resources development and training, intra- and inter-sectorial collaboration, feasibility.

II. Walt and Gilson's (1994) *Policy Analysis Framework* incorporating[1]:
- Context;
- Content;
- Process;
- Actors (individuals and groups).

III. Factors identified by the project partner investigators.

3.3. Qualitative content analysis

Two team members were involved in the analysis of the policy documents. Each team member independently analysed one document and then compared coding decisions. Only minor differences were identified and the analysis framework was revised to clarify these points of difference. Subsequent documents were analysed by one or other team member using the revised analysis framework. Analysis was an iterative process with minor adjustments to the framework based on specific issues identified during analysis of particular documents.

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[1] See Figure 1 Walt and Gilson Policy Analysis Framework page 23
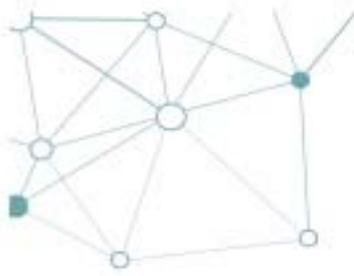
Analysis focussed on identifying the strengths/facilitators and gaps/barriers in each policy document related to the inclusion of people with intellectual disability in mental health/health policy. Analysis included: the language used to refer to people with mental illness, strategies for ensuring input of people with intellectual disability, family members/carers and service providers in policy development, and strategies proposed for ensuring mental health services were accessible and responsive to the specific needs of people with intellectual disability and family members/carers. As it became evident that the majority of mental health and health policy documents included limited or no mention of people with intellectual disability, particular attention was paid to omissions - what was *not* included was determined to be as important at what *was* included. This review was conducted in a rapidly changing environment in the disability, mental health and health sectors with new policy constantly emerging. The report represents therefore a 'snapshot' in time.

3.4. Governance

Project group meetings were held regularly during the document finding and analysis phases. The meetings included project partner investigators with a special interest in mental health, health and disability policy. The meetings provided opportunities for partners to question the policy document inclusion criteria and analysis approaches, contribute to the analysis framework, and provide information about additional policies to include in analysis. In this way, the project group members acted as a sounding board, checking mechanism, and quality control for the project team. A draft of the report was circulated to project group members and changes made based on feedback.

4. Results

Documents gathered were mapped to develop a representation of the current framework for intellectual disability mental health policy as shown in figure 1. Figure 1 provides an overview of Australian Commonwealth and State/Territory disability and mental health legislation and included Commonwealth disability, mental health and health policy documents. The disability and mental health legislation and policy documents are framed within the international United Nations Convention on the Rights of People with Disabilities to which Australia is a signatory.

In order to set the overall context of policy for people with disability and more specifically people with intellectual disability, analysis was undertaken to identify the key overarching disability policy settings in relation to this group.
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Figure 1 Relevant Australian Legislation and Commonwealth Policy

UNITED NATIONS CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES
2006; Ratified by Australia in 2008

DISABILITY LEGISLATION
Commonwealth
Disability Services Act, 1986
Disability Discrimination Act, 1992
National Disability Insurance Scheme Act, 2013
State/Territory
Disability Services legislation
Anti-discrimination legislation
Guardianship legislation
NDIS related legislation

MENTAL HEALTH LEGISLATION
Commonwealth
Disability Discrimination Act, 1992

State/Territory
Mental Health Acts
Anti-discrimination legislation

HEALTH LEGISLATION
Commonwealth
National Health Act, 1953
63 other pieces of legislation

COMMONWEALTH MENTAL HEALTH POLICY
- National Mental Health Policy, 2008
- Mental Health Statement of Rights and Responsibilities 1991 (updated 2012)

INCLUDED MENTAL HEALTH DOCUMENTS
- LiFE Framework of Suicide Prevention in Australia, 2007
- Framework for Implementation of National Mental Health Plan 2003-2008 in Multicultural Australia
- COAG National Action Plan on Mental Health 2006-2011
- 4th National Mental Health Plan, 2009-2014
- e-Mental Health Strategy for Australia, 2012
- National Aboriginal and Torres Strait Islander Suicide Prevention Strategy, 2013
- National Review of Mental Health Programs and Services, 2015
- COAG Roadmap for National Mental Health Reform, 2012-2022

INCLUDED COMMONWEALTH DISABILITY DOCUMENTS
- Shut Out Report, 2009
- National Disability Agreement, 2009
- National Disability Strategy, 2010-2020
- Productivity Commission Report: Disability Care and Support, 2011
- National Disability Insurance Scheme, 2013

INCLUDED COMMONWEALTH HEALTH DOCUMENTS
- COAG National Health Reform Agreement, 2011
- National Women's Health Policy, 2010
- Building on the Strength of Australian Males, 2010
- The National Drug Strategy, 2010-2015
- National Aboriginal and Torres Strait Islander Health Plan, 2013-2023

4.1 Disability legislation and policy

Over the past six years the fragmentation and lack of access to disability supports throughout Australia have been highlighted in two key reports, *Shut Out: The experience of people with disabilities and their families in Australia, 2009* and the *Productivity Commission Report: Disability Care and Support, 2011.* Resulting from these reports were the *National Disability Agreement* (NDA), the *National Disability Strategy* (NDS) and, most recently, the *National Disability Insurance Scheme* (NDIS). Together, the NDA, NDS and NDIS have led to significant changes in the way disability services and supports are planned and delivered to people with disability including those with intellectual disability and mental illness. These changes are embedded in legislation and policy at Commonwealth and State/Territory levels.

4.1.1 Disability Legislation

Three key pieces of Commonwealth legislation underpin disability policy and practice at a national level and within the States and Territories.

The *Disability Services Act, 1986* (DSA) aims to assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community. The Act is focussed on de-institutionalising segregated services, increasing the range of service options available to people with disability, and fostering the inclusion of people with disability in wider community life. Twelve disability service standards outline the Government's expectations around service quality and outcomes. Subsequent to, and in line with, the Commonwealth Act, all States and Territories passed disability legislation.

The *Disability Discrimination Act 1992* (DDA) provides protection against discrimination based on disability and promotes equal opportunity and access for people with disability. The DDA covers discrimination in the following areas of life: employment, education, access to premises used by the public, provision of goods, services and facilities, accommodation, purchase of land, activities of clubs and associations, sport, and administration of Commonwealth Government laws and programs. Subsequent to, and in line with, the Commonwealth Act, all States and Territories passed anti-discrimination legislation.

The *National Disability Insurance Scheme Act, 2013* (NDIS) sets out the principles under which the NDIS will operate including: how a person becomes an NDIS participant, planning, funding of reasonable and necessary supports, registration of providers, the governance of the National Disability Insurance Agency, and the processes for internal and external review of decisions made under the Act. The NDIS is an insurance model providing individualised support for eligible people with permanent and significant disability.

4.1.2 Disability Policy

Five key Commonwealth disability reports and policy documents were analysed with the objective of identifying the overarching context of current policy settings in relation to disability. Analysis specifically addressed the framing of intellectual disability within these documents.
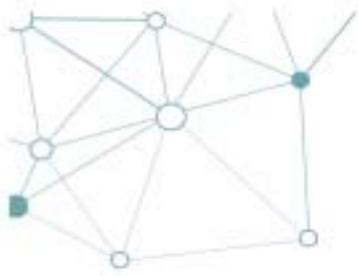
While none are specific to people with intellectual disability, all documents include reference to this group. Additionally, the documents were scanned for attention to mental health generally and for attention to mental ill-health of people with intellectual disability specifically. Overall, these key documents included mention of both people with intellectual disability and people with mental ill-health. There was only limited attention given to the mental ill-health of people with intellectual disability.

I. *Shut Out: The experience of people with disabilities and their families in Australia, 2009.*

The *Shut Out* report was prepared at the request of the Commonwealth government by the National People with Disabilities and Carer Council to inform the development of a *National Disability Strategy*. In compiling the report, the authors held forums in metropolitan and regional areas across Australia attended by more than 2,500 people. The authors also received more than 750 written submissions from individuals, organisations, peak bodies and government, of which 9% identified intellectual disability as a group of concern.

The main messages contained in the *Shut Out* report relate to the struggles experienced by people with disability and their carers to access the services and supports they needed. The report authors identified the need for access barriers to be removed so people with disability and their carers could lead the lives they desired.

There is little mention of mental illness in the report although a number of mental health organisations were listed as contributors. On page 33, it is noted that there was "little awareness of the mental health needs of people with intellectual disability, particularly as they age". Addressing mental ill-health of people with intellectual disability is described as "a pressing issue for future planning". This report informed the development of the *National Disability Strategy* – a ten year plan for disability services in Australia described below.

II. *National Disability Agreement (NDA), 2009.*

The *NDA* delineates clear roles and responsibilities for Commonwealth and State and Territory governments around the provision of services to people with disability. The *NDA* provides, for the first time in Australia, nationally agreed objectives and outcomes for people with disability, families and carers to have an "enhanced quality of life and participate as valued members of the community" (p. 3).

Under the agreement, the Commonwealth have responsibility for income support and employment services and the States/Territories for accommodation, respite and community support services. A set of performance indicators and benchmarks are identified to guide implementation of the agreement. The *NDA* should be read in conjunction with the *National Health Reform Agreement*. The *NDA* remains in place until the full roll out of the NDIS scheduled for 2020.
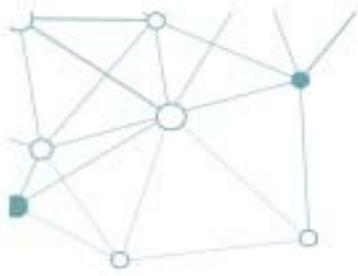
III.   National Disability Strategy (NDS), 2010-2020

Informed by the *Shut Out* report, the aim of the *NDS* is to ensure that people with disability have opportunities to fully participate in the economic, social and cultural life of the nation. The *NDS* outlines a cohesive approach, in line with the UNCRPD, across governments in mainstream and disability specific areas of public policy. To achieve a cohesive approach, the strategy identifies that coordinated planning is required across all portfolios and areas of government. The NDS adopts the social model of disability whereby "attitudes, structures and practices are disabling and can prevent people from enjoying economic participation" (p. 16).

The *NDS* covers six policy areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; health and wellbeing. The NDS addresses the interests of people with a range of impairments including intellectual disability and psychosocial disability. The specific needs of people with intellectual disability are mentioned in the section on health and wellbeing with a statement that they are a disadvantaged group with comparatively poor health status. For example, people with intellectual disability may have a 20 year lower life expectancy than the general population. The *NDS* highlights the need to include issues specific to people with disabilities, including mental ill-health, within key public health strategies with particular reference to the *4th National Mental Health Plan*. In relation to people with intellectual disability, on page 62 of the *NDS* it is stated: "Psychiatric disorders are among the conditions that are frequently not well diagnosed or managed in people with intellectual disability".

People with intellectual disability are also discussed in the section on rights protection, justice and legislation citing evidence that people with intellectual disability are 10 times more likely to have experienced abuse than non-disabled people, and people with intellectual disability are overrepresented both as victims and offenders in the criminal justice system.

Implementation plans, governance structures including annual reports to COAG, stakeholder engagement through advisory groups, and monitoring and reporting mechanisms are included in the *NDS* to ensure accountability across each of the six policy areas.

IV.   Productivity Commission Report: Disability Care and Support, 2011

Following on from the issues raised in the *Shut Out* report and implementation problems related to a lack of resourcing of the *NDS*, the Australian government asked the Productivity Commission to conduct an inquiry into the need for and feasibility of a long term national disability care and support scheme. The Commission heard 23 days of testimony in formal hearings and received nearly 1,100 submissions from people with disability, family members/carers, service providers, government and business. The Commission proposed a national disability insurance scheme whereby all Australians with significant and permanent disability would get long term care and support. The Commission advocated three tiers of support with Tier 3 providing the most intensive support for 410,000 people; Tier 2 providing information website referral services and community engagement for 4 million people with disability and 800,000 carers, and Tier 1 encapsulating social
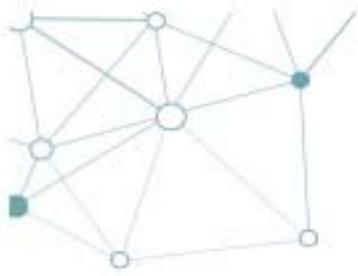
participation for the entire Australian population.

The report identifies and validates the need for both people with intellectual disability and people with mental illness to be included in the proposed national disability insurance scheme. Both groups are discussed throughout the report. The report recommended that there should be "full coverage" (p. 62, Vol 1), for people with intellectual disability and coverage for community (as distinct from specialist mental health) supports for people with mental illness (p. 188, Vol 1). The report also identified that some people with intellectual disability have mental ill-health with specific reference to the NSW Council for Intellectual Disability submission that stated there was a "lack of expertise in the mental health sector in dealing with people with intellectual disability who also had mental illness" (p. 190-191, Vol 1).

*V.   National Disability Insurance Scheme, 2013*

The release of the Productivity Commission's report was followed by a national grassroots campaign *'Every Australian Counts'* that mobilised 150,000 people to advocate for the adoption of the recommendations of the report. The Commonwealth government legislated to introduce the National Disability Insurance Scheme (NDIS) commencing 1 July, 2013. The scheme was initially introduced in seven trial sites involving 19,817 participants. It is anticipated that when the scheme is fully operational in 2020, it will provide funded support packages to 460,000 individual Tier 3 participants.

Under the NDIS, every Australian born with or acquiring a disability before the age of 65 and whose disability is permanent and significantly affects their functional capacity will be covered. The NDIS includes people with intellectual, physical, sensory and psychosocial disability. According to the NDIS website, the scheme heralds an entirely new approach to disability services that:

- is built around the needs and the potential of the individual;

- sees the individual as a life-long investment, rather than a year-to-year unit of cost;

- replaces the welfare model of disability services with an insurance model.

The 2014-2015 annual report of the body that administers the NDIS, the National Disability Insurance Agency (NDIA), identified that 25% of current NDIS participants had an intellectual disability and 6% a psychosocial disability. As only the primary disability is reported there are no data showing the percentages of participants with dual diagnosis of intellectual and psychosocial disability. The Mental Health Coordinating Council report on the experiences of people with psychosocial disability in the Hunter, New South Wales NDIS trial site identified 1,090 NDIS participants with a primary diagnosis of psychosocial disability who also had an approved plan (Mental Health Coordinating Council, 2015). Within the NSW trial site context the large residential centres of Morisset, Stockton and Kanangra currently accommodate 662 people with complex support needs including those with intellectual disability and mental illness. The MHCC report highlights that the relocation of these people to community settings will require specific advocacy and supported decision making (Mental Health Coordinating Council, 2015).

In order to ensure input from NDIS users, family members, professionals, academics and advocates, the NDIA set up a number of reference groups around specific issues. The groups
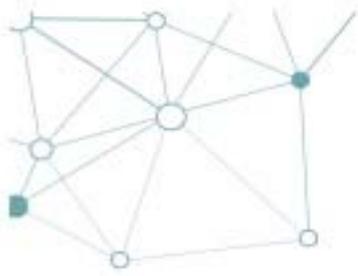
include an Intellectual Disability Reference Group and a Mental Health Sector Reference Group. The Intellectual Disability Reference Group is tasked with advising on (among other matters): equity of access to the NDIS, a definition of intellectual disability, and decision making for people with complex impairment (NDIA Annual Report 2014-2015). The Mental Health Sector Reference Group has direct links to the National Mental Health Consumer Forum. The Mental Health Sector Reference Group is tasked with advising on the progressive integration of psychosocial disability into the NDIS and efforts to reconcile one of the key eligibility criteria of the NDIS - permanent disability - with the focus in the mental health sector on recovery (NDIA Annual Report 2014-2015).

One of many challenges faced by the NDIA is to ensure that health and other mainstream services fulfil their universal service obligations to people with disability. To this end, a set of principles to determine the future funding and delivery responsibilities of the NDIS and other service systems was released in 2013 and revised at the end of 2015. Underpinning these principles is the right of people with disabilities to access the services available to all Australians. Mental health was identified as one of 11 service systems included in the principles. Under the principles, the health system maintains responsibility for clinical mental health services and residential in-patient treatment or rehabilitation. The health and community services system has responsibility for supports relating to co-morbidity with a mental health issue where the co-morbidity is clearly the responsibility of that system (e.g., treatment for a drug and/or alcohol issue). The NDIS is identified as having responsibility for non-clinical supports focussed on a person's functional ability that will enable the person with mental illness to participate in community, social and economic life (Principles to Determine the Responsibilities of the NDIS and Other Service Systems, 2013, revised November 2015).

Together, these five key national disability documents provide a comprehensive framework of the current landscape in Australia in relation to people with disability. The NDIS clearly applies to people with intellectual disability and those with mental illness and acknowledges dual diagnosis.

4.2 Mental Health and Health legislation and policy

4.2.1. Mental health legislation

In recognition of the importance of legislation to policy development and implementation, mental health legislation for all States/Territory was accessed (see Table 1 for a list of legislation by jurisdiction). The legislation in all jurisdictions uses a consistent definition of mental illness in line with that provided earlier in this report (p. 9).

Jurisdictional legislation typically includes provisions related to the assessment, treatment, care, rehabilitation and protection of people with mental illness. All the legislation refers to the need for treatment practices to be the least restrictive and informed by human rights
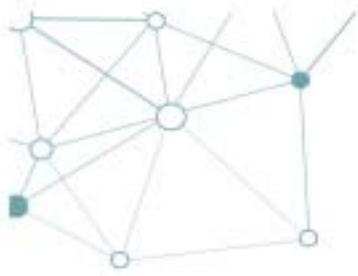
principles. All jurisdictions include information about monitoring bodies such as review tribunals, community or official visitors, and chief psychiatrist roles. Voluntary and involuntary treatment in both in-patient and community settings is covered by most jurisdictions (the Queensland and Victorian legislation only cover involuntary treatment).

All jurisdictions' legislation included mention of people with intellectual disability who may also have a mental illness. The Queensland, Victorian, Tasmanian and Western Australian legislation used the term 'intellectual disability', the amended NSW legislation used the term 'intellectual disability or developmental disability', the South Australian legislation used the term 'developmental disability of the mind', the ACT legislation used the term 'mental impairment' and the Northern Territory legislation referred to 'complex cognitive impairment' defined as those who are 'intellectually impaired, neurologically impaired or have an acquired brain injury and behavioural disturbance (aggressive or irresponsible behaviour)'.

In all legislation, intellectual disability and associated terms are included in the list of conditions that, of themselves, should not be taken to indicate a mental illness. Other mentions of intellectual disability and associated terms relate to forensic parts of the Acts including fitness to plead and the need for additional support.

Table 1 Mental Health Legislation

Jurisdiction	Act
Australian Capital Territory (ACT)	Mental Health (Treatment & Care) Act 1994 (amended 2013)
New South Wales (NSW)	Mental Health Act 2007 No. 8 (amended 31/8/15)
	Mental Health Commission Act 2012
Northern Territory	Mental Health and Related Services Act 2014
Queensland	Mental Health Act 2000 (current as at 1 July 2014)
South Australia	Mental Health Act 2009
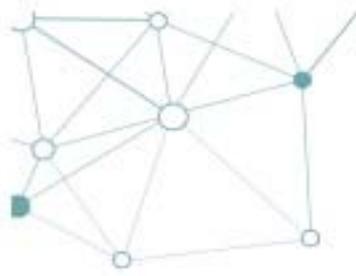
Tasmania	Mental Health Act 2013
Victoria	Mental Health Act 2014
Western Australia	Mental Health Act 1996 (version as at 3/11/14)

4.2.2 Mental health and health policy

Sixty one mental health and health policy and associated documents met the inclusion criteria. Table 2 provides details of the 11 key overarching mental health policy document/s identified for the Commonwealth and each State/Territory.

Table 2 Key Mental Health Policy Documents

Jurisdiction	Key mental health policy documents (N =11)
Federal	National Mental Health Policy, 2008; Fourth National Mental Health Plan: An Agenda for Collaborative Government in Mental Health, 2009-2014; Mental Health Statement of Rights and Responsibilities, 2012 Roadmap for National Mental Health Reform, 2012-2022 (COAG).
ACT	Building a Strong Foundation: A framework for promoting mental health and well-being in the ACT, 2009-2014.
NSW	NSW: A New Direction for Mental Health, 2006-2011.
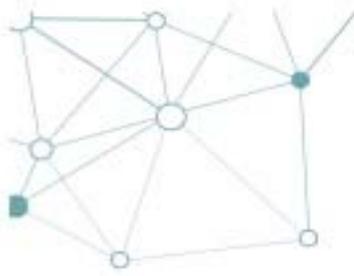
Northern Territory	Missing as Mental Health policy document was not available on line.
Queensland	Queensland Plan for Mental Health, 2007-2017.
South Australia	South Australia's Mental Health and Wellbeing Policy, 2010-2015.
Tasmania	Tasmania Mental Health Strategic Plan, 2006-2011 – Partners towards recovery.
Victoria	Because Mental Health Matters: Victorian mental health reform strategy, 2009-2019.
Western Australia	Mental Health 2020: Making it personal and everybody's business: Reforming Western Australia's mental health system, 2010-2020.

Fifty other associated policy documents were identified. Table 3 (pages 24-26) provides information on all documents included in the analysis. In summary:

- 37 of the 61 were mental health specific policy and related documents. The other 24 were general health policy and related documents that included mention of mental health;

- 19 of the 61 documents included a mention of people with 'intellectual disability' and/or associated terms; 15 of the 19 mentions were in mental health specific documents;

- 46 documents used the broad term 'disability' with 16 of these documents also including specific mention of people with intellectual disability. The term 'disability' was most frequently used associated with the disabling effects of living with mental ill-health or chronic disease;

- 30 documents used the term 'complex needs' associated with either mental ill-health or chronic health conditions. None used it specifically in relation to people with intellectual disability;

- 2 documents made single references to 'special populations'. Neither document provided a definition for who was included under this term. Both these documents mentioned intellectual disability although not related to the 'special population' references;

- 2 documents included mention of 'vulnerable populations' – 1 in relation to Aboriginal and Torres Strait Islander peoples with disability and the other in relation to people with chronic disease.
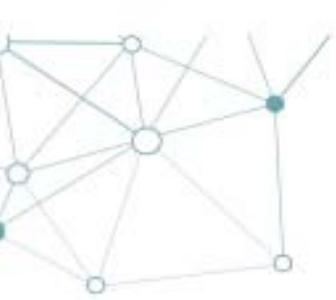
Table 3 Included Mental Health and Health Policy Documents

| Document ID	POLICY/DOCUMENT TITLE (*N* = 61)	Year/s	Mention of ID
C	**COMMONWEALTH** (*n* = 15)		
	MENTAL HEALTH DOCUMENTS		
C1	Framework for the implementation of the National Mental Health Plan in Multicultural Australia	2003–2008	Yes
C2	Council of Australian Governments (COAG) National Action Plan on Mental Health	2006-2011	Yes
C3	The Living Is For Everyone (LIFE) Framework (national framework for suicide prevention)	2007	No
C4	National Mental Health Policy	2008	No
C5	Fourth National Mental Health Plan: An Agenda for Collaborative Government in Mental Health	2009-2014	Yes
C6	E-mental health strategy for Australia	2012	No
C7	COAG Roadmap for National Mental Health Reform	2012-2022	Yes
C8	Mental Health Statement of Rights and Responsibilities 1991	Updated 2012	Yes
C9	National Aboriginal and Torres Strait Islander Suicide Prevention Strategy	2013	No
C10	National Review of Mental Health Programmes and Services	2015	Yes
	HEALTH DOCUMENTS (included mental health)		
C11	Building on the Strengths of Australian Males	2010	No
C12	National Women's Health Policy	2010	No
C13	The National Drug Strategy	2010-2015	No
C14	COAG National Health Reform Agreement	2011	No
C15	National Aboriginal and Torres Strait Islander Health Plan: Closing the Gap	2013-2023	Yes
NSW	**NEW SOUTH WALES (NSW)** (*n* = 10)		
	MENTAL HEALTH DOCUMENTS		
NSW1	NSW Aboriginal Mental Health and Well Being Policy	2006-2010	No
NSW2	Multicultural Mental Health Plan	2008-2012	Yes
NSW3	Safe Start Strategic Policy	2009	No
NSW4	NSW Suicide Prevention Strategy	2010-2015	Yes
NSW5	NSW School-Link Strategy and Action Plan	2014-2017	No
NSW6	NSW Living Well, A Strategic Plan for Mental Health in NSW	2014-2024	Yes
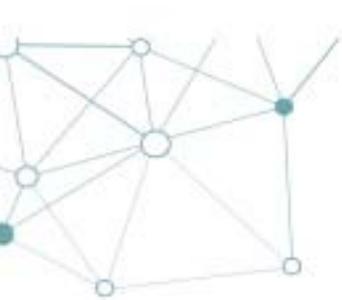
	HEALTH DOCUMENTS (included mental health)		
NSW7	Women's Health Plan	2009-2011	Yes
NSW8	Men's Health Plan	2009-2012	No
NSW9	Youth Health Policy: Healthy Bodies, Healthy Minds, Vibrant Futures	2011-2016	Yes
NSW10	NSW Aboriginal Health Plan	2013-2023	No
VIC	**VICTORIA (VIC)** (*n* = 9)		
	MENTAL HEALTH DOCUMENTS		
VIC1	Victorian strategy for safety and quality in public mental health services	2004-2008	No
VIC2	Caring together: An action plan for carer involvement in Victorian public mental health services	2006	No
VIC3	Next steps: Victoria's suicide prevention forward action plan	2006	No
VIC4	Cultural diversity plan for Victoria's specialist mental health services	2006-2010	No
VIC5	Planning framework for public rural mental health services	2007	No
VIC6	Shaping the future: The Victorian mental health workforce strategy Final report	2009	No
VIC7	Because Mental Health Matters – Victorian Mental Health Reform Strategy	2009-2019	Yes
	HEALTH DOCUMENTS (included mental health)		
VIC8	Victorian Health Priorities Framework: Metropolitan Health Plan	2012-2022	No
VIC9	Koolin Balit: Victorian Government Strategic Directions for Aboriginal Health	2012-2022	Yes
QSLD	**QUEENSLAND (QSLD)** (*n* = 5)		
	MENTAL HEALTH DOCUMENTS		
QSLD1	The Queensland Government Suicide Prevention Strategy	2003-2008	No
QSLD2	Queensland Plan for Mental Health	2007-2017	Yes
QSLD3	Improving Mental Health and Wellbeing. Queensland Mental Health, Drug and Alcohol. Strategic Plan	2014-2019	Yes
	HEALTH DOCUMENTS (included mental health)		
QSLD4	Making Tracks Towards Closing the Gap in Health Outcomes for Indigenous Queenslanders by 2033: Policy and Accountability Framework	2010	No
QSLD5	Queensland Youth Strategy - Connecting Young Queenslanders	2013	No
WA	**WESTERN AUSTRALIA (WA)** (*n* = 5)		
	MENTAL HEALTH DOCUMENTS		
WA1	WA Suicide Prevention Strategy	2009–2013	No
WA2	Mental Health 2020: Making it Personal and Everybody's Business	2010-2020	No
WA3	Consultation Draft: The WA Mental Health, Alcohol and Other Drug Services Plan	2015-2025	Yes
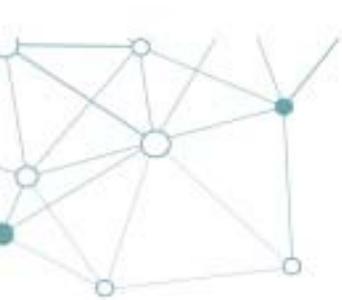
	HEALTH DOCUMENTS (included mental health)		
WA4	WA Women's Health Strategy	2013-2017	No
WA5	WA Aboriginal Health and Wellbeing Framework	2015-2030	No
SA	**SOUTH AUSTRALIA (SA)** (*n* = 7)		
	MENTAL HEALTH DOCUMENTS		
SA1	SA's Mental Health and Wellbeing Policy	2010-2015	No
SA2	SA Suicide Prevention Strategy	2012-2016	No
	HEALTH DOCUMENTS (included mental health)		
SA3	SA's Health Care Plan	2007-2016	No
SA4	SA Women's Health Action Plan	2010-2011	No
SA5	The Aboriginal Health Care Plan	2010-2016	No
SA6	Health Policy for Older People	2010-2016	No
SA7	SA Alcohol and other Drug strategy	2011-2016	No
TAS	**TASMANIA** (*n* = 4)		
	MENTAL HEALTH DOCUMENTS		
TAS1	Mental Health Strategic Plan	2006-2011	No
TAS2	Building the Foundations for Mental Health and Wellbeing: A strategic framework and action plan for implementing promotion, prevention and early intervention (PPEI) approaches in Tasmania	2009	Yes
TAS3	Tasmania's Suicide Prevention Strategy: A strategic framework and action plan	2010-2014	No
	HEALTH DOCUMENTS (included mental health)		
TAS4	Alcohol, Tobacco and Other Drug Services: A five year plan	2008-13	No
NT	**NORTHERN TERRITORY (NT)** (*n* = 2)		
	MENTAL HEALTH DOCUMENTS		
NT1	NT Suicide Prevention Strategic Action Plan	2014-2018	No
	HEALTH DOCUMENTS (included mental health)		
NT2	NT Health Strategic Plan	2014-2017	No
ACT	**AUSTRALIAN CAPITAL TERRITORY (ACT)** (*n* = 4)		
	MENTAL HEALTH DOCUMENTS		
ACT1	Building a Strong Foundation: A Framework for Promoting Mental Health and Well-being in the ACT	2009-2014	No
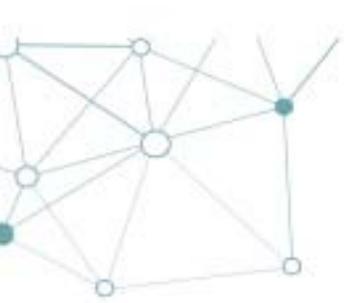
ACT2	Managing the risk of suicide: A suicide prevention strategy	2009-2014	Yes
	HEALTH DOCUMENTS (included mental health)		
ACT3	Improving women's access to health care services and information	2010-2015	No
ACT4	ACT Primary Health Care Strategy	2011-2014	No
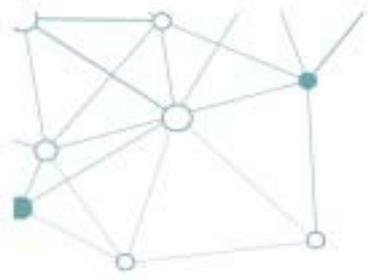
4.3 Applying the policy analysis framework

The model of health policy analysis developed by Walt and Gilson (1994) takes into account the context, actors, process and content involved in policy development. Along with matching elements from the *WHO Checklist for Evaluating a Mental Health Plan,* the Walt and Gilson model was used to guide this analysis of mental health and health policy in Australia. Figure 2 provides a diagrammatic representation of Walt and Gilson's analysis model.

Context

Actors
- as individuals
- as members of groups

Content   **Process**
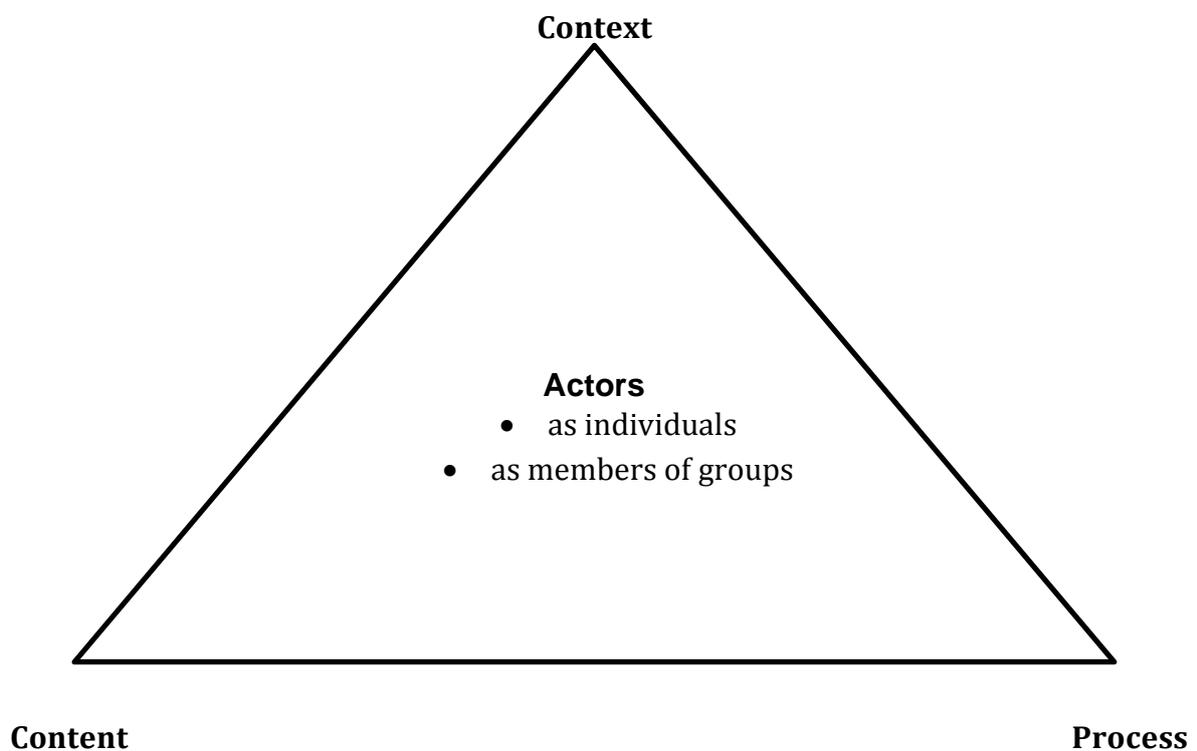
Figure 2 Model for health policy analysis (from Walt and Gilson, 1994, p. 354).

4.3.1 Context

The context in which policy is developed and analysed involves a macro approach to identify the contextual factors underpinning governmental policy decisions. In the early part of the twentieth century, Australian mental health policy and service provision was focussed on specialist health care largely provided in psychiatric hospitals. Community services for people with mental illness were limited and societal attitudes were best characterised as "out of sight out of mind".

From the 1970s onwards a shift occurred such that community-based care increasingly became the preferred option (Rosen, 2006). It took many years however
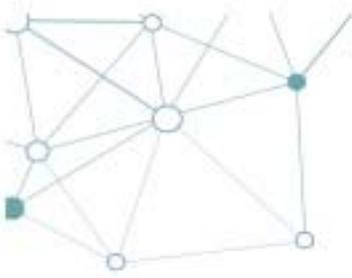
for public funding to shift from hospital to community with a resulting lack of support for people with mental illness living in the community (Rosen, 2006; Whiteford & Buckingham, 2005). Consumer and advocacy groups along with mental health providers led a sustained campaign to shift community and political attitudes to community support for people with mental ill-health (Rosen, 2006). The most recent mental health policy documents (2005-2015) reported on here reflect this change in context such that the focus is on prevention, early intervention and recovery within the community. A concurrent shift has occurred in the disability policy and service provision context with a focus on inclusion, early intervention and person-centred support within the community (COAG National Disability Strategy, 2011).

This analysis of the mental health and health policy documents was focussed on how people with intellectual disability were represented in and aligned with the overall context of individual policy documents. There was no overt alignment between mental health and intellectual disability contexts. Mental health policy documents reflected human rights principles however only three documents (C8, NSW6, WA2), specifically mentioned the UNCRPD despite the convention's inclusion of people with mental illness in Article 1: "People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNCRPD Optional Protocol p., 5).

4.3.2 Actors/Stakeholders

In keeping with the Actor component of Walt and Gilson's model, Colbatch (2009) suggested a focus on stakeholders' input into policy content by applying the following questions about policy development:

- Who wrote the policy?
- Who informed what was written in the policy?
- Who is the policy written for?

Policy development involves a range of stakeholders[2] with a vested interest in the policy and its implementation. Government ministers, bureaucrats, interest groups, consumers, academics, service providers and professionals and the general public all have an interest in public policy. How these stakeholders are engaged in the policy making process, at what point their involvement is sought, the representativeness of

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[2] The term stakeholders (rather than actors) in used throughout this report as it is the current term used in Australian policy discourse.
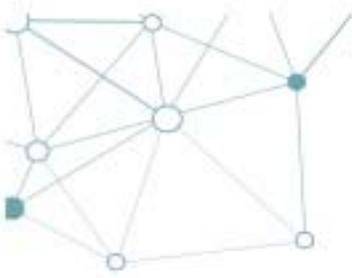
those consulted and how or whether their views are reflected in the resulting policy are all important questions (Colbatch, 2009).

The majority (*n* = 36) of policy documents (C1, C3, C7, C11, C13, C14, C15, NSW1, NSW2, NSW3, NSW4, NSW6, NSW9, NSW10, VIC1, VIC4, VIC5, VIC7, VIC8, VIC9, QSLD1, QSLD2, QSLD3, WA1, WA2, WA5, SA2, SA4, TAS1, TAS2, TAS3, TAS4, NT1, ACT1, ACT2, ACT3, ACT4) identified a consultation process involving stakeholder groups to inform the policy development. Involvement strategies included: appointed stakeholder advisory groups, community consultations with individuals and organisations, written submissions, expert forums, intergovernmental feedback. The majority of documents that mentioned stakeholder involvement in policy development provided only broad consultation information with limited detail about the timeframes for consultation or the numbers or roles of those involved.

Twenty four documents had no mention of consulting with stakeholders in policy formulation. In particular, while it seems vitally important to ensure the involvement of consumers, their family members/carers and advocates in the policy making process, as those who will be most affected, their exclusion was notable. None of the analysed mental health and health policy documents mentioned the inclusion of people with intellectual disability, their family members/carers and those who work with them as among the stakeholders consulted.

4.3.3 Process

The process of making policy describes how policy agendas are set, developed and implemented. Mental health is one area of policy that has been approached at the Commonwealth and State/Territory levels. A series of national documents agreed upon by all Commonwealth and State/Territory Ministers for Health via the Council of Australian Governments (COAG) have informed mental health policy and practice within each jurisdiction (see Figure 1, p 15). The Council of Australian Governments (COAG) *National Action Plan on Mental Health, 2006-2011* (C2 p. i), identified that:

"…Australian leaders recognised that mental health is a major problem for the Australian community and committed to reform the mental health system in Australia. The Council of Australian Governments (COAG) has agreed to a National Action Plan on Mental Health. The Plan provides a strategic framework that emphasises coordination and collaboration between governments, private and non-government providers in order to deliver a more seamless and connected care system, so that people with mental illness are able to participate in the community".
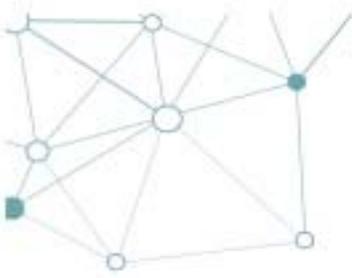
Prior to the National Action Plan, the 1991 (updated in 2012) Mental Health Statement of Rights and Responsibilities (C8) provides an overarching framework to guide policy and practice and inform consumers and families/carers. The Commonwealth and each of the State/Territory mental health policy documents reflect the Mental Health Statement of Rights and Responsibilities and the COAG National Action Plan. Consistent with these documents, mental health policy aims to improve:

- mental health and facilitate recovery from illness through a greater focus on promotion, prevention and early intervention;

- access to mental health services including more stable accommodation and support, and meaningful participation in recreational, social, employment and other activities in the community;

- the care system through a focus on better coordinated care and building workforce capacity.

Given the focus on person-centred and rights-based approaches, the extent to which mental health policy aligns with the values, principles and objectives specified in the UNCRPD was investigated. As mentioned previously, only three documents referred to the UNCRPD: the *Commonwealth Mental Health Statement of Rights and Responsibilities 2012* (C8), NSW *Living Well: A strategic plan for mental health services in NSW, 2014-2024* (NSW6)[3] and the Western Australian *Mental Health 2020* (WA2). Nonetheless, the tone and language used across documents was consistent with a rights-based approach. For example, the UNCRPD referred to dignity, autonomy, independence, choice, active involvement in decision-making, accessibility of services and information, importance of the person's family, participation and inclusion, and equality. The language used in the mental health policy documents was couched around: respect for the person, equity, citizenship, importance of family and carers, reduction of stigma, participation and inclusion, and accessibility. The *National Mental Health Policy, 2008* (C4 p., 19) stated:

"People with mental health problems and mental illness have the same rights as other Australians to full social, political and economic participation in their communities."

Four documents referred to other international rights' charters including:

- UN Universal Declaration of Human Rights, 1948 (C5)

- UN Convention on the Rights of the Child, 1989 (C8)

- UN Declaration on the Rights of Indigenous People, 2008 (C14)

- International Covenant on Economic, Social and Cultural Rights, 1976 (SA1).

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[3] NSW10 is described in more detail on pages 34-35, 37-38.
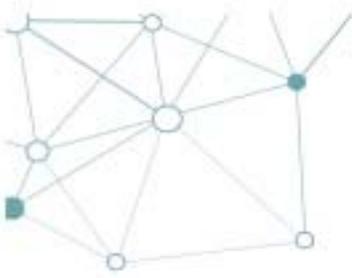
4.3.4 Content

Content refers to the technical features of the policy – what is included, how the policy should be operationalised and organisational issues (Walt & Gilson, 1994). Australian mental health and health policy document content strengths and weaknesses in relation to people with intellectual disability are a focus of this report. The weaknesses are described in relation to the lack of inclusion of mention of people with intellectual disability. Given the identified lack of representation of people with intellectual disability in these documents, the strengths relate to generic policy strengths that may be applied to include people with intellectual disability.

Mental health policy documents' content weaknesses

In analysing the mental health and health policy documents we focussed on five content related questions regarding people with intellectual disability:

  I.   To what extent and in what ways is intellectual disability included in the content?

 II.   Are there strategies for addressing the mental health needs of people with intellectual disability?

III.   To what extent are the strategies linked to clear, measureable actions or targets?

 IV.   What is the plan for translating policy into accessible services for people with intellectual disability?

  V.   What is missing or not clear in this policy in relation to people with intellectual disability with mental ill-health?

I. Inclusion of intellectual disability

Nineteen of the 61 documents included some mention of intellectual disability (see Table 3). People with intellectual disability were mentioned as constituting one of a number of higher risk groups for mental illness. This was most clearly stated in the *Fourth National Mental Health Plan* (C5, p.70):

"People with intellectual disability are at increased risk of experiencing a mental illness, yet this is often overlooked and access to appropriate treatment for both disabilities are limited."
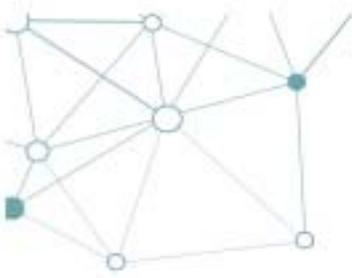
In the *National Review of Mental Health Programmes and Services* (C10, p. 108 Vol 1), the need was identified to "explore opportunities for joint care planning between mental health and intellectual disability services….to provide a truly 'no wrong door' holistic response to people with concurrent needs."

II. Strategies for addressing the mental health needs of people with intellectual disability

Only two documents provided strategies for addressing the mental health needs of people with intellectual disability.

The Victorian *Because Mental Health Matters* reform strategy (VIC7) identifies the need to build the capacity of the primary health, disability and mental health services to identify, treat, and manage people with co-existing problems such as those with intellectual disability.

The NSW *Living Well* (NSW6) strategic plan for mental health services mentions the establishment in 2009 by the NSW Government of a Chair of Intellectual Disability Mental Health at UNSW Australia. The document identifies a range of projects undertaken by the Chair, Professor Julian Trollor, including e-learning supports and the development of the *Accessible Mental Health Services for People with an Intellectual Disability: A guide for providers* (Department of Developmental Disability Neuropsychiatry, 2014) outlining principles and practical strategies to develop inclusive and accessible services.

III. Strategies linked to clear, measureable actions or targets

The same two documents identified strategies for people with intellectual disability linked to clear measureable actions or targets.

The Victorian *Because Mental Health Matters* reform strategy (VIC7) identified the need for greater proficiency in identifying mental illness in people with intellectual disability and once identified, to provide a more integrated response. The recommended way of achieving this is through designated co-existing disability portfolio roles within adult mental health services. Additional training and supervision were recommended to improve specialist assessment, treatment and care for people with severe mental illness and intellectual disability.
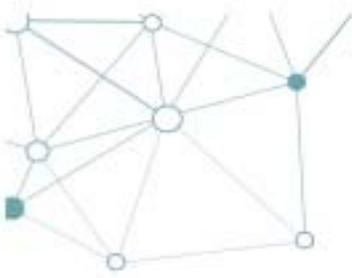
The NSW *Living Well* (NSW6) strategic plan for mental health services identified five action areas for improving access to mental health services for people with intellectual disability:

a) Implementation of the *Accessible Mental Health Services for People with an Intellectual Disability: A guide for providers* (Department of Developmental Disability Neuropsychiatry, 2014);

b) Training for all mental health and disability sector staff in recognition, assessment, referral pathways and treatment for people with an intellectual disability and mental illness;

c) Preparing for the NDIS by developing partnerships between NSW Health, community-managed and private sector supports for public mental health services to work with people with intellectual disability;

d) Developing a recovery-oriented model of care for public mental health services to work with people with intellectual disability;

e) Developing accessible information for people with intellectual disability, their families and carers about mental health services.

IV. Plan for translating policy into accessible services for people with intellectual disability

No document mentioned including people with intellectual disability in service design, building their capacity to manage their mental health needs, or designing communication strategies to facilitate their involvement and understanding about mental health services. Two NSW documents included mention of issues related to accessible services for people with intellectual disability.

The NSW *Living Well* (NSW6) strategic plan proposes the need for a more integrated approach between disability and health services. Concerns are also raised in this document about how people with mental illness will be accommodated within the National Disability Insurance Scheme (NDIS).

While not specifically related to mental health, the NSW *Women's Health Plan* (NSW7) identifies a need to develop an information kit about general health issues across the lifespan for women with intellectual disability, their family members/carers, clinical educations and organisations and health services.
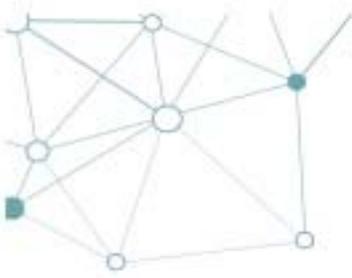
V. Content missing or not clear in relation to people with intellectual disability and mental ill-health

With the exception of the Commonwealth, Victorian and NSW documents described above, there was a lack of awareness of the specific needs and strategies for overcoming barriers for people with intellectual disability to be included in mainstream mental health services. The majority of those documents that made mention of intellectual disability failed to provide strategies for addressing the service barriers experienced by this group.

### *Mental health policy documents' content strengths*

We identified five strengths common to the included mental health and health policy documents: a values-based approach, recognition of diversity, a life-course approach, focus on workforce development, and building in checks and balances.

A values-based approach

Underpinning the aims and articulated across the Commonwealth and State/Territory mental health policy documents is a consistent values-based approach to mental health involving nine key principles:

a) Promotion of mental health;

b) Prevention of mental illness;

c) Provision of early intervention;

d) Access to appropriate treatment/services to provide continuity and coordination;

e) Recovery leading to participation and inclusion in the community;

f) Person-centred across the life-course via a focus on the consumer, carers and family;

g) Rights-based with elimination of stigma and discrimination associated with mental ill-health;

h) Whole-of-government approaches to provide a 'no wrong door' experience;

i) Priority on community-based interventions.

These values are in keeping with those espoused in disability-specific policy documents described earlier in this report (pp. 17-20).
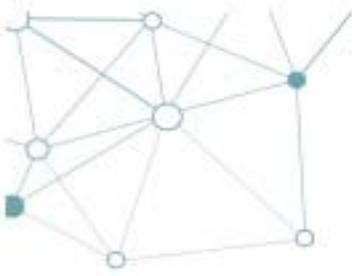
Recognition of diversity

In recognition of the health inequities experienced by people in minority groups within Australian society, all Commonwealth and State/Territory policy documents included statements about the need for additional attention to be paid to the mental health needs of peoples from:

- Aboriginal and Torres Strait Islander backgrounds;
- Culturally and linguistically diverse (CALD) backgrounds;
- Rural and remote areas.

In addition to the mention of these groups in all policy documents, a number of jurisdictions had separate policy documents that addressed the specific issues for: Aboriginal and Torres Strait Islander peoples (e.g., C9, C15, NSW1, NSW10, VIC9, QSLD4, WA5, SA4) and those from CALD backgrounds (e.g., C1, NSW2, VIC4). Victoria was the only jurisdiction to have a specific framework around rural mental health service provision (VIC5).

Additional groups identified as requiring special consideration in some, but not all documents, included people:

- with a co-existing disability (physical, mental, sensory or intellectual)

(C3, C7, C8, C9, C10, C11, C12, C13, NSW3, NSW6, NSW9, VIC7, QSLD1, QSLD3, SA4, SA7, WA3, WA4, TAS3, TAS4, ACT2, ACT3);

- involved with the criminal justice system

(C8, C9, C11, C13, NSW2, NSW9, VIC3, VIC7, QSLD1, QSLD2, QSLD3, SA4, SA1, WA3, TAS2, TAS3, ACT2);

- who identify as lesbian, gay, bisexual, transgender and intersex (LGBTI)

(C8, C10, C11, C12, C13, NSW3, NSW6, VIC7, QSLD1, QSLD3, WA4, TAS2, TAS3, NT1);

- affected by socio-economic disadvantage

(C3, C4, C7, C8, C11, C13, C15, NSW3, NSW4, NSW9, SA4, WA4, NT1);

- with substance misuse problems

(C1, C7, C8, C9, C10, C15, NSW9, VIC7, QSLD2, QSLD3, WA3);

- who are homeless

(C4, C8, NSW9, VIC3, VIC7, SA7, NT1)
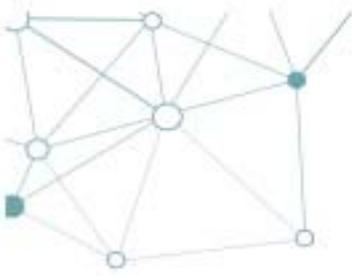
- who are women

(NSW2, QSLD3, SA2, WA5).

Given the connection between substance misuse and physical and mental health, a number of specific policy documents were targeted at drug and alcohol issues (C13, QSLD3, WA3, SA7, TAS4). The specific health needs of women are addressed by five jurisdictions via women-specific policy documents (C12, NSW7, WA4, SA4, ACT3). The Commonwealth and NSW also have policies specifically related to men's health (C11, NSW8).

A life-course approach

All policy documents used a life-course frame to discuss the physical and emotional wellbeing of people across the lifespan. Similar descriptors were used to separate out lifespan categories according to: young children, adolescents/youth, young adults, adults, and older adults.

NSW was the only jurisdiction to have a specific policy aimed at addressing the mental health of women during pregnancy and infants in the first two years of life (NSW5). NSW also had a policy related to the mental health of children and young people attending school and technical and further education (TAFE) (NSW5). NSW and Queensland had specific policy documents addressing the issues of adolescents/youths (e.g., NSW9, QSLD5). South Australia had a policy document related to the health requirements of older people (SA6).

Given the link between mental illness and suicide, all jurisdictions had suicide prevention policies targeted across the life-course (C3, NSW4, VIC3, QSLD1, WA1, SA2, TAS3, NT1, ACT2). Only two of these documents mention people with intellectual disability (NSW4, ACT2). The NSW document is in relation to the assessment for suicide risk of people in the criminal justice system including people with cognitive impairment who may be at risk of self-harm. The ACT document identifies young people aged 12-25 years with a developmental or intellectual disability as among a group at risk of self-harm.

Focus on workforce development

Training and supporting the workforce engaged in health and mental health service provision was included in the majority of documents. Workforce development centred on:
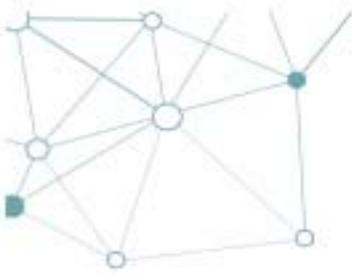
- Building the capacity of public, private and non-governmental organisation sectors to work with people with mental/health issues

(C2, C4, C6, C7, C9, C10, C11, C12, C13, C15, NSW1, NSW3, NSW4, NSW5, NSW6, NSW7, NSW8, NSW9, NSW10, VIC1, VIC2, VIC3, VIC5, VIC6, VIC7, VIC8, VIC9, QSLD1, QSLD2, SA2, SA4, SA6, SA7, WA1, WA3, WA4, WA5, TAS1, TAS2, TAS4, NT2, ACT1, ACT3, ACT4);

- Building a culturally competent workforce

(C1, C6, C8, C9, C10, C15, NSW1, NSW2, NSW5, NSW6, NSW10, VIC4, VIC6, VIC9, QSLD4, SA5, SA6, WA3, NT2);

- Recognition of geographic workforce constraints especially in rural and remote areas

(C5, C8, C11, C12, C15, VIC5, VIC6, SA3, SA7, TAS3);

- Training staff to work in recovery-oriented ways

(C5, C8, NSW6, VIC6, TAS2).

In particular, Victoria identified workforce as a key component of delivering mental health reforms with the *Shaping the future: The Victorian mental health workforce strategy* report (VIC6). The report (VIC6, p. 4) identified the need to build the "capacity and capability of the specialist mental health workforce" to deliver "flexible, relevant and responsive" services to people with mental health problems.

Building in checks and balances

The majority of mental health and health policy documents included sections on accountability, monitoring, evaluation and research.

Accountability included:
- annual reporting mechanisms / governance structures (e.g., C1, C2, C13, C15, NSW4, NSW9, QSLD3, QSLD5, SA2, SA4, SA5, WA3, WA4, TAS1, TAS3, NT2, ACT3);

- development of key performance measures (e.g., C3, C5, C13, VIC1, VIC5, WA1, WA4, TAS3, ACT4);

- data collection (e.g., C12, NSW7, QSLD4, SA7, TAS3, ACT2).
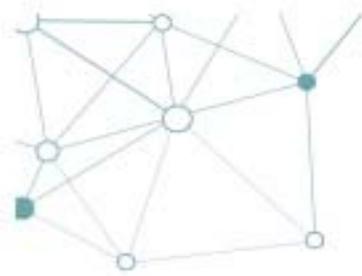
Monitoring included:

- establishing key indicators of change (e.g., C7, C8, NSW4, NSW5, NSW9, SA7, WA2, QSLD3, VIC4);

- establishment of monitoring groups involving key stakeholders (e.g., C3, C8, NSW1, ACT1, ACT2, SA1, WA2);

- reporting on data including National mental health data collection and reporting (e.g., C7, VIC3, ACT2);

- operational plans (e.g., TAS1, TAS2);

- setting targets for reform (e.g., C7).

Evaluation included:

- independent evaluation after 5 years (e.g., C2, C3, VIC2, NSW4);

- development of evaluation framework (e.g., C3, QSLD2, WA4, TAS3);

- consumer, carer and broader community perceptions (e.g., C5, VIC3, VIC8);

- development of best-practice models (VIC3);

- quality and complaints (e.g., C5).

Research included:

- address gaps and improve service delivery (e.g., C4, C8, C12, NSW2, VIC3, VIC6, SA1, SA2, SA5, TAS3);

- improve access to data (e.g., C7, VIC6, QSLD4);

- improve links between research and knowledge management (QSLD1).

The recent introduction of the NDIS means it is too early to track at policy or service delivery levels the impact of the universal service obligation agreements on access to mental health services by people with intellectual disability. Nonetheless, advocacy by government officials and professionals working with people with this group has already resulted in recommendations for change in one jurisdiction, NSW through the *Living Well* strategic plan (NSW10).
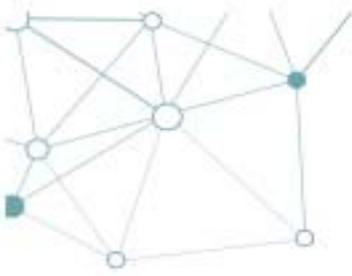
4.4 Policy Case Study: New South Wales

Intellectual disability mental health policy is by nature of Australia's federated system differently structured and articulated in each Australian state and territory jurisdiction. A detailed analysis of each State and Territory framework (or lack of) is beyond the scope of this report. However, in this section we describe the NSW *Living Well* (NSW10) strategic plan document in more detail and make links between it and the disability policy context to highlight ways in which the specific needs of people with intellectual disability and mental ill-health may be addressed. NSW was chosen as a positive policy exemplar for a number of reasons:

I. of all the documents included in the analysis, the *Living Well* document is the most cohesive in addressing the issue of people with intellectual disability and mental ill-health;

II. the research team conducting the policy analysis is based in NSW;

III. all partner organisations are from NSW and so were able to provide valuable additional information about the development of the *Living Well* strategic plan.

NSW legislation and policy

Figure 3 provides an overview of and relationship between the NSW disability, mental health and health legislation, included policy and associated documents. The associated documents: *NSW Health Disability Action Plan, 2010* and the *Memorandum of Understanding* (MOU) between NSW Health and the Department of Ageing, Disability and Home Care (ADHC), 2011 indicate the whole of government approach to disability advocated by the NSW government and, in particular, via the MOU, recognition of the specific health care needs of people with intellectual disability. The *Living Well Strategic Plan for Mental Health Services NSW 2014-2024* addresses the mental health needs of people with intellectual disability with Chapter 7 of the plan describing the gap in mental health care for this group and outlining specific strategies to address the gap. The bi-lateral agreement between the Commonwealth and NSW: *Transition to a NDIS, 2015* sets out the arrangements for transition to the full scheme NDIS in NSW by July 2018. Under this agreement, the NSW government will cease to provide specialist disability services once full rollout is achieved.

Figure 3 Mapping of NSW Legislation and Policy

NSW DISABILITY LEGISLATION
Guardianship Act, 1987
Disability Discrimination Act, 1993
Disability Inclusion Act, 2014 (replaced
Disability Services Act, 1993)

NSW MENTAL HEALTH LEGISLATION
Guardianship Act, 1987
Mental Health (Forensic Provision) Act, 1990
NSW Mental Health Act, 2007 (reviewed 2014)
Mental Health Commission Act, 2012

NSW HEALTH LEGISLATION
31 separate pieces of legislation
administered by NSW Health

Bi-lateral agreement between the
Commonwealth and NSW: Transition to a
NDIS, 2015

INCLUDED MENTAL HEALTH POLICIES
- NSW Aboriginal Mental Health and Well-being Policy, 2006-2010 (currently under review)
- Multi-cultural Mental Health Plan, 2008-2012
- Safe Start Strategic Policy, 2009
- NSW Suicide Prevention Strategy, 2010-2015
- NSW School-Link Strategy & Action Plan, 2014-2017

INCLUDED GENERAL HEALTH POLICIES
- Women's Health Policy, 2009-2011
- Men's Health Policy, 2009-2012
- Youth Health Policy, 2011-2016
- NSW Aboriginal Health Plan, 2013-2023
- NSW State Health Plan: Towards 2021

Chapter 7: Care for All
People with intellectual disability
represented as a population with specific
mental health needs

STRATEGIC PLAN
Living Well: A Strategic Plan for Mental
Health in NSW 2014-2024

ASSOCIATED DOCUMENTS
- NSW Health Disability Action Plan, 2010;
- MOU between NSW Health & ADHC re provision of services to people with ID and mental illness, 2011

Living Well: a positive policy exemplar

Living Well: A strategic plan for mental health services in NSW 2014-2024 (NSW6), a report by the Mental Health Commission of NSW, was developed with input from the NSW government departments of Health, Family and Community Services, Education and Communities, and Justice. In December 2014, the NSW Government endorsed the _Living Well_ strategic plan as underpinning and informing the development and reform of the NSW mental health system over the following ten years. The NSW government accepted all 141 actions contained in the plan. At that time, the government made an initial $115 million investment in improving mental health services with the aim of making mental health services more responsive to individual needs and supporting people to stay out of hospital and in their community (see information about the investment on the Mental Health Commission NSW website http://nswmentalhealthcommission.com.au/our-work/taking-on-the-challenge-of-change). Since this initial investment, there has been no further public announcement about the Government's plan for implementation (personal correspondence with Mental Health Commission NSW).

The _Living Well_ plan provides an example of a document in which the mental health of people with intellectual disability is recognised as an issue requiring dedicated strategies to ensure appropriate and accessible services. Within Chapter 7 of the report under a heading 'Care for All' (pp. 88-91) people with intellectual disability are described as a 'special' population group[4]. In making the case for the focus on people with intellectual disability, the report highlighted that about 2% of the population has an intellectual disability and there are estimates that approximately half of people with intellectual disability have experienced mental ill-health. Indicating problems for people with intellectual disability and mental illness getting appropriate help, the report stated (p. 88): "People with intellectual disability are more likely than others to experience mental illness, and yet access to mental health services for people with intellectual disability is limited and falls far short of that for the general population".

In recognition of the particular needs of this group, the NSW government funded a Chair of Intellectual Disability Mental Health at UNSW Australia which commenced in 2009. The information in Table 4 below is summarised from the _Living Well_ plan to show that the Chair has been responsible for developing a number of strategies aimed at reducing barriers to mental health services for people with intellectual disability in NSW.

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[4] Other special population groups mentioned in Chapter 7 are LGBTI, multi-cultural, people with eating disorders and those with borderline personality disorders.
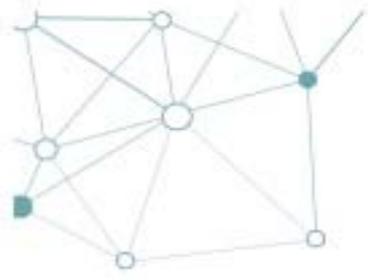
Table 4 NSW exemplar barriers and strategies

Barriers to mental health services access for people with intellectual disability	Strategies aimed at reducing barriers
Communication difficulties	Develop accessible information for people with intellectual disability, their families and carers about mental health services.
Atypical and complex presentations	Develop a recovery-oriented model of care for public mental health services to work with people with intellectual disability.
Lack of training about intellectual disability for mental health professionals and about mental health for disability professionals	E-learning website providing: up-to-date information to service providers and carers about intellectual disability and mental health; extra training for health and disability professionals to build their capacity to support people with intellectual disability and mental illness;
	An Accessible Mental Health Services for People with an Intellectual Disability: a guide for providers outlining principles and practical person-centred, inclusive and accessible services;
	Training for all mental health and disability sector staff in the recognition, assessment, referral pathways and treatment for people with intellectual disability and mental illness
Poorly developed interagency service models resulting in people with intellectual "falling between the gaps"	Developing partnerships between NSW Health, community-managed and private sector supports for people with intellectual disability and mental illness
Inadequate resourcing in both sectors	Coordination of care and support under the NDIS

The strategies included in the *Living Well* document indicate a way forward for policy and practice to address the barriers faced by people with intellectual disability who have a mental illness.
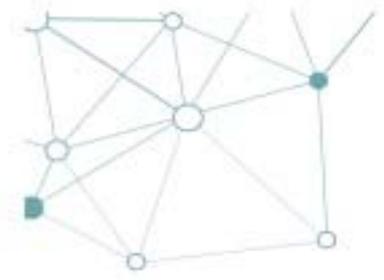
5. Discussion

Public policy drives the investment and actions governments make in response to identified issues with service delivery priorities responsive to policy directions. Governments face many competing demands for recognition of special interest groups and issues in creating public policy. The lack of recognition and accommodation of the specific mental health needs of people with intellectual disability identified in this report is one such pressing issue. There is considerable evidence that people with intellectual disability have a high incidence of mental ill-health and experience limited access to mainstream mental health services. The *Fourth National Mental Health Plan* (C5) acknowledges this situation but fails to provide policy direction on how to address the issue. The current poor mental health outcomes of people with intellectual disability will only improve when their specific needs are addressed in policy and practice.

Why should this gap be addressed in public policy? A comparison of population and prevalence of mental ill-health among people with intellectual disability and for Aboriginal and Torres Strait Islander peoples highlights the case for a concerted focus on the specific mental health and health needs of these particular groups. The proportion of the Australian population who have an intellectual disability (1 - 2%) is similar to the proportion of Australians from Aboriginal and Torres Strait Islander backgrounds (3% according to AIHW 2015 estimates). Fifty seven percent of people with intellectual disability are estimated to have a mental disorder (ABS 2010; Trollor, 2014) while approximately 30% of Aboriginal and Torres Strait Islander peoples reported experiencing high or very high levels of psychological distress with 11% of visits to general practitioners during the period 2008-2013 related to mental ill-health (AIHW, 2015). The need to address issues related to the mental health of Indigenous Australians has rightly been recognised as a priority within all included policy documents and dedicated strategies to address this issue have been identified. However, issues on a similar or even greater scale for people with intellectual disability remain largely unaddressed in any systemic or systematic way.

Issues for people with intellectual disability are often subsumed within the encompassing general category of 'disability'. Disability is defined by the International Classification of Functioning (ICF) as the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, developmental, or some combination of these that significantly impacts on functional capacity (http://www.who.int/classifications/icf/icf_more/en/). A disability may be present from birth, or occur during a person's lifetime. Many of the mental health, health and disability policy documents interrogated in this study echo this lack of differentiation along impairment lines, referring to disability without specific mention of intellectual disability. While there are good arguments for the recognition of a unifying experience of disability as one of marginalisation and often entrenched and systemic
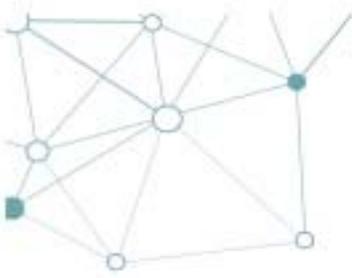
discrimination, the lack of attention to the specific experiences related to different impairments may mean the specific needs for support required by people with intellectual disability are overlooked. Many people with intellectual disability experience challenges with literacy and communication skills that make it difficult for them to use mainstream health and mental health services (Department of Health UK, 2001). There is evidence that this group requires specific expertise, modifications and adaptations to be well supported in health and mental health services (Department of Health UK, 2001). With the exception of the NSW and Victorian examples provided earlier, recognition of the need for these accommodations is absent from the mental health and health documents analysed for this report.

A further dimension to lack of recognition of the accommodations required to support individuals with intellectual disability and mental ill-health and their families is the need for improved systemic responses. The *National Disability Strategy* sets out the need for a high level policy framework to "give coherence to, and guide government activity across mainstream and disability-specific areas of public policy" (National Disability Strategy, p. 9), with a specific focus on enabling people with disability to "attain highest possible health and wellbeing outcomes throughout their lives" (National Disability Strategy, p. 59). This requirement points to the need for capacity building in mainstream settings and for training for mental health and health staff in how to best support the inclusion of individuals with intellectual disability in their services (Department of Health UK, 2001). Similarly, staff working in the disability sector, require training in how to recognise and support people with intellectual disability who present with mental health problems. The NSW example provides a template for ways in which both these aims may be achieved.

The UK *Valuing People: A new strategy for learning disability for the 21st century* (Department of Health UK, 2001) provides a useful model for how specialist and mainstream mental health services can support children, adolescents and adults with intellectual disability and mental ill-health. Strategies suggested in the *Valuing People* white paper include: agreements between health authorities and local councils for joint child and adolescent mental health plans to include 24 hour coverage and outreach services; early intervention and prevention programs (p. 41); national service frameworks that include the development of accessible materials and information; investment in strategies to promote collaboration between disability and mental health services; development of expertise among care providers in both intellectual disability and mental health; role of specialist disability staff to support a person with intellectual disability to access mental health services (p. 66-67).

Despite the shortcomings in the Australian mental health and health policy documents in relation to people with intellectual disability, there is cause for optimism regarding the ways in which mental health, health and disability policy may be made more inclusive of the needs of people with intellectual disability and mental illness. The
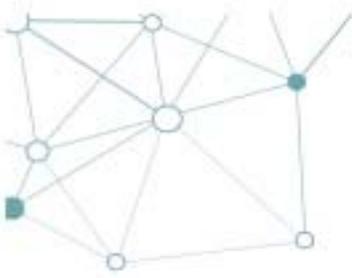
values underpinning all policy documents regardless of population and content indicates a consistent platform of rights-based, consumer and strengths focussed principles. These values provide a shared starting point from which to develop policy that is inclusive of the specific requirements and needs of people with intellectual disability and mental illness.

6. Inclusive Intellectual Disability Mental Health Policy

The review presented in this report provides evidence that policy addressing the mental health needs of people with intellectual disability in Australia is currently underdeveloped and lacks coherence. This study has presented the case for action to recognise and address the mental health needs of people with intellectual disability in policy. With full implementation of the NDIS imminent this challenge is now more urgent as the interface between health and mental health services and specialist disability services moves firmly on to the policy agenda. The ultimate goal of the NDIS would see seamless support for people with intellectual disability who experience mental illness and for the psychosocial disability that results.

The evidence presented in this report suggests that there remain significant policy challenges to achieving the desired outcome of a co-ordinated national strategy to enhance inclusive intellectual disability mental health policy. The report also highlights the shared disability / mental health policy and practice values that are based on inclusive, person-centred, community-based and strengths-based approaches. This shared values-base provides a platform on which to build. As a next step to the development of inclusive policy, accurate nationwide data is required that shows the prevalence and causes of mental illness among people with intellectual disability; and the barriers experienced by people with intellectual disability in accessing, or trying to access, mental health services. Aims 1 and 3 of the *Improving the Mental Health Outcomes of People with Intellectual Disability* NHMRC-funded project will address these points (see page 8). The development of a partnership of interested stakeholders (Aim 4) will ensure the ongoing development and application of evidence-based approaches to inform a co-ordinated national strategy. We suggest that good policy in this area requires the articulation of a new approach and strategies across policy domains consistent with Walt and Gilson's (1994) framework: context, stakeholders, process and content. Figure 4 provides an overview of what inclusive intellectual disability mental health policy should include across each of these domains.

Figure 4 Inclusive Intellectual Disability Mental Health Policy

CONTEXT
UNCRPD
NDIS/MH interface
Incidence & prevalence of
IDMH

STAKEHOLDERS
People with ID/MH, families &
carers
Disability service providers &
professionals
MH service providers &
professionals
Community
Policy makers

PROCESS
Human Rights
Whole of government
Cross sector partnerships
Workforce
training/professional
development & resources
Specialist input

CONTENT
Evidence-based
Across the life-course
Measureable actions and targets
Strategies for accessible services

KNOWLEDGE TRANSLATION PLAN & STRATEGIES
Bridge research-to-policy-and-practice gap

6.1 Context

The context in which policy is developed and analysed involves a macro approach to identify the contextual factors underpinning governmental policy decisions.

Overarching principle: mental health and intellectual disability share a common history and philosophy moving from segregated to community-based, person-centred and inclusive service delivery.

Strategies: the context in which inclusive intellectual disability mental health policy will be developed and implemented will recognise:

- The UNCRPD that advocates equality, choice and control for all people with disability including people with intellectual disability and people with mental illness;

- The interface between, and alignment of, Commonwealth and State/Territory-based policy processes in disability and health/mental health including the NDIS Interface Principles, NDS and Mental Health reforms;

- The imperative of addressing the mental health needs of people with intellectual disability as indicated by the incidence and prevalence of mental illness for this group.

6.2 Stakeholders

Stakeholders include individuals or representatives who are (or should be) engaged in the policy making process due to a personal or professional interest in the policy topic.

Overarching principle: stakeholders from across policy, practice and lived experience provide input to develop strategies for inclusion of people with intellectual disability in mental health policy and practice for national implementation.

Strategies:
- Stakeholder mapping to identify the key players with whom to engage and their roles and responsibilities including:
    - Individuals with intellectual disability and mental ill-health, their family members and carers;
    - Disability service providers and professionals;
    - Mental health service providers and professionals;
    - Community members;
    - Commonwealth, State/Territory and peak body policy makers.
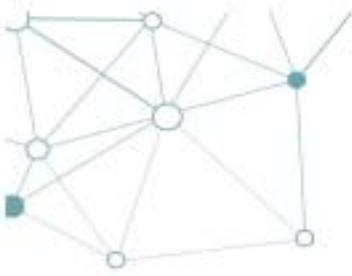
- The NDIA Intellectual Disability and Mental Health Reference Groups, which include individuals representing each of the above stakeholder groups, working collaboratively to draft policy and strategies for use across the two groups within the NDIS.

6.3 Process

The process of making policy describes how policy agendas are set, developed and implemented.

Overarching principle: national commitment via legislation, policy and funding to meet the needs of people with mental illness and of people with lifelong disability such as intellectual disability.

Strategies: inclusive intellectual disability mental health policy will be cognisant of the following:

- Human rights as all people with disability are entitled to receive the supports and services they require to lead a full life in their community;

- Whole of government recognition of the mental health needs of people with intellectual disability;

- Cross sector partnerships working towards a 'no wrong door' approach to service provision such that people receive the support they need from the most appropriate sector (i.e., people with intellectual disability with mental illness are able to access an informed and responsive mental health services);

- Workforce training, professional development and resources that prepare and equip the disability and health/mental health workforces to deliver a high standard of support to people with intellectual disability and mental illness;

- Access to specialist input from the disability and mental health sectors as required (i.e., mental health practitioners with expertise in working with people with a dual diagnosis of intellectual disability and mental illness).

6.4 Content

Content refers to the technical features of the policy – what is included, how the policy should be operationalised and organisational issues.

Overarching principle: policy based on best available evidence clearly articulates inclusive strategies across the life course and ensures mechanisms to evaluate their effectiveness.

Strategies: inclusive intellectual disability mental health policy will:
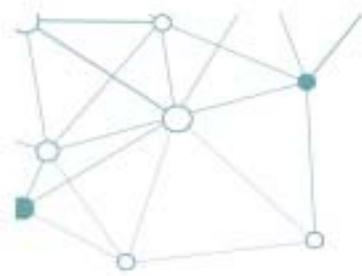
- Be based on the best available evidence about the mental health needs of people with intellectual disability;

- Acknowledge and address the issues that individuals with intellectual disability and mental illness face across their life course;

- Establish measureable actions and targets assessed via monitoring, evaluation and research;

- Articulate strategies for increasing the accessibility of disability, mental health and health services for people with intellectual disability with particular attention paid to augmentative and alternative communication strategies (e.g., use of visuals, speech-generating devices), information format (e.g., Plain English, visuals, universal signs), adaptation of models of practice, physical modifications, and staff expertise.

6.5 Knowledge translation approach

Knowledge Translation (KT) is the exchange, synthesis, and ethically-sound application of knowledge within a complex system of interactions among researchers and users to accelerate the capture of the benefits of research for all (Canadian Institutes of Health Research).

Overarching principle: a KT approach will ensure inclusive intellectual disability mental health policy will be informed by up-to-date research evidence and integrated into best practice.

Strategies: KT plans and strategies are required to address the identified research-to-policy-and-practice gaps between service users (people with intellectual disability and family/carers), practitioners, researchers and policy makers (Lavis, 2006). Development of KT plans involves (Barwick, 2010) the:

- articulation of KT goals;

- development of key messages related to goals and evidence;

- identification of key stakeholders so that KT strategies are tailored to specific audiences.

7. Conclusion

Based on the evidence of this analysis of existing Australian Commonwealth and State and Territory policy documents on representation of intellectual disability in mental health and health policy documents, there is a clear need to develop a comprehensive policy framework underpinned by the inclusion of people with intellectual disability, and in line with Australia's obligations under the UNCRPD. This inclusive intellectual disability mental health policy will take into account the context within which the
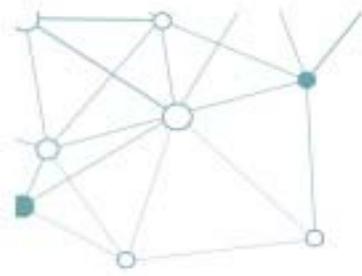
policy is developed, the key stakeholders, the process of developing inclusive policy and the content tailored to the needs of people with intellectual disability and mental ill-health. A knowledge translation approach will ensure that policy is informed by best evidence and practice and, that end users are engaged throughout the policy process. An inclusive approach to the development and implementation of intellectual disability mental health policy will address the current lack of attention, as highlighted in this report, to the important area of how to best meet the mental health needs of individuals with intellectual disability.
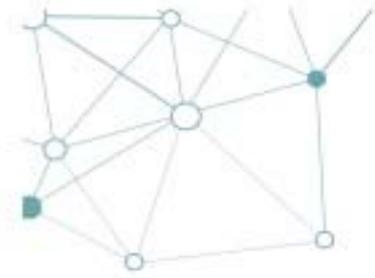
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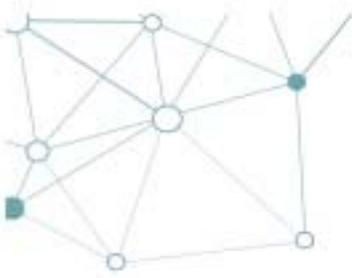
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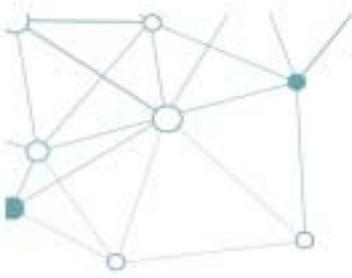
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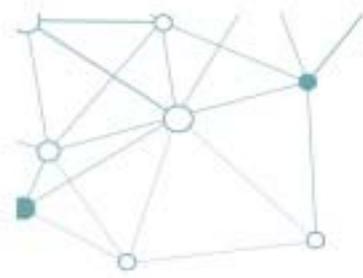
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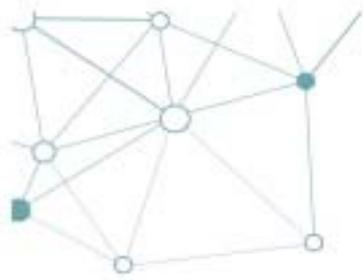
Appendix A Partnership Team

This project is funded by a National Health and Medical Research Council Partnerships for Better Health Project Grant (APP 1056128). The Partnership team consists of:

Chief Investigators

Julian Trollor, Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Australia

Eric Emerson, Centre for Disability Research and Policy University of Sydney & Centre for Disability Research Lancaster University, United Kingdom

Rhoshel Lenroot, Neuroscience Research Australia, Randwick, NSW, Australia & School of Psychiatry, School of Psychiatry, UNSW Australia, & Child and Adolescent Mental Health Services, Southeastern Sydney Local Health District, Australia

Karen Fisher, Disability Research Program, Social Policy Research Centre, UNSW Australia

Kimberlie Dean, Forensic Mental Health, School of Psychiatry, UNSW Australia

Leanne Dowse, Intellectual Disability and Behaviour Support (IDBS), School of Social Sciences, Arts and Social Science, UNSW Australia

Associate Investigators

Eileen Baldry, School of Social Sciences, Arts and Social Science, UNSW Australia

Tony Florio, Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Australia

Grant Sara, Health System Information and Performance Reporting Branch, NSW Ministry of Health

Phillip Snoyman, NSW Department of Justice - Corrective Services NSW, Sydney, Australia

Les White, Agency for Clinical Innovation & NSW Ministry of Health, Sydney, Australia

Project Staff

Ulrika Athanassiou, Intellectual Disability and Behaviour Support (IDBS), School of Social Sciences, Arts and Social Sciences, UNSW Australia

Angela Dew, Intellectual Disability and Behaviour Support (IDBS), School of Social Sciences, Arts and Social Sciences, UNSW Australia

Preeyaporn Srasuebkul, Developmental Disability Neuropsychiatry (3DN), School of Psychiatry UNSW Australia

Erin Whittle, Developmental Disability Neuropsychiatry (3DN), School of Psychiatry,
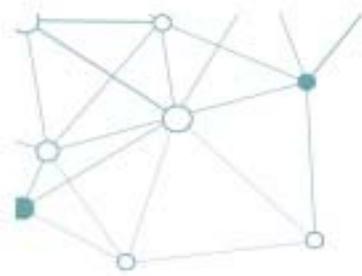
UNSW Australia

Simone Reppermund, Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Australia

Partner Organisations

Agency for Clinical Innovation – Intellectual Disability Network, represented by Tracey Szanto

NSW Department of Family & Community Services - Ageing, Disability and Home Care, represented by David Coyne and Carol Hannaford

NSW Department of Education & Communities, represented by Melissa Clements

NSW Department of Justice - Corrective Services NSW, represented by Phillip Snoyman

NSW Ministry of Health – Justice Health & Forensic Mental Health Network, represented by Kimberlie Dean

Mental Health Commission of NSW, represented by Sarah Hanson

NSW Ministry of Health – Mental Health & Drug & Alcohol Office, represented by Christine Flynn

Mental Health Review Tribunal, represented by Anina Johnson

National and NSW Council for Intellectual Disability, represented by Jim Simpson

National Disability Services, represented by Philippa Angley and Gordon Duff

NSW Office of the Public Guardian, represented by Kathy King and Justine O'Neill

NSW Ombudsman, represented by Kathryn McKenzie
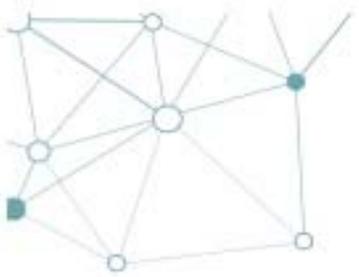
Appendix B Policy Analysis Framework

ACTORS	CONTEXT	PROCESSES	CONTENT
Who was involved in formulating the policy document?	**What is the context for the development of the policy?**	**How was the policy issue identified?**	**What is included in the policy document?**
• Politicians • Bureaucrats • Consumers • Service providers/professionals • Academics	Macro Micro Inter-sectorial • International • National • State • Local/community • Individual • Worldwide trends • Research	• Previous policy • Crisis driven • Needs assessment • Situational analysis	Strategies • Timeframes • Indicators • Targets Activities • Definitions & language • Person/s responsible/carer/guardian • Outputs • Obstacles / risks • Costs / funding • Coordination and

	• Advocacy • Legislation Rurality Life-course		management • Evaluation of quality / monitoring & complaints mechanisms / research • Human resources/workforce • Knowledge Translation strategies
How were they involved – individually, in groups, by submission, in person?	**How is intellectual disability represented in and aligned with the context?** ID included singularly and/or in combination with other issues - complexity	**What was the impetus for developing and implementing change?**	**To what extent and in what ways is intellectual disability included in the content?**
Were people with intellectual disability, their carers, those who work with them represented?	**Is the policy in line with best practice and human rights principles? Is the UNCRPD and/or underlying rights principles referred to?**	**To what extent does policy conform with the values, principles and objectives specified in the UN Convention?**	**Are there strategies to address the mental health needs of people with intellectual disability?** Is the need for communication adjustment included?
			To what extent are the strategies outlined for people with intellectual disability
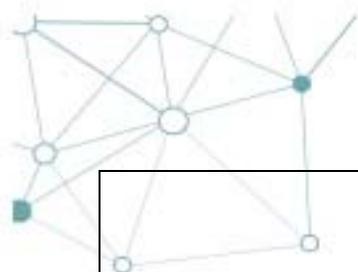
			linked to clear, measurable actions or targets?
			Focus on building the capacity of the person with disability to identify/manage their mental health needs
			Identify role of supported decision maker
			What is the plan for translating the policy into accessible services for people with intellectual disability?

What is missing or not clear in this policy in relation to people ID and MH issues?