

Department of Developmental Disability Neuropsychiatry

Never Stand Still

UNSW Medicine

School of Psychiatry

Strategic Plan

2013 to 2015



Foreword

A mental illness diagnosis may channel people through to the supports and services they need, qualify them for funding, affirm their experience, and bring recognition and understanding from health professionals and the wider community.

Conversely, a diagnostic label may become a sort of shorthand that thwarts more creative thinking about the situation of an individual person and triggers instead a cascade of standardised medication regimens and care protocols.

When people with an intellectual disability develop a mental illness – which they do at rates of up to four times those of others in the community – this double bind is further amplified.

First, it is very likely that the illness will not be promptly or adequately recognised. When psychological distress manifests primarily through behaviour, particularly in someone whose ability to communicate verbally may be limited, it may be misattributed as a facet of the intellectual disability.

Then, if the person is diagnosed with a mental illness, it is probable that much of the thinking that informs their care will be derived from studies conducted with people whose experience is not complicated by intellectual disability. Health professionals may also find there is little or no institutional provision for them to involve other services supporting the person in their other health and social needs.

What should we do to break down these diagnostic silos, which can cause so much damage to people by leaving them in unnecessary distress?

Disability Care, the renamed National Disability Insurance Scheme, offers a promising template. It frames qualification for assistance around a person's level of need, not their diagnosis. Even so, the services from which individual support and care packages will be drawn are based generally on old models which view mental illnesses and intellectual disabilities as discrete entities, and may not flexibly respond to someone's complex, overlapping or unusual difficulties.

We need to develop a new set of thinking about how we make support available, to accommodate the reality that people cannot be described by a diagnosis, or even a collection of diagnoses, but have an infinite variety of needs, wishes, aspirations and social circumstances.

The NSW Mental Health Commission in March 2014 will present to Government its recommendations for change to how support is provided for people who experience mental illness. The Commission, which is an independent statutory agency, has been charged with leading reform not just within the health portfolio, but across the whole of government including housing, justice, education, employment and community services – any of which may have a profound effect on the lives of people who experience mental illness.

We need to listen to people themselves, and their families and carers, to make sure the support we offer is aligned to individual needs, not diagnostic categories. That is doubly true when mental illness occurs alongside another complex condition, such as intellectual disability.

I commend 3DN's Strategic Plan 2013 to 2015, which provides a powerful intellectual and professional framework on which a personcentred approach to support can be built.

It is heartening to see the emphasis on collection of epidemiological data that records the actual experience of people with mental illness and intellectual disability, rather than making assumptions about them. I welcome also the acknowledgement that much more sophisticated training will be required to meet the specialised needs of these people, and that clinicians must collaborate across agency boundaries if they are to secure the best support for their clients.

I am especially delighted to see this Plan recognise the need for health professionals to involve themselves actively in policy development, advocacy and lobbying. All of our voices will be needed to make a meaningful difference in the lives of people with mental illness and intellectual disability.

John Feneley *NSW Mental Health Commissioner*

Message from the Chair



The Department of Developmental Disability Neuropsychiatry (3DN) has grown rapidly since it was established by the Chair of Intellectual Disability Mental Health in 2009. From the start, 3DN has been fortunate to have a passionate and dedicated staff, who have worked hard to improve the mental health and quality of life of people with an intellectual or developmental disability. The team's dedication has now resulted in our first Strategic Plan, which will guide our work over the next three years.

The breadth of our work to date has been substantial, and a clear vision and plan for future work has emerged from our initial efforts. In the context of national disability reform, this Strategic Plan will assist us to maintain our focus in a rapidly changing environment. It will guide our contribution towards the attainment of the highest possible standard of mental health and wellbeing for people with an intellectual or developmental disability.

The core strengths of our plan include its solid grounding in a human rights framework, and its collaborative, interdisciplinary and consumer focus. Our work is shaped by the experiences of individuals with an intellectual or developmental disability, their carers, families and advocates.

The rich sharing of these stories with our staff in clinical, educational, research and social settings tells of major barriers to access to mental health services, and of substantial unmet need. These lived experiences underscore the urgency of our vision, and maintain our hope that our work will be of direct benefit to the lives of people with an intellectual or developmental disability.

We look forward to continuing to refine our strategy, as we work towards improving mental health policy and practice for people with an intellectual or developmental disability. I hope you enjoy reading this Plan and stay in touch with our work. You can find us at our Facebook page or at – www.3dn.unsw.edu.au

Associate Professor Julian Trollor

Chair, Intellectual Disability Mental Health Head, Department of Developmental Disability Neuropsychiatry, UNSW

Vision

The highest attainable standard of mental health and wellbeing for people with an intellectual or developmental disability.

Mission

To improve mental health policy and practice for people with an intellectual or developmental disability.

Guiding Principles

The principles that guide the work of our Department are:

Human rights

People with an intellectual or developmental disability have the right to the highest attainable standard of health and mental health care.

· Equity in mental health care

People with an intellectual or developmental disability have the right to equitable access to mental health services, delivered by an appropriately skilled workforce.

· Excellence and academic leadership

As a centre of expertise, we provide high quality advice and promote excellence in clinical practice, research, education and policy.

· Innovation in health services

We translate research into practical benefit at the level of health systems and workforce capacity. We encourage the use of sound evidence in the implementation of new ideas.

Collaboration

We value the multidisciplinary context of our work. We actively engage stakeholders to share expertise and promote integrated systems in health and disability. We actively seek the participation of people with an intellectual or developmental disability. We value our collaborations with carers and family members.

Ethical conduct

We act in accordance with professional and industry codes of conduct and practice, the human rights of people with an intellectual or developmental disability, and the Guiding Principles in this Plan.

Introduction

The Department of Developmental Disability Neuropsychiatry (3DN) was established by the Chair of Intellectual Disability Mental Health in 2009. The Chair is funded by Ageing, Disability and Home Care, Department of Family and Community Services NSW.

3DN is part of the School of Psychiatry within UNSW Medicine. We champion the right of people with an intellectual or developmental disability to the same level of health and mental health care as the rest of the population. We promote a standard of excellence in clinical practice, research, workforce development, education and policy in the field of intellectual and developmental disability mental health.

Context for the Strategic Plan

There are an estimated 300,000 to 400,000 people with an intellectual disability in Australia, and many more with developmental disabilities. Despite experiencing a higher rate of mental illness compared with the general population, people with an intellectual or developmental disability are far less likely to access appropriate mental health services compared to those without an intellectual or developmental disability. Mental health and disability service systems do not generally work well together, and there is little professional expertise in area of intellectual and developmental disability mental health.

Many of the underlying causes of the poor health status of people with an intellectual or developmental disability derive from the social environment in which they live, including health care systems. Recognition of these social determinants of health provides a strong impetus for actions to

improve the quality and accessibility of mental health services for people with an intellectual or developmental disability.

In 2008, Australia ratified the United Nations Convention on the Rights of Persons with Disabilities, outlining its commitment to achieving the highest standard of health care attainable for people with a disability. Realising this right to health care, and responding to health inequities, requires concerted action and investment in research, policy, services and workforce development.

Now more than ever, health care providers must be able to respond to people's individual needs, and collaborate across sectors. This level of response is called for at a national level, with major reform in the disability service system resulting in an increased emphasis on the individual needs and choices of people with a disability.

Against this backdrop, 3DN has evolved as a leading academic department in the area of intellectual and developmental disability mental health in adults. This plan sets out our strategic approach to significantly improve mental health policy and practice for people with an intellectual or developmental disability.

Our Strategic Plan shows our activity in the areas of consultancy, building capacity and research. These three areas are mapped against the level of impact of our work (people, the workforce, systems and policy).



SP1. Improve mental health outcomes for people with an intellectual or developmental disability.

- **1.1** Deliver interventions and education to people with an intellectual or developmental disability and their carers.
- **1.2** Deliver clinical consultations.
- **1.3** Produce diagnostic tools.
- **1.4** Document the experience of people with an intellectual or developmental disability and their carers.
- 1.5 Develop clinical services.
- **1.6** Deliver mental health promotion and prevention initiatives.
- 1.7 Build an epidemiological profile of people with an intellectual or developmental disability and mental health issues, including more accurate prevalence statistics.
- **1.8** Investigate specific neuropsychiatric disorders in people with an intellectual or developmental disability.
- 1.9 Analyse the impact of ageing and dementia in people with an intellectual or developmental disability and identify predictors of healthy ageing.

SP2. Increase the knowledge, skills and confidence of the health workforce to deliver quality care and support to people with an intellectual or developmental disability.

- **2.1** Develop a competency framework for the mental health workforce.
- **2.2** Encourage the recruitment of appropriately skilled professionals in health and disability services.
- **2.3** Create authoritative, good quality, accessible education and training resources.
- 2.4 Engage in teaching in intellectual and developmental disability mental health at the undergraduate, postgraduate and community levels.
- **2.5** Analyse the training needs of the health and mental health workforce.

SP3. Promote greater integration between disability and mental health systems and improve access for people with an intellectual or developmental disability.

- **3.1** Analyse current support systems.
- **3.2** Develop pathways to mental health care.
- **3.3** Develop frameworks to guide service delivery.
- **3.4** Foster collaboration and build relationships between agencies.
- 3.5 Raise awareness of the barriers to mental health service access for people with an intellectual or developmental disability.
- **3.6** Investigate the health and mental health service needs of people with an intellectual or developmental disability.
- **3.7** Investigate the health and mental health service use of carers.

SP4. Highlight the importance of intellectual and developmental disability mental health initiatives and funding.

- **4.1** Develop policy and legislative advice and recommendations.
- **4.2** Advocate the implementation of relevant policies and frameworks.
- **4.3** Enhance lobbying success using the improved evidence base resulting from our research activity.
- 4.4 Increase awareness of the health and mental health needs of people with an intellectual or developmental disability.
- 4.5 Build the evidence base in the field of intellectual and developmental disability mental health, including the collection and collation of accurate epidemiological data and the publication of high quality work in peer-reviewed journals.

Strategic Priorities

	Research	 1.7 Build an epidemiological profile of people with an intellectual or developmental disability and mental health issues, including more accurate prevalence statistics. 1.8 Investigate specific neuropsychiatric disorders in people with an intellectual or developmental disability. 1.9 Analyse the impact of ageing and dementia in people with an intellectual disability and intellectual disability and identify predictors of healthy ageing. 	2.5 Analyse the training needs of the health and mental health workforce.
Objectives	Building capacity	1.5 Develop clinical services.1.6 Deliver mental health promotion and prevention initiatives.	2.3 Create authoritative, good quality, accessible education and training resources. 2.4 Engage in teaching in intellectual and developmental disability mental health at the undergraduate, postgraduate and community levels.
	Consultancy	 1.1 Deliver interventions and education to people with an intellectual disability or developmental disability and their carers. 1.2 Deliver clinical consultations. 1.3 Produce diagnostic tools. 1.4 Document the experience of people with an intellectual or developmental disability and their carers. 	2.1 Develop a competency framework for the mental health workforce. 2.2 Encourage the recruitment of appropriately skilled professionals in health and disability services.
Level of	impact	People	Workforce
Stratonic Drioritu	חומנים ויחונים	SPI. Improve mental health outcomes for people with an intellectual or developmental disability.	SP2. Increase the knowledge, skills and confidence of the health workforce to deliver quality care and support to people with an intellectual or developmental disability.

	Level of		Objectives	
און סובלור בווחוור	impact	Consultancy	Building capacity	Research
		3.1 Analyse current support systems.	3.5 Raise awareness of the barriers to mental health service	3.6 Investigate the health and mental health service needs of
SP3. Promote greater integration between disability and mental health services and improve		3.2 Develop pathways to mental health care.	intellectual or developmental disability.	people with an intellectual or developmental disability 3.7 Investigate health and mental
access for people with an intellectual or developmental disability.	Systems	3.3 Develop frameworks to guide service delivery.		health service use of carers.
		3.4 Foster collaboration and build relationships between agencies.		
		4.1 Develop policy and legislative advice and recommendations.	4.4 Increase awareness of the health and mental health needs of	4.5 Build the evidence base in the field of intellectual and
SP4. Highlight the importance of intellectual disability mental	Policy	4.2 Advocate the implementation of relevant policies and frameworks.	developmental disability.	health, including the collection and collation of accurate epidemiological data and the publication of high quality work in
		4.3 Enhance lobbying success using the improved evidence base resulting from our research activity.		peer-reviewed journals.

Definitions

· 'Consultancy'

includes clinical work, delivering interventions, sharing expertise, giving advice, advocacy and collaborations.

'Building capacity'

includes teaching, training, aspects of health promotion, development of educational resources and other professional development activities.

· 'Research'

includes studies and data analysis, or the development of policies, frameworks and tools.

· 'People'

refers to people with an intellectual or developmental disability and their carers and family members.

'Workforce'

includes the mental health, health and disability workforces.

'Systems'

includes disability and mental health services and others that these have an interface with.

'Policy'

refers to the frameworks which outline how systems should work and how services should be delivered.

