

A Model of Care for Adults with an Intellectual Disability (ID) and Co-occurring Mental Disorders

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

A Briefing Paper for the NSW Agency for Clinical Innovation (ACI) Intellectual Disability Network

June 20th 2014

Associate Professor Julian Trollor

Chair, Intellectual Disability Mental Health
Head, Department of Developmental Disability Neuropsychiatry
School of Psychiatry, Faculty of Medicine
University of New South Wales, Sydney
j.trollor@unsw.edu.au

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The Department of Developmental Disability Neuropsychiatry (3DN)
The University of New South Wales, Sydney AUSTRALIA

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Principles Underpinning a Model of Care in ID Mental Health

In *Accessible Mental Health Services for People with an Intellectual Disability: The Guide* (Department of Developmental Disability Neuropsychiatry, 2014) we articulate how mental health services should be provided to persons with an ID across Australia and 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. Key documents of interest include the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) and the World Health Organisation (WHO) *Zero Draft: Global Mental Health Action Plan 2013-2020* document (World Health Organization, 2012).

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.

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 Guide' has also articulated the key components of accessible mental health service have also been articulated. These include:
 - a. Adaptation of clinical approach, including:
 - a. Adequate preparation
 - b. Making 'reasonable adjustments' to practice
 - c. Effective communication with the person with an ID and their carers
 - d. Inclusion of the person in decision making to the greatest extent possible,
 - e. Having a clear framework for working with families and carers
 - b. The right to access generic and specialist services.
 - c. Identification of clear care and referral pathways.
 - d. Education and Training for mental health professionals
 - e. Adopting a multiagency approach which minimises service boundary distinctions in the provision of holistic care
 - f. Collection and interrogation of data on service provision and outcomes
 - g. Inclusion of people with an ID in policy and services development

Matching Clinical Services to Level of Complexity

One of the central concepts to be represented in any service development is the varied 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 or 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 (NSW Government, 2010).
- 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.

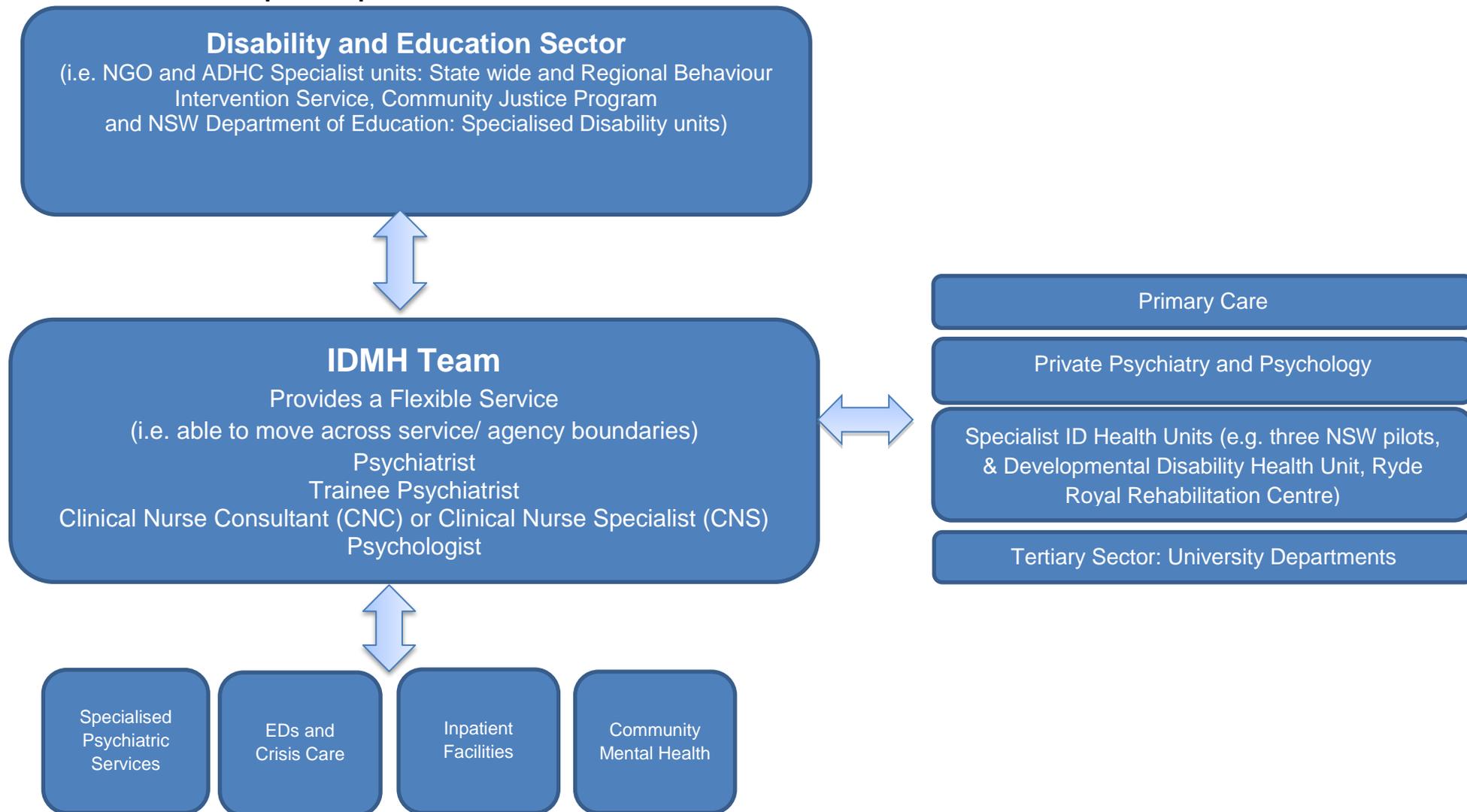
Proposed Service Structure

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 within NGO disability service providers.
- (4) Supports the building of capacity by engaging in training, educational initiatives and research.
- (5) 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).
- (6) 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 local area, 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' (NSW Government, 2010), and the NSW Health 'Service Framework on the Health of Persons with ID' (NSW Ministry of Health, 2012), and the development of a National Guide on IDMH and the National Roundtable on IDMH.

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. 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.
 - Complexity related to the need for extensive interdisciplinary and interagency collaboration.
 - 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.
 - 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. Interfacing with third parties such as families can be complex and time consuming and may contribute directly to increased patient management costs.
- The National Disability Insurance Scheme (NDIS) 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 will need to be explored to see if it can accommodate the complexity of people with ID and mental disorders.

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 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 ACI.
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. Any model of care developed 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.

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