



Clinical Services Planning for Adults with an Intellectual Disability (ID) and Co-occurring Mental Disorders

Never Stand Still

Medicine

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The Department of Developmental Disability Neuropsychiatry (3DN) have made representations to the NSW Mental Health Commission on the need for improvement in the provision of mental health services for people with an Intellectual Disability (ID) and co-occurring mental illness. Through these representations 3DN were invited to contribute this paper to the *Models of Care Project*.

Overview

This document articulates the rationale for a specific model of public mental health care for adults with an Intellectual Disability (ID) and co-occurring mental health disorders. It is hoped that this paper will inform the NSW Mental Health Commission in their *Models of Care Project* so that persons with an ID are better accommodated in the public mental health service systems in NSW in the future.

The proposed model of care works flexibly across inpatient, emergency and community sectors, and has a strong emphasis on in-reach into government and non-government disability sectors. It is founded on the principles of human rights, inclusion, person-centredness, the promotion of independence, recovery-oriented practice and sound evidence. Several key elements support its implementation including: upholding the right to access services, clear articulation of referral and treatment pathways, effective communication, collaboration between specialist and mainstream services, ongoing education and training and interagency collaboration. We argue that the implementation of this model should incorporate ongoing evaluation, research and capacity-building. In funding and resourcing this model, we strongly believe that the complexities of the population and their service needs should be taken into account. Finally, building a model which reduces unnecessary hospitalisation is likely to be more cost-effective and awaits formal evaluation.

We greatly appreciate the opportunity to provide comment to the NSW Mental Health Commission in their *Models of Care Project* and we look forward to working with The Commission on improving mental health service provision for people with ID into the future.

Intellectual Disability: An Important Minority Group for Mental Health Services

What is an ID?

Intellectual Disability (ID), also known as Intellectual Developmental Disorder (IDD) is a disorder which arises in the developmental period (before the age of 18 years) and involves deficits in both intellectual and adaptive functions [1-3].

- Deficits in intellectual functions are assessed by both clinical assessment and by standardised testing of reasoning, problem solving, planning, abstract thinking, judgement, academic learning and learning from experience. Below average intelligence measured as an Intelligence Quotient (IQ) of 70 and below on standardised tests, is consistent with the presence of an ID [1-3].
- ID involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:
 - The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory [1][3].
 - The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities [1][3].
 - The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks [1][3].

Prevalence of ID

People with an ID account for approximately 1.8% of the population and are at a significant disadvantage [4].

- Prevalence of ID is difficult to ascertain because estimates of prevalence vary according to the source. Data on prevalence often conflates prevalence statistics on ID with other cognitive disabilities and self-identification of ID is not reliable and may lead to underestimation of prevalence.
- Key sources of data include the State based Minimum Dataset (MDS) (which measures only those in receipt of services) and the ABS Survey of Disability, Ageing and Carers (SDAC).

ID has a Key Bearing on Mental Health across the Lifespan

Increased Prevalence of Mental Disorders in People with an ID

People with an ID experience very poor mental health compared to the general population, with common mental disorders occurring around two to three times more frequently [5-8]. A predisposition to mental ill health is apparent across the lifespan, including in children, younger people, adults [6] and older adults.

- For example, schizophrenia appears to be over-represented by two to four times, and has an earlier onset in people with an ID [9-10].
- Higher rates of dementia are apparent in older persons with an ID compared to the general population [5][11].
- At any one time, an estimated 20-40% of people with an ID will be experiencing a mental disorder of some kind [5][12-13].

Vulnerability of People with an ID to Mental Disorders

Vulnerability to mental disorders in people with an ID is underpinned by a variety of biological, psychological, and social factors:

- Specific genetic conditions associated with ID can increase the risk of psychopathology [13], as can developmental brain abnormalities and pharmacological treatments and their side effects [14]. People with an ID are also at increased risk of a range of physical health conditions [15-17], a factor which increases the risk for mental ill-health.
- ID usually affects a person's coping skills and autonomy, creating greater susceptibility to stress, and thereby increasing psychological vulnerability [18]. Furthermore, people with an ID experience higher rates of physical and sexual abuse [19] which can further magnify their vulnerability to mental ill-health.
- Further risk arises from the reduced opportunities to engage in a range of life choices, and restricted social networks that people with an ID often experience. Other social factors that have an impact on mental health include: poverty; a higher likelihood of contact with the criminal justice system; negative experiences during schooling; and financial and emotional strain within the family [9][20].

Complexity of Mental Disorders in People with an ID

The level of ID and the presence of any associated communication difficulties each affect how symptoms of mental ill-health manifest in people with an ID.

- People with milder ID and good communication skills are usually able to describe what they are experiencing, and typically present in a manner familiar to most mental health professionals.

- However, presentation is often atypical in those with more severe ID or in people with communication difficulties. This can mean that mental disorders may present as problematic behaviours [21-22]. Individuals showing behavioural changes therefore require careful assessment for a range of potential contributing factors. These contributing factors could include possible underlying mental or physical health conditions. These kinds of complex presentations highlight the importance of specialised and multidisciplinary approaches to the assessment of behavioural difficulties in people with an ID.
- It is critical for those working within the mental health profession to understand the phenomenon of 'diagnostic overshadowing'. Diagnostic overshadowing means that symptoms of mental-ill health are misattributed to the ID rather than being recognised as part of the manifestation of a mental disorder [3].

Current Service Access

Despite the over-representation of mental disorders in people with ID, access to mental health services for people with ID is limited and falls far short of that for the general population.

- Australian research following a cohort of children and adolescents with ID for 14 years demonstrated that just 10% of those with a mental disorder received intervention [23]. This compares unfavourably with access to mental health supports for the general population which has been estimated to be about 35% over a one year period [24].
- Potential barriers to accessing effective mental health care for people with ID in an Australian and NSW context include: a lack of substantial epidemiological data on prevalence of mental illness in people with ID; a lack of data on the interaction between, and distinct roles and responsibilities of disability and mental health services [25]; a lack of training and confidence of mental health professionals [26-29]; poor understanding by carers [30], disability and mental health workers of the manifestations of mental disorders in people with ID [31-32]; a lack of coherent service models and funding for ID mental health services [25]; lack of coordination between services and treating agencies [33]; and a lack of specific inclusion of people with ID in mental health policy.
- There are a number of laudable State and National policy initiatives in ID health and mental health, such as: the NSW Health Service Framework on the Health of People with ID [34]; the NSW Health ADHC Memorandum of Understanding on the Mental Health of People with ID [35]; the National Roundtable and the development of a National Guide on the issue (both funded by the Commonwealth Department of Health, formerly the Department of Health & Ageing).
- The strong link between disability, physical and mental health in people with ID highlights the importance of policy and legislation which clearly addresses the complex issues for this population and articulates a joint framework for cross-agency service provision [25].
- There has also been some service development in this area in NSW, with the funding of the pilot multidisciplinary teams in ID health, each of which includes a mental health component. The most established of these is the MRID.net in the South Eastern Sydney and Illawarra Shoalhaven Local Health Districts, which is a specialist multidisciplinary health service led by the Kogarah Diagnostic and Assessment Service (DAS) at St George Hospital.
- While these laudable initiatives go some way to improving the system to better meet these needs, specific service and policy development within mental health is required.

The Impact of Lack of Services and Poor Access

Implications for the individual with ID

Although outcome data is not available, it is a reasonable assumption that the relative lack of accessible and appropriately skilled mental health services and practitioners results in lower rates of treatment and recovery from mental illness for people with an ID. Furthermore, the lack of application of preventative mental health care means that vulnerabilities and risk of relapse remain unchecked. For a person with ID, continuing symptoms of mental ill health often manifest as challenging behaviour, which if unaddressed leads to social and workplace exclusion [36].

Implications for carers

Informal care for people with ID forms the backbone of supports for people with ID. Inadequate access to mental health services and appropriately skilled clinicians adds significantly to the burden associated with this caring role, and diminishes quality of life for the carer and the person with an ID.

- Informal care provided to people with a disability (including ID) saves the health economy over \$30 billion per year, equivalent to 62% of formal health care costs for Australia [37]. Of all carers, those providing informal care to people with ID are the most likely to need additional support [37].
- Carer stress and burden is significant for those carers caring for a person with ID and mental disorder. This is especially the case where mental ill health is associated with challenging behaviour [38].
- There is an expanding population of elders with ID who are supported by ageing carers, whose own support needs will increase and must be met for them to maintain the carer role. In the general population, adding caregiver interventions to standard dementia treatments would increase fiscal savings [39] for those caring for elders with ID and co-occurring mental illness, such as the dementias. Carers, disability and health care systems will face significant challenges as the population with ID ages, as little is currently known about the cognitive, functional, psychosocial or health trajectories of this group as they age.
- Anecdotally, carers report substantial distress and dissatisfaction when they are unable to access appropriately skilled mental health practitioners¹.

Implications for services

- The current structure of services results in people falling between the gaps in services, with neither health nor disability taking full responsibility, nor having the skills appropriate in dealing with the complexity presented by people with ID and mental disorders. This situation is further aggravated by the lack of adequate resources across the divergent sectors. The NSW Ombudsman found that as a result of this culture of siloing and a lack of an appropriate model of care for treating mental illness in the population of people with ID, hospital rehabilitation units were in effect becoming long-stay units for people with an ID as there was no appropriate step-down level of community support [40].
- Baldry et al. [41] in fact argue for a revision of the very structure of services to one that recognises the complexity of a person's life and moves away from the linear structure that services are dictated by. This has been backed up by others in the field [42] who have argued that the way in which services have been conceptualised has hindered any overall

¹ Personal communication to Assoc. Prof Trollor in stakeholder consultations for the National Guide, IDMH. Currently in preparation.

reform in the provision of mental health services, and that the response to providing mental health services has been ad hoc, piecemeal and crisis driven for many years. This linear framework has served to entrench both the siloing of expertise and the culture of response to treatment and provision of services based around agency jurisdictional boundaries. As we know, people's lives are far more nuanced and complex and this needs to be reflected in the way services are provided and policy is developed.

Specific Populations with Complex Needs

Each of the populations below represents specific sub-populations with complex needs which are not typically being addressed in a cohesive manner by service systems.

Offenders with ID and Mental Disorders

People with ID and mental ill health are at higher risk of engaging in offending behaviours than the general population, and this results in an overrepresented in courts [20], and prisons [41, 43-44]. A substantial proportion of these individuals have a comorbid mental disorder [41].

Adults with ID and cognitive disability are particularly vulnerable to a life of entrenchment in the criminal justice service without appropriate supports [41].

- Implications for service models: specific resourcing and expertise are needed to meet the need of these individuals in the community, in consultation with programs such as the NSW Department of Family & Community Services, Ageing, Disability & Home Care (ADHC) community justice program, and within corrections and forensic mental health systems.

People with ID and Substance Use Disorders

Conventional services and models have struggled to provide accessible services for these groups.

- Implications for service models: Reasonable adjustments and appropriate models await development.

People with ID, Mental Disorders and Complex Physical Disabilities

Presentations in these individuals can often be ambiguous and require high level expertise in assessment and management.

- Implications for service models: Specific services multidisciplinary and multi-specialist should be developed and should be uniformly accessible across NSW.

Aboriginal Australians with an ID

There has been limited focus on this group which often suffers multiple disadvantage and is over-represented in the criminal justice system. The NSW Mental Health Commission is urged to highlight specific focus on this area, and particularly the intersection of ID, mental disorder and offending.

- Implications for service models: This area is being explored extensively by a project in which 3DN are involved, led by Professor Eileen Baldry². We suggest that some of the findings of the indigenous component of this project will be relevant to The Commission's work.

² See <http://www.mhdcd.unsw.edu.au/> for more details.

People with ID and Challenging Behaviour

Challenging behaviour is common in people with ID, particularly in people with more severe ID, and those with limited communication skills. Challenging behaviours are more commonly seen in individuals with mental ill health. It is common for mental disorders to present with new onset or escalation of challenging behaviour. At present, mainstream mental health services do not engage in the assessment or management of challenging behaviour in people with ID. This is illogical given: a) the central role for mental health professionals in determining, or ruling out underlying mental disorder, b) the important aspects of managing challenging behaviour include consideration and expert review of psychotropic drug treatment.

- Implications for service models: Appropriately skilled assessment and management of challenging behaviour should be available within publically funded mental health services.

Further Arguments for Building Enhanced Services

Comprehensive service development in ID mental health is necessary in order to meet fundamental human rights obligations to this minority group. As above, there is clear and consistent need on the basis of over-representation of mental disorders in people with an ID, and limited access and availability of appropriate services. Furthermore, although limited in scope, available data in NSW adds impetus to this argument:

- A recent report for the NSW Department of Family & Community Services, Ageing, Disability & Home Care (ADHC) undertaken by Price Waterhouse Cooper (PWC) found that people with an ID and co-occurring psychiatric disability were intense users of hospital services (frequent visits to inpatient and ED with short lengths of stay) [45].
- Preliminary data linkage performed by 3DN (between ambulatory (or 'community') mental health service data and the Disability Minimum dataset in a subset of 20% of the NSW population - to be submitted for publication) found similar results: those with an ID had 1.8 times more face-to-face contacts than those without ID (i.e. the general population) and that on average these were 2.6 times longer than the contacts of those without ID. We also found that people with ID were under-represented for more common mental illnesses, such as depression and adjustment disorders, which may indicate either an under recognition of disorders in this population or a problem of access.
- At 3DN we are currently in the process of obtaining linked data between health and disability for inpatient and emergency departments for the whole of NSW. This linked set will detail the epidemiology of mental illness in the population of persons with an ID in NSW and provide us with a clearer picture of access and service level usage for this population. It will also provide comparative analysis between those with ID and those without an ID in the NSW population. This data will be pivotal in informing the development of NSW mental health services for this population group from 2014 and into the future. In the absence of this data present, we can only piece together the picture of service provision for this population in NSW.

Priorities for Action

- A number of priority areas for action for the coming five years have been identified by a recent National Roundtable on Intellectual Disability Mental Health (held in Canberra, May

2013, referred to hereafter as 'National Round Table')³. While these have application nationally, their adoption by NSW public mental health services is integral to their realisation at a national level. Many of these can build on existing services or initiatives while some others will require resources and development. These are:

- i) Inclusion of persons with ID in all mental health and mental health reform initiatives
- ii) Prevention and timely intervention
- iii) Equitable access and skilled treatment
- iv) Establish a pool of specialists in intellectual disability mental health
- v) Collaboration between agencies at State and National levels
- vi) Workforce education development and training for staff across sectors and,
- vii) Collection and engagement with data at both service provision and policy development levels.

Principles for Service and Policy Development in ID Mental Health

The National Guide ('The Guide') on Intellectual Disability Mental Health⁴, which articulates how mental health services should be provided to persons with an ID across Australia, has laid out the following principles as central to the development of models of care and policy for mental health services to people with an ID:

A. *Human Rights*

A human rights framework for health care for people with a disability means that people with an ID have the right to the highest attainable standard of health without discrimination. Furthermore, mental health consumers with reduced capacity, including those with an ID, should be supported to understand and exercise their rights [46]. Key documents of interest include the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [47] and the World Health Organisation (WHO) *Zero Draft: Global Mental Health Action Plan 2013-2020* document, [48].

B. *Inclusion*

People with an ID have the right to full participation in all aspects of community life and should be able to access all components of mental health services, including mainstream and specialised mental health services. They should not be refused access to a service due to the presence of an ID.

C. *Person-Centred*

A person-centred approach to service provision maximises the involvement of the person with an ID in decision-making, rather than viewing them as passive recipients of care. In a person-centred approach, the individual is central to their care plan and to any decisions made with respect to their mental health.

³ Further information is detailed in the Communiqué issued from the Roundtable here: <http://www.nswcid.org.au/images/communique.pdf>

⁴ Currently in preparation, the development of which has been funded by the Commonwealth Department of Health, formerly the Department of Health & Ageing. To be released end of 2013.

D. Promoting Independence

A model of mental health care for people with an ID should recognise the autonomy of individuals with an ID whilst acknowledging their age and capacity, and work in a manner that maximises their independence.

E. Recovery-Oriented Practice

Recovery-oriented practice relates specifically to the mental health of the person rather than support for their ID. Recovery-oriented practice moves the focus away from simply ameliorating mental disorders towards more holistic care; providing long-term supports that promote ongoing well-being and involves collaborative agency engagement.

F. Evidence Based

The decisions made by health and disability professionals should be informed by the best available evidence. Professionals should continually seek to enhance their knowledge of new and existing interventions and to incorporate these into their practice.

Key Components of ID Mental Health Services

- The key components we believe are central to the ongoing development of the service are listed here. As with the Principles above, these have also been developed as part of 'The Guide':
 - a. The right to access services must be upheld.
 - b. Professionals must be able to be flexible in their approach and communicate effectively.
 - c. Specialised Intellectual Disability Mental Health Services must be provided that support mainstream services in the provision of care.
 - d. Professionals must be able to identify care and referral pathways for treatment.
 - e. Education and Training must be provided to professionals and professionals must seek to use and acquire this knowledge in their work in an ongoing manner.
 - f. Agencies must cooperate with a multidisciplinary approach in a spirit of collaboration.
 - g. Data must be collected and integrated into ongoing service development and improvement.

Matching Clinical Services to Level of Complexity

One of the central concepts to be represented in service development is that there are varying levels of complexity in people with ID and mental disorders. Complexity can best be understood in terms of 'low', 'medium' and 'high' levels, and an analysis of existing strengths of the public mental health service system, as well as the capacities that require development, are listed below.

Low complexity

A person with ID in this category would typically have a mild level of ID and good verbal skills.

- In this scenario, presentation with a mental disorder would be in a manner familiar to most health service providers. Assessment and management can usually proceed as usual. The

need for specialist review will be occasional, and aimed at optimising intervention or reviewing unexpected outcomes.

- Standard models such as early intervention and proactive case management are able to be applied.
- The challenge for the service becomes: a) ensuring that all staff are appropriately skilled in the recognition of ID and in the management of mental disorders in this setting; b) ensuring that all aspects of the service have defined clinical pathways that are accessible to the person with ID; c) ensuring that there is a clear framework for working with disability related supports; and d) ensuring that, should it be necessary, access to more highly specialised IDMH service is available.

Medium complexity

A person with ID in this category may have their presentation made more complex by the presence of communication difficulties (for example, a co-occurring autistic disorder); an atypical course response to treatment or outcome; the presence of a degree of challenging behaviour; or the presence of medical comorbidities or complications from treatment.

- In this scenario, some public mental health services may have some existing strengths which can be mobilised, such as: a) some staff with specific training in IDMH; b) local partnerships with disability services under the MOU [35].
- However, as complexity increases, mental health services are more likely to view this scenario as not within their direct remit, and may defer responsibility to the disability sector.
- Service system enhancements that would improve the current state include: a) ensuring access to specific training for all staff; b) collation of information about key ID mental health and disability resources; c) the identification of key service pathways for a person with ID moving through the local mental health system; d) development of accessible information on mental illness and the service for people with ID and their carers; and, e) access to specialised IDMH teams (see below) for the purposes of consultation and intermittent review, in a way which supports capacity development in the mainstream service.

High complexity

A person with ID in this category would include: a person with severe or profound levels of ID; a person with any level of ID but with other multiple physical comorbidities; a person with ID and comorbid severe personality disorder, or severe challenging behaviour.

- In this scenario, presentation with a mental disorder would not usually be familiar territory to mainstream services.
- Specific specialist IDMH capacity is therefore required. Specialist IDMH services may work with mainstream services to eventually transition a person to mainstream if the psychiatric support needs are stabilised and well defined.
- Professional skills required include: a) skills development to an advanced level; b) in-depth knowledge of the interaction between health, mental health and behaviour; and, c) detailed knowledge of the assessment and management of challenging behaviour.
- Services would also require the capacity for: a) developing and implementing training for staff in mental health and disability sectors; and, b) evaluation and capacity to implement evidence from research and models of best practice.

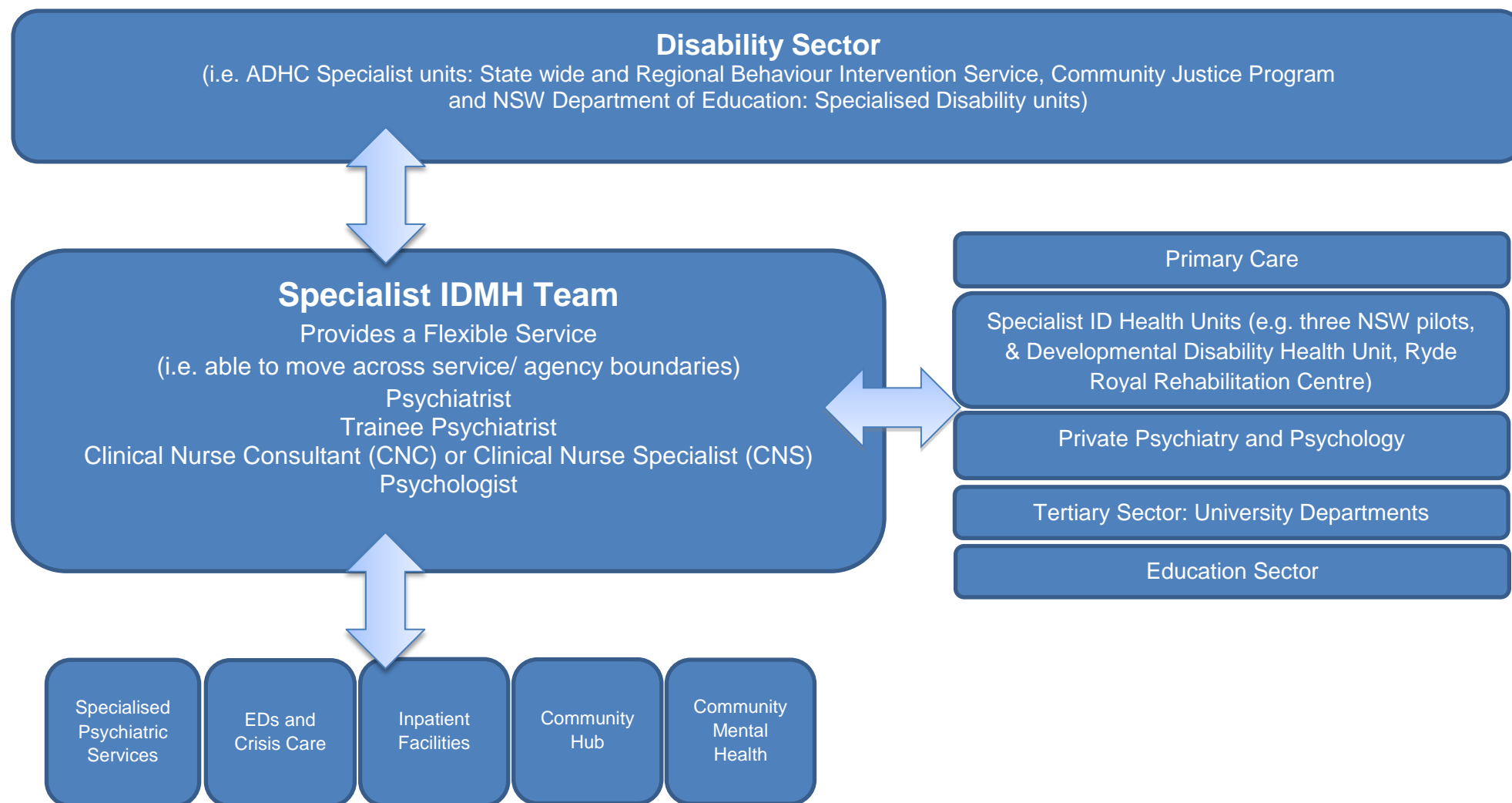
Proposed Service Structure

In line with the above information, a model of care for the provision of public mental health services to people with an ID should be one that:

- (1) Builds capacity in mainstream community and inpatient mental health services to provide for the needs of people with an ID and mental disorder of 'low' complexity.
- (2) Develops specialist capacity to meet the needs of more complex cases and to support the generic capacity above.
- (3) Engages in direct mental health service provision within the disability sector, via in-reach clinics that complement multidisciplinary hubs set up under the National Disability Insurance Scheme (NDIS).
- (4) Provides in-reach services to newer community mental health initiatives such as the 'hub' model currently under discussion in NSW [49]
- (5) Supports the building of capacity by engaging in training, educational initiatives and research.
- (6) Develops links and provides in-reach to other specialist mental health teams (e.g. early psychosis, rehabilitation, older person's mental health, perinatal, consultation-liaison services).
- (7) Liaises with, and supports referral from primary care providers and from other sources such as courts, prison release programs, drug and alcohol services, aboriginal medical services, CALD services etc.

A team model is proposed below which represents the nucleus of a potential new service. Such services would need to be available within each Medicare Local, in proportion to the population being serviced and other considerations as outlined below. The work-up of such a model, including comprehensive costing, is work that should be undertaken by experienced health economists. However, we make some further suggestions below which need to be considered in any funding model.

Relational Structure of Proposed Specialist IDMH Team



Staff for Specialist IDMH Team

Staff	Role
Psychiatrist	<ul style="list-style-type: none"> - Leadership of team - Attendance or availability for all clinics - Review of inpatients - Assist with planning educational activities.
Trainee Psychiatrist	<ul style="list-style-type: none"> - Attendance at all clinics - Review of urgent cases - Review of inpatients - Key point of contact for all clinical inquiries
CNC/CNS	<ul style="list-style-type: none"> - Assist in reviews - Liaise with and provide educational support to nursing staff and allied health - Development of educational programs - Key point of contact for all clinical inquiries
Psychologist	<ul style="list-style-type: none"> - Attendance at all booked clinics - Key advisor regarding behavioural management - Involvement in educational program

How would such a Model Assist?

1. It meets an immediate need to provide comprehensive psychiatric review of people with ID.
2. As a recognised component of the mental health service, it improves accessibility of mental health services for people with ID, who are often turned away, their needs considered too complex for time-poor, ill-trained clinicians.
3. It provides a much needed forum for semi-urgent review of individuals who may otherwise remain unserved and subsequently present in crisis to the Emergency Department or with Police for acute mental health assessment.
4. Such a service would also provide more specialised review and advice to staff and patients already in case management within the service.
5. The service model develops, at a local level, a shared forum for cross-collaboration between disability and mental health. In that, both agencies are engaged in identifying innovative strategies to improve service to those with ID and mental health issues.
6. The model sits well with current National and State policy and service initiatives, such as the MOU between NSW Health and Ageing, Disability and Home Care (ADHC) on the 'Provision of Services to Persons with ID and Co-occurring Mental Illness' [35], and the NSW Health 'Service Framework on the Health of Persons with ID' [34], and the development of a National Guide on IDMH and the National Roundtable on IDMH. It also complements work that both agencies are party to seeking solutions and building capacity on this issue, such as the development of Core Competencies in IDMH, and the National Health & Medical Research Council (NHMRC) Partnerships for Better Health project, 'Improving Mental Health Outcomes for Persons with ID', among other laudable initiatives that demonstrate the commitment of governments to improving their performance on this issue.

Funding and Resourcing the Model

The workup of a model, including comprehensive costings should be undertaken by experienced health economists. However, we wish to make some recommendations below to be considered in the development of any funding model.

- Funding should take into consideration a combination of: the prevalence of ID in the general community, the prevalence of mental illness in people with an ID, and the clinical complexity of this population.
- There is a hidden cost in not providing a service. This cost is to the public health sector (higher Emergency Department presentations in crisis, longer stays in inpatient facilities), to the individual and their families, and to the community in maintaining the current ill-effective 'model' of provision.
- In calculating the funding implications of a both an ID and mental illness diagnosis we propose that any emerging model must adequately account for the following complexities:
 - Complexity in communication, due to cognitive, mental health, hearing and visual problems or combinations of these factors [50-53]. These result in the need for longer consultations in every phase of management.
 - Diagnostic complexity: An accurate diagnosis is more challenging in people with ID compared to the general population and requires more time for the clinician and clinical service [53-54].
 - Complexity related to the need for extensive interdisciplinary and interagency collaboration [54].
 - Increased medical complexity due to much higher rates of pre-existing medical conditions in people with ID. This necessitates more detailed monitoring of physical health including the impact of psychopharmacology on medical comorbidities [54].
 - Complexities related to third party involvement in consultations: People with ID may rely more heavily on third parties such as friends, family or support staff, to assist them with communication, and thus effective mental health consultations require the team to engage and consult with a number of third parties [53-54]. Interfacing with third parties such as families can be complex and time consuming and may contribute directly to increased patient management costs [55].
- The National Disability Insurance Scheme (NDIS)⁵ [56] will not provide funding for direct clinical services. Any enhancements therefore will need to come directly from mental health funding.
- The impact of introduction of national Activity Based Funding (ABF) for mental health in 2013 and the new Australian Mental Health Care Classification System (AMHCC) currently being developed by the Independent Hospital Pricing Authority [57] will need to be explored to see if it can accommodate the complexity of people with ID and mental disorders.
- While we were unable to identify any pre-existing model accounting for the specific increased costs associated with a both ID and mental illness diagnosis, costing estimates for other dual diagnoses associated with ID suggests that such a complexity adjustment may need to be significant. For example, a UK study exploring the funding repercussions of a dual diagnosis of Autism Spectrum Disorder (ASD) and ID reported a £0.43 million lifetime cost difference for treating someone with ASD and ID compared to ASD alone (£1.23 million versus £0.80 million) [58].

⁵ Briefly named 'DisabilityCare Australia' under the Federal Labor Government (July –September 2013), now re-coined NDIS.

Recommendations and Conclusions

People with an ID experience high rates of mental disorder and poor access to mental health services. The mental health of people with an ID can only be improved through concerted effort across a number of sectors. The public mental health system has a pivotal role to play in this process. There appears to be a window of opportunity to act to improve this situation, and innovation is required. The funding of a flexible model in which a designated team interacts with a range of components of the mental health and disability system appears the most viable way of proceeding. Such a team would assist by building and supporting generic capacity in the mainstream mental health services, as well as providing a much needed and highly visible point of entry and reference for people with ID and their carers, as well as other professionals from the health and disability sectors. Our recommendations aim to inform the NSW Mental Health Commission's *Models of Care Project* so that persons with an ID are better accommodated in the health and mental health service system in NSW into the future. Our recommendations are that:

1. The development of a model of care for adults with ID and mental disorders as proposed in this document, or as modified by subsequent discussion, is supported by the Commission.
2. Any models of care promoted are underpinned by principles of: human rights, inclusion, person-centredness, promotion of independence, recovery-oriented practice and a sound evidence base.
3. This model of care is grounded by the key components of: upholding the right to access services, flexibility among staff and effective communication, collaboration between specialist and mainstream services, a clear articulation of referral and treatment pathways, ongoing education and training, interagency collaborative effort, and the collection, use and analysis of data.
4. The funding and resourcing of a model of care for people with ID and co-occurring mental illness should adjust for the complexities in treating this population and should aim to prevent unnecessary hospitalisation.
5. The key elements of evaluation, research, education and capacity building are incorporated into the ongoing implementation of the model.

Once again, we greatly appreciate the opportunity to provide comment to the NSW Mental Health Commission in their *Models of Care Project* and we look forward to working with The Commission on improving mental health service provision for people with ID into the future.

References

1. American Association of Intellectual and Developmental Disabilities. Retrieved from: <http://aaidd.org/intellectual-disability/definition#.Uk5lniSngJ2>
2. World Health Organisation ICD-10. Retrieved from: <http://www.who.int/classifications/icd/en/>
3. American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-5. 2013, Arlington, VA: American Psychiatric Association Publishing.
4. AIHW (2003). Disability Prevalence and Trends AIHW. Canberra, AIHW. Cat. No. DIS 34.
5. Cooper, S.-A., et al., *Mental ill-health in adults with intellectual disabilities: prevalence and associated factors*. The British Journal of Psychiatry, 2007. **190**(1): p. 27-35.
6. Einfeld, S.L., et al., *Psychopathology in young people with intellectual disability*. JAMA: the journal of the American Medical Association, 2006. **296**(16): p. 1981-1989.
7. Cooper, S. A., et al. "Psychosis and adults with intellectual disabilities. Prevalence, incidence, and related factors." *Social Psychiatry & Psychiatric Epidemiology*. 2007. **42**(7): 530-536.
8. Emerson, E., Einfeld, S. & Stancliffe, R.J. *Predictors of the persistence of conduct difficulties in children with cognitive delay*. Journal of Child Psychology and Psychiatry, 2011. **52**(11): p. 1184-1194.
9. Emerson, E., *Poverty and people with intellectual disabilities*. Mental Retardation and Developmental Disabilities Research Reviews, 2007. **13**(2): p. 107-113
10. Borthwick-Duffy, S. A. "Epidemiology and Prevalence of Psychopathology in People With Mental Retardation." *Journal of Consulting and Clinical Psychology*, 1994. 62(1): 17-27.
11. Cooper, S.-A. "Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities." *The British Journal of Psychiatry*. 1997. 170(4): 375-380.
12. Einfeld, S., et al. "Inter-Rater Reliability of the Diagnoses of Psychosis and Depression in Individuals with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities*. 2007. 20(5): 384-390.
13. Cooper, S. and A. Holland (2007). "Dementia and mental ill-health in older people with intellectual disabilities." *Psychiatric and Behavioural Disorders in Development Disabilities and Mental Retardation*.
14. Tonge, B.J. and S.L. Einfeld, *Psychopathology and Intellectual Disability: The Australian Child to Adult Longitudinal Study*, in *International Review of Research in Mental Retardation*. 2003, Academic Press. p. 61-91.
15. O'Hara, J. and J. O'Hara, *Attending to the health needs of people with intellectual disability: quality standards*. *Salud Publica de Mexico*, 2008. **50 Suppl 2**: p. s154-9.
16. Scheepers, M., et al., *Reducing health disparity in people with Intellectual Disabilities: A report from Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities*. *Journal of Policy and Practice in Intellectual Disabilities*, 2005. **2**(3/4): p. 249-255.
17. Wallace, R.A., et al., *On the need for a specialist service within the generic hospital setting for the adult patient with intellectual disability and physical health problems*. *Journal of Intellectual & Developmental Disability*, 2008. **33**(4): p. 354-61.
18. Janssen, C., C. Schuengel, and J. Stolk, *Understanding challenging behaviour in people with severe and profound intellectual disability: a stress - attachment model*. *Journal of Intellectual Disability Research*, 2002. **46**(6): p. 445-453.
19. McCarthy, M. and M. CQSW, *The sexual support needs of people with learning disabilities: A profile of those referred for sex education*. *Sexuality and Disability*, 1996. **14**(4): p. 265-279.

20. Vanny, K., et al., *Mental illness and intellectual disability in magistrates courts in New South Wales, Australia*. Journal of Intellectual Disability Research, 2009. **53**(3): p. 289-297.
21. Department of Health (UK), *Valuing People: A New Strategy for Learning Disability for the 21st Century*, Social Care Policy and Innovation Department of Health, Editor. 2001: UK.
22. Chan, J., C. Hudson, and C. Vulic, *Services for adults with intellectual disability and mental illness: Are we getting it right?* Advances in Mental Health, 2004. **3**(1): p. 24-29.
23. Tonge, B. and Einfeld, S. "The trajectory of psychiatric disorders in young people with intellectual disabilities." Australian and New Zealand Journal of Psychiatry. 2000. 34(1): 80-84.
24. Slade, T., et al., *2007 National Survey of Mental Health and Wellbeing: methods and key findings*. Australian & New Zealand Journal of Psychiatry, 2009. **43**(7): p. 594-605.
25. Evans, E., Howlett, S., Kremser, T., Simpson, J., Kayess, R. & Trollor, J. "Service development for intellectual disability mental health: a human rights approach " Journal of Intellectual Disability Research. 2012. 56(11): 1098-1109.
26. Edwards, N., N. Lennox, and P. White, *Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability*. Journal of Intellectual Disability Research, 2007. **51**(Pt 1): p. 75-81.
27. Phillips, A., J. Morrison, and R.W. Davis, *General practitioners' educational needs in intellectual disability health*. Journal of Intellectual Disability Research, 2004. **48**(Pt 2): p. 142-9.
28. Torr, J., Lennox, N., Cooper, S-A., Rey-Conde, T., Ware, R.S., Galea, J. & Taylor, M. "Psychiatric care of adults with intellectual disabilities: changing perceptions over a decade." Australian and New Zealand Journal of Psychiatry. 2008. 42: 890-897.
29. Jess, G., et al., *Specialist versus generic models of psychiatry training and service provision for people with Intellectual disabilities*. Journal of Applied Research in Intellectual Disabilities, 2008. **21**: p. 183-193.
30. Moss, S., et al., *Mental disorders and problematic behaviours in people with intellectual disability: future directions for research*. Journal of Intellectual Disability Research, 1997. **41**(6): p. 440-447.
31. Costello, H., N. Bouras, and H. Davis, *The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities*. Journal of Applied Research in Intellectual Disabilities, 2007. **20**: p. 228-235.
32. Patel, P., D. Goldberg, and S. Moss, *Psychiatric morbidity in older people with moderate and severe learning disability. II: The prevalence study*. British Journal of Psychiatry, 1993. **163**: p. 481-91.
33. Cohen, K., *Mental Health Table Forum. Which doors lead to where? How to enhance access to mental health service: Barriers, facilitators and opportunities for Canadians' Mental Health*. 2010: Ottawa.
34. NSW Ministry of Health (2012 (JULY)). Service Framework to Improve the Health Care of People with Intellectual Disability. NSW Ministry of Health. SYDNEY.
35. NSW Ministry of Health (2012). Memorandum of Understanding & Guidelines Between Ageing, Disability and Home Care, Department of Human Services NSW and NSW Health In the Provision of Services to People with an Intellectual Disability and a Mental Illness. NSW Ministry of Health, SYDNEY.
36. Emerson, E. (2001). Challenging Behaviour: Analysis and Intervention in People With Severe Intellectual Disabilities, Cambridge University Press.

37. Access Economics. *The economic value of informal care*. 2005; Available from: <http://www.accesseconomics.com.au/publicationsreports/getreport.php?report=6&id=6>
38. McIntyre, L. L., Blacher, J., & Baker, B. L. Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research*, 2002. 46(3), 239-249.
39. Weimer, D.L. and M.A. Sager, *Early identification and treatment of Alzheimer's disease: Social and fiscal outcomes*. *Alzheimer's and Dementia*, 2009. 5(3): p. 215-226.
40. Ombudsman, N. S. W. (2012 November). Denial of Rights: the need to improve accommodation and support for people with psychiatric disability. A Special Report to Parliament under s.31 of the Ombudsman Act 1974. N. S. W. Ombudsman. Sydney.
41. Baldry, E., et al. "Reducing Vulnerability to Harm in Adults With Cognitive Disabilities in the Australian Criminal Justice System." *Journal of Policy and Practice in Intellectual Disabilities*. 2013.10(3): 222-229.
42. Whiteford, H., et al. "Mental health service system improvement: Translating evidence into policy." *Australian and New Zealand Journal of Psychiatry*. 2013. 47(8): 703-706.
43. Hayes, S., et al. "The prevalence of intellectual disability in a major UK prison." *British Journal of Learning Disabilities*. 2007. 35(3): 162-167.
44. Indig, D. and J. Justice (2011). 2009 NSW Young People in Custody Health Survey: Full Report, Justice Health.
45. P. W. C. (2012). Use of emergency and inpatient hospital services by ADHC clients – Final Report. Sydney, Ageing, Disability & Home Care (ADHC), Department of Families and Community Services NSW.
46. Standing Council on Health, *Mental health statement of rights and responsibilities*. 2012, Safety and Quality Partnership Subcommittee of the Mental Health Standing Committee of the Standing Council on Health and endorsed by Australian Health Ministers.
47. United Nations, *Convention on the Rights of Persons with Disabilities*. 2006, United Nations: Geneva.
48. World Health Organization, *Zero draft: global mental health action plan 2013-2020*. 2012, World Health Organization: Geneva.
49. "Innovative New Service Set to Reform Mental Health Delivery in NSW" Retrieved September 25 Sept 2013 from: <http://www.kevinhumphries.com.au/media/media-releases/innovative-new-service-set-to-reform-mental-health-delivery-in-nsw.html>
50. Belva, B. C., Matson, J. L., Sipes, M., & Bamburg, J. W. An examination of specific communication deficits in adults with profound intellectual disabilities. *Research in developmental disabilities*, 2012. 33(2), 525-529.
51. Iacono, T., & Johnson, H. Patients with disabilities and complex communication needs. The GP consultation. *Australian family physician*, 2004. 33(8), 585.
52. Moss, S., Bouras, N., & Holt, G. (2000). Mental health services for people with intellectual disability: a conceptual framework. *Journal of Intellectual Disability Research*, 44(2), 97-107.
53. Krahn, G. L., Hammond, L., & Turner, A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental retardation and developmental disabilities research reviews*, 2006. 12(1), 70-82.
54. Department of Developmental Disability Neuropsychiatry (3DN), (2013), *intellectual disability mental health e-Learning*. Retrieved September 20, 2013, from: www.idhealtheducation.edu.au
55. Royal Australasian College of Physicians (2013). *RACP submission to consultation paper: pricing framework for Australian public hospital services 2014-15*. Retrieved September 20,

2013 from:

[http://www.ihpa.gov.au/internet/ihpa/publishing.nsf/Content/2ABE18AE222343F7CA257BC7000071FD/\\$File/RACP_30-07-13.pdf](http://www.ihpa.gov.au/internet/ihpa/publishing.nsf/Content/2ABE18AE222343F7CA257BC7000071FD/$File/RACP_30-07-13.pdf)

56. DisabilityCare Australia (2013). *People with disability*. Retrieved September 20, 2013 from, <http://www.disabilitycareaustralia.gov.au/people-disability>
57. Independent Hospital Pricing Authority IHPA (2013). *Mental health care*. Retrieved September 20, 2013 from: <http://www.ihpa.gov.au/internet/ihpa/publishing.nsf/Content/mental-health>
58. Knapp, M., Romeo, R., & Beecham, J. Economic cost of autism in the UK. *Autism*, 2009. 13(3), 317-336.