



Council for
Intellectual Disability

SOME STEPS UP THE MOUNTAIN

Audit report on action from the National Roundtable on the Mental Health of People with Intellectual Disability

November 2014

Prepared by

NSW Council for Intellectual Disability (NSW CID) in collaboration with the
Department of Developmental Disability Neuropsychiatry UNSW,
Queensland Centre for Intellectual and Developmental Disability, and
Australian Association of Developmental Disability Medicine



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EXECUTIVE SUMMARY

The problem

The research shows that people with intellectual disability have very high rates of mental disorders but poor access to mental health care. When there is access to care, the care is often not appropriate. Mental health professionals lack training and lack access to specialists in intellectual disability mental health. Diagnosis is often very challenging.

Often, mental health and disability professionals need to collaborate closely to work out appropriate responses to challenging behaviour of a person with intellectual disability.

Poor mental health for people with intellectual disability has considerable cost to individuals and to governments. This includes considerable cost to the health and disability budgets, notably including the National Disability Insurance Scheme.

A range of key national policy initiatives support action on the mental health of people with intellectual disability.

The Roundtable

The Roundtable was funded and supported by the Australian Government Department of Health and Ageing and brought together 95 leaders in mental health, disability and related spheres from around Australia. This included the senior mental health public servants and/or chief psychiatrists from the Commonwealth, States and Territories. The Roundtable occurred in May 2013.

Roundtable participants supported eight key elements of an effective system of mental health care for people with intellectual disability. These cover:

1. Inclusion of intellectual disability mental health in all mental health initiatives.
2. Prevention and timely intervention.
3. Equitable access to, and skilled treatment by, mental health services.
4. Specialist intellectual disability mental health services to support mainstream services.
5. Collaboration between disability, schools, mental health and other agencies.
6. Workforce education and training.
7. Enhanced data collection.
8. Addressing contributors to multiple disadvantage.

The audit

The audit survey sought from Roundtable participants a report on action on the eight key elements of reform in the 12 months following the Roundtable.

A wide range of incremental actions have been taken over the last year and across the eight key elements of reform. Most of these are valuable but limited and/or local. Some of the more significant actions are:

- Launch of *The Guide: Accessible mental health services for people with intellectual disability* – Provides detailed guidance to mental health practitioners and services.
- Incremental expansion of availability of specialists and trainees in intellectual disability mental health in some States.
- Stepping Stones – Positive parenting for parents of children with disability – Trial program aimed at reduced emotional and behavioural problems.
- Various training initiatives including online learning for GPs and psychiatrists and an intellectual disability mental health e-learning platform.

In all the mainland States, there has been at least some systematic consideration of reforms that can be made.

Where to from here?

The challenge now is for Government agencies, professional associations and others both to continue incremental action and to incorporate that into systematic and holistic action on the eight key elements of reform.

Current opportunities for action include:

- Using the design and trial sites of the NDIS to establish robust systems for collaboration between the NDIS and mental health services.
- The review of mental health services and programs currently being finalised by the National Mental Health Commission.
- The pending 10 year strategic plan for mental health in NSW.
- Building on the range of Statewide initiatives currently on foot in WA and Queensland.
- Action by mental health services to implement *The Guide: Accessible mental health services for people with intellectual disability*.
- Action by the NDIS and others to facilitate better take up on Medicare annual health assessments for people with intellectual disability.
- Capitalising on the momentum within the RANZCP to develop the intellectual disability Interest Group into a College Section.

THE PROBLEM

Between 1% and 3% of the population has an intellectual disability. Established risk factors for mental disorders commonly exist for people with intellectual disability including social exclusion and isolation, poverty, contact with the criminal justice system, misuse of drugs and alcohol, poor physical health, physical disability and intellectual disability itself.

The research indicates that, at any one time, between 20% and 40% of people with intellectual disability have mental disorders, including schizophrenia being 2-4 times more prevalent than in the general population.

The research evidence on the mental health of people with intellectual disability shows:

- poor access to mental health care,
- frequent errors in diagnosis,
- psychiatrists and GPs perceiving themselves to be inadequately trained and
- psychiatrists perceiving people with intellectual disability as receiving a poor standard of mental health care.

The impact of an intellectual disability on a person's functioning varies greatly from person to person and will be increased if the person also has a mental disorder. An intellectual disability impedes a person's ability to access health care.

Mental health services need to accommodate mental health needs and disability services focus on disability support needs.

It is often very difficult to diagnose a mental disorder of a person with intellectual disability. Challenging behaviour of people with intellectual disability can have various contributors including unmet communication and environmental needs and mental disorders. It is often very difficult to determine the exact contributors. Disability and health professionals have complementary and interconnected roles in assessing and responding to challenging behaviour. A multidisciplinary approach is often vital to addressing complex challenging behaviour.

NATIONAL POLICY FRAMEWORK

A range of key national policy initiative support national action on the mental health of people with intellectual disability - in particular, the National Disability Insurance Scheme (NDIS), National Roadmap for Mental Health Reform, the National Disability Strategy and its underpinning UN Convention on the Rights of Persons with Disabilities

THE COST OF INACTION

As well as the human cost of poor mental health to people with intellectual disability and their families, there is great cost to governments:

- Financial cost for the disability services sector due to increased support needs of a person with an intellectual disability plus a mental disorder and psychosocial disability. This cost will be particularly clear in the entitlement based National Disability Insurance Scheme
- Financial cost to the health sector due to inadequate mental health prevention, early intervention and treatment so that a condition becomes chronic and/or acute
- Financial cost to the justice system related to offending behaviour
- Financial cost to the economy and taxation revenue due to reduced employment for people with intellectual disability and family members.

For more detail and references in relation to all of the above issues, see the Roundtable Background Paper at www.nswcid.org.au/standard-english/se-pages/health.html

THE ROUNDTABLE

Participants

The Roundtable was held in Canberra on 22 May 2013 and brought together 95 participants from around Australia. Representation included:

- The senior mental health public servants and/or chief psychiatrists from the Commonwealth, States and Territories.
- The Chair and CEO of the National Mental Health Commission.
- The Presidents of the RANZCP and RACGP, and of the Paediatric and Child Health Division of the RACP, and senior representatives of other professional associations.
- Senior representatives of disability, school education and justice health agencies.
- Parents, advocates and professionals with expertise in the mental health needs of people with intellectual disability.

The Roundtable was funded and supported by the Australian Government Department of Health and Ageing.

The full list of participants is in the Roundtable Communiqué at www.nswcid.org.au/standard-english/se-pages/health.html

Roundtable Outcomes

The Roundtable Communiqué sets out eight key elements of an effective system of mental health care for people with intellectual disability. These elements are set out in full in Appendix A and cover:

1. Inclusion of intellectual disability mental health in all mental health initiatives.
2. Prevention and timely intervention.
3. Equitable access to, and skilled treatment by, mental health services.
4. Specialist intellectual disability mental health services to support mainstream services.
5. Collaboration between disability, schools, mental health and other agencies.
6. Workforce education and training.
7. Enhanced data collection.
8. Addressing contributors to multiple disadvantage.

The Communiqué also provides a menu of priority actions that Roundtable participants and their agencies could take towards the achievement of the key elements.

THE AUDIT

Audit process

The audit occurred in July to September 2014. Its purpose was to establish what action had occurred to improve the mental health of people with intellectual disability since the Roundtable. The audit survey sought from each Roundtable Participant a report on actions on the eight key elements of reform. The survey form is at Appendix B.

29 participants or their organisations responded to the survey comprising:

- The Commonwealth Department of Health
- The Government mental health agencies in NSW, Victoria and Western Australia
- Professional colleges and associations - Royal Australian College of General Practitioners, Royal Australian and New Zealand College of Psychiatrists, Australian College of Rural and Remote Medicine, Australian College of Mental Health Nursing, Australian Association of Developmental Disability Medicine, Australian Society on Intellectual Disability, Professional Association of Nurses in Developmental Disability Australia
- Psychiatrists with expertise in intellectual disability mental health (8)
- Disability advocacy groups (4)

- Disability service provider organisations (3)
- Other government agencies – education and justice health (2)

NSW CID also obtained relevant information in a less formal form from a range of other agencies and sources. This complemented the survey responses to provide a reasonably comprehensive national picture of action since the Roundtable.

The full results from the audit are at *Collation of Survey Responses*.

Key findings

A wide range of incremental actions have been taken by Roundtable participants over the last year and across the eight key elements of reform adopted at the Roundtable. Most of these are valuable but limited and/or local. More significant actions include:

- The Queensland Roundtable on the Mental Health of People with Intellectual Disability (Organised by National Disability Services Qld, Queensland Centre for Intellectual and Developmental Disability and others)
- The NSW Mental Health Commission including a clear focus on intellectual disability mental health in its preparation of the draft Strategic Plan for Mental Health in NSW. The Commission's *Living Well* report includes a specific section on intellectual disability with findings and proposals very similar to those from the Roundtable. The NSW Government's release of the Strategic Plan is awaited.
- Stepping Stones – Positive parenting for parents of children with disability – Trial program aimed at reduced emotional and behavioural problems. (Queensland, Monash and Sydney Universities)
- Launch of *The Guide: Accessible mental health services for people with intellectual disability* – Provides detailed guidance to mental health practitioners and services to accommodate people with intellectual disability. (Department of Developmental Disability Neuropsychiatry UNSW)
- Incremental expansion of availability of specialists and trainees in intellectual disability mental health in some States, including with support from the Commonwealth Specialist Training Programme.
- Significant enhancement of collaborative actions between mental health and other agencies.
- Various training and resource initiatives including online learning for GPs and psychiatrists (RACGP, Queensland groups and RANZCP), an intellectual disability mental health e-learning platform (Department of Developmental Disability Neuropsychiatry UNSW), development of IDMH competencies frameworks in NSW and WA.
- Partnerships for Better Health Project – This NHMRC funded linkage project is led by the Department of Developmental Disability Neuropsychiatry UNSW and aims to:
 - Create an annualised linkage of administrative minimum datasets between mental health and other agencies in NSW.

- Analyse Commonwealth and State mental health policy with a view to enhancing its inclusion of intellectual disability mental health.
- Engage with consumers and family and non-family carers to inform improved action on intellectual disability mental health.
- Determine an evidence-based approach to intellectual disability mental health service development, policy and reform.

In all the mainland States, there has been at least some systematic consideration of reforms that should and can be made.

Many local and incremental initiatives have occurred within existing resources. More major initiatives have flowed from specific funding by Governments.

Some negative changes are reported associated with general health and welfare initiatives of the Commonwealth Government and State budget cuts. Also, activity based funding may negatively impact on people with intellectual disability unless there is a funding loading for this group.

Many survey participants commented on the NDIS, some positively and some sceptically. Some intellectual disability psychiatrists in NSW were concerned about their State Government's plan to cease being a disability service provider once the NDIS is fully in place. The psychiatrists were concerned about the loss of structures and expertise that exist in Ageing, Disability and Home Care NSW (ADHC) to address complex challenging behaviour and work collaboratively with mental health services. Also, what will become of some health initiatives that are funded by ADHC, including the Chair in intellectual disability mental health, many regional outreach clinics by specialist intellectual disability psychiatrists and advanced trainee positions in intellectual disability psychiatry?

Factors reported as driving positive change in intellectual disability mental health included raised awareness and visibility of the issue, increased collaboration across the sector from advocacy to professionals, the long term commitment of leaders in intellectual disability mental health and the Roundtable itself.

WHERE FROM HERE?

The challenge now is for Government agencies, professional associations and others both to continue incremental action and to incorporate that into systematic and holistic action on the eight key elements of reform.

Some things are particularly clear:

- Unless people with intellectual disability are squarely considered in each and every mental health reform, there is a high probability that the reform will not take account of their particular needs – that is the lesson of the history of recent decades.

- Continued and concerted action is required across all of the eight key elements of reform.
- Specialist intellectual disability health services are vital to driving and informing reform across the eight elements. A high proportion of the advances that have occurred in recent years have been driven or informed by the expertise in those services.
- Systemic advocacy for people with intellectual disability also has had a vital role in raising the profile of intellectual disability mental health including in the leadership of the Roundtable. With changes related to NDIS implementation, the future of that advocacy is uncertain and needs to be assured.

There are great opportunities flowing from the implementation of the NDIS and the National Disability Strategy with its expectation on health services to much better accommodate people with disability. The combination of these reforms can lead to much better disability support, better mental health support and better collaboration between service systems. However, this will not just happen. It will require concerted action by relevant agencies at national, state/territory and local levels.

NSW CID recently conducted a national conference, *Getting the Best from the NDIS, Making it work for people with intellectual disability*. The conference report highlights issues needing to be addressed to ensure the NDIS works well for people with intellectual disability.

www.nswcid.org.au/standard-english/se-pages/past-events.html

“Key messages” from the conference included:

Meeting complex needs

Comprehensive, person centred, active support is the basis for meeting complex needs.

Robust systems are needed so that skilled professionals can be identified, accessed and act as a close knit team.

Historically, State/Territory disability agencies have developed systems to meet complex and specialist needs. The NDIA should identify and ensure the maintenance of key functions of these systems in a form appropriate to the NDIS environment.

Ensuring good health care

Strong collaboration between disability and health services is key to addressing the stark inequalities in physical and mental health experienced by people with intellectual disability.

NSW and some other State/Territory Government disability services fund vital health services for people with intellectual disability. Unless the Commonwealth

Government commits to continuing these services, they and their funding should be brought under State/Territory health agencies.

The initial roll-out of the NDIS in trial sites around Australia is an opportunity for the NDIA and local health services to establish robust systems to meet the needs of people who have complex challenging behaviour and mental health needs. These should include a specialist intellectual disability mental health capacity.

Some other current opportunities for action are:

- The review of mental health services and programs currently being finalised by the National Mental Health Commission.
- The pending 10 year strategic plan for mental health in NSW. In keeping with the plan's precursor, the *Living Well* report, the strategic plan should include action on each of the Roundtable key elements of reform.
- Building on the range of Statewide initiatives currently on foot in Western Australia and Queensland.
- Action by mental health services to implement *The Guide: Accessible mental health services for people with intellectual disability*.
- Enrolment of people with intellectual disability for eHealth records – either by the person with disability or by a family member or other authorised representative.
- Action by the NDIS and others to facilitate better take up on Medicare annual health assessments for people with intellectual disability.
- Implementation of the nationally consistent collection of data on school students with disability, which will take place in all Australian schools from 2015 education.gov.au/nationally-consistent-collection-data-school-students-disability
- Capitalising on the momentum within the RANZCP to develop the intellectual disability Interest Group into a College Section.

Further development of intellectual disability mental health specialists is a key driver of ongoing change. This could occur in a range of forms including State wide consultancy capacities, intellectual disability mental health programs in NDIS trial sites and a national centre of excellence.

COLLATION OF SURVEY RESPONSES

1. What initiatives have occurred in your sphere since May 2013 to improve the mental health of people with intellectual disability?

Element 1 - Inclusion in all mental health initiatives

Inclusion in the development of the draft Strategic Plan for NSW

The NSW Mental Health Commission has prepared this draft plan which sets out a 10 year vision for reform of mental health services. The Commission ensured strong input from the ID sector via:

- A survey of over fifty disability organisations and
- Interviews with three people with ID/mental illness and three carers.
- Consultation with the ID Network of the Agency for Clinical Innovation in NSW Health

The Commission has released a report that is a precursor to the plan – *Living Well: Putting People at the centre of mental health reform in NSW*. This report includes a specific section on intellectual disability with findings and proposals very similar to those from the Roundtable. nswmentalhealthcommission.com.au/

Queensland Roundtable on the Mental Health of People with ID

Attended by approximately 40 people from key health, disability, education, consumer and community service organisations.

(Organised by National Disability Services Qld and others)

www.ndsqldprojects.net/mental-health-roundtable.html

eHealth records

Information and a procedure are now available for family members and others to become authorised representatives for people with intellectual disability who do not understand eHealth decisions. The representative can then register the person for an eHealth record.

www.ehealth.gov.au/internet/ehealth/publishing.nsf/content/resources

www.ehealth.gov.au/internet/ehealth/publishing.nsf/Content/faqs-individuals-authorized-reps

Options are also being explored to allow public guardians/advocates to become authorised representatives.

(Commonwealth Department of Health)

National Recovery Oriented Mental Health Framework

The Framework is inclusive of people with intellectual disability and implementation is a matter for individual sectors based on local needs.

(Commonwealth Department of Health)

Submissions to Queensland Mental Health Act Review

(NDS Qld and others)

Consumer advice to NSW Health

Inclusion of a member with ID on the Consumer Sub-committee which provides advice to the NSW Mental Health Program Council.

(NSW Health)

Submissions to the National Mental Health Commission's Review of Mental Health Services and Programmes

For example, the RACGP expressed concern that the 'Access to Allied Psychological Services (ATAPS)' and 'Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access)' initiatives do not cater to the mental health needs of people with an ID. Investment is needed in resources for GPs and specialist education and training.

Element 2 - Prevention and timely intervention

Stepping Stones – Positive parenting for parents of children with disability

Trial program aimed at reduced emotional and behavioural problems.
(Professors Tonge and Einfeld and others)

GP annual health assessments

- Residents in funded supported accommodation in Victoria are now required to have an Annual Health Assessment (MBS 703, 705, 707) with their GP. (Department of Human Services Victoria)
- Video resource for people with ID about use of the CHAP tool for annual health assessments. (National Disability Services Qld and Queensland Centre for Intellectual and Developmental Disability with funding from Gold Coast Medicare Local)

Expansion of ID health clinics in NSW

Health and mental health clinics have been extended to regional schools, to regional group homes and to Juvenile Justice accommodation. These clinics provide early intervention and reduce presentation to hospitals and to police.
(Kogarah Developmental Assessment Service)

Development of School Kit

On-line guidance for teachers, parents and service providers about health-related resources available to children with ID at school.
(Kogarah Developmental Assessment Service)

Hospitalisation project

Protocols are being developed for prevention of presentation to hospital of those with ID, to establish protocols and procedures for those that do present and to educate front line medical staff about autism and ID.
(Kogarah Developmental Assessment Service)

Development of trauma informed protocols

Many with ID have traumatised backgrounds which go largely unrecognised. Protocols are being established to sensitise service providers to trauma issues.
(Kogarah Developmental Assessment Service)

School-Link magazine

Articles on mental health of people with ID, including articles on responsibilities and rights for carers accessing the health system and on pathways to care for challenging behaviour and mental health.
(Children's Hospital at Westmead)

Family and clinical services education

Education days for family and other clinical services with focus on timely interventions.
(Queensland Centre for Intellectual and Developmental Disability)

Early identification in Queensland schools

Education Queensland is establishing a process to support early identification of students who have psychological/psychiatric issues.

Advocacy support to assist with self determination

(Canberra Men's Centre)

Position Statement - Early Intervention for Children with Developmental Disabilities

This RACP position calls for a rethink around the provision of early intervention services for children with disabilities in Australia. The position statement makes recommendations including:

- Equity of access to intervention and other services, irrespective of the medical diagnosis of a child with a disability;
- Ensuring services are aligned with the United Nations Convention on the Rights of the Child and the Convention on the Rights of People with Disabilities; and
- Ensuring a coordinated, planned, family-centred approach that reflects a longer term approach to health and wellbeing outcomes.

Element 3 - Equitable access to, and skilled treatment by, mental health services

Launch of The Guide: Accessible mental health services for people with ID

Provides detailed guidance to mental health practitioners and services to accommodate people with an ID. The Commonwealth Department of Health funded The Guide and describes it as “a resource expected to support frontline mental health providers, including those funded to deliver Commonwealth programs, to improve accessibility and service delivery to improve mental health outcomes of people with intellectual disability”.

(Department of Developmental Disability Neuropsychiatry UNSW)

3dn.unsw.edu.au/

Competencies for mental health workers

A draft of competencies in ID mental health for NSW mental health workers has been developed for consultation. This manual will assist mental health workers to understand their roles and responsibilities when working with people with ID.

(Department of Developmental Disability Neuropsychiatry UNSW)

Inclusion in draft Strategic Plan for mental health in NSW

(NSW Mental Health Commission)

Accessible justice health services in NSW

A project to consider how services can be more accessible to people with cognitive disability including considering legislative change and preparing the agency for the NDIS.
(Justice Health and Forensic Mental Health Network NSW)

Models of care in WA

In collaboration with other agencies and carers, the MHC WA is developing evidence based models of care for individuals with developmental disabilities and mental health problems. This includes examination of the workforce and infrastructure requirements to implement the models of care.

(Mental Health Commission WA)

WA Disability Health Network

This network has supported the introduction of disability liaison positions in health services. Also, options are being identified to better support people with disability and mental health problems to access public hospitals.

(Mental Health Commission WA)

Building capacity in Victoria

Report titled *Building Capacity to Assist Adult Dual Disability Clients Access Effective Mental Health Services*. (Office of the Senior Practitioner)

www.dhs.vic.gov.au/about-the-department/our-organisation/organisational-structure/our-groups/office-of-professional-practice/research-and-evaluation-opp/disability-building-capacity-to-assist-adult-dual-disability-clients-access-effective-mental-health-services

An officer from the Office of the Senior Practitioner has been seconded to the Chief Psychiatrist to advise on action.

Action in Hunter New England mental health services

- Strategic plan includes to close the gap on ID mental health.
- Recruiting CNC (Disability) to support staff and clients.
- Admission assessments being done by senior psychiatrists.
- Working with the NDIA to maintain action on the MOU with Ageing, Disability and Home Care NSW.

Telehealth video consultations

With other medical organisations, the RACGP has recently developed new guidelines to support the interprofessional collaboration between GPs and other specialists by telehealth video consultations. Telehealth can provide opportunities for individuals with an intellectual disability to receive convenient and accessible treatment.

Online guidelines for GPs

Developing online guidelines for the assessment and management of behaviours of concern in people with ID.

(RACGP with Centre for Developmental Disability Health Victoria and others)

Element 4 - Specialist IDMH services to support mainstream mental health services

Commonwealth Specialist Training Programme

Psychiatry is a priority for 2014. A broad definition will continue to ensure that intellectual disability psychiatry is eligible for funding

(Commonwealth Department of Health)

ID Mental Health Team in Townsville

New small team within public mental health unit - 0.1 consultant psychiatrist, 0.1 registrar, 0.5 team leader – previous dual disability coordinator position.

Registrar at QCIDD

Full time positions in 2014 and 2015. Funded by Commonwealth Specialist Training Program. With psychiatrist, provides specialist ID mental health service and supports mainstream disability and mental health services.

(Queensland Centre for Intellectual and Developmental Disability)

Rural access to a specialist

Monthly psychiatrist telehealth to New England Area of NSW. GP participates and learns.

(Reported by Dr McIntyre)

Expansion of psychiatric service at Centre for Disability Health SA

Increases the capacity to provide services and to consult with and provide education to mainstream mental health services and advocate for individuals with ID and mental health disorders.

Outreach specialist psychiatry in Tasmania

TazReach administers the federal specialist rural outreach program in Tasmania. This program has funded an outreach service in the north and south of Tasmania for 12 annual visit by psychiatrists specialising in ID. This service provides access to psychiatric assessment to people who would not otherwise access mental health services, in particular those with neurobehaviour problems rather than a distinct mental illness such as a psychotic or serious mood disorder. The service also provides diagnostic clarification and clinical support to mainstream mental health services. At times, registrars and medical students attend for the day or for a rotation.

(Reported by RANZCP)

Children's Hospital at Westmead

- Specialist consultation and training - Support for pilot ID health teams and training paediatric trainees and senior trainees in ID psychiatry. Includes an STP funded position.
- New clinical psychologist for Autism Intervention

Kogarah Developmental Assessment Service

- Secondment of psychiatrist trainees and fellows to specialist ID health service – Develops skills and some have gone on to establish a career in ID mental health.
- Expanded liaison with mental health services occurs through ED, general wards and in MH inpatient units – In SE Sydney and the Illawarra

Giant Steps Autism School Sydney

Privately-funded psychiatry clinics.

Specialised skills in justice health in NSW

One psychiatric registrar has recently completed the ID mental health fellowship and another has just commenced. The service has also identified staff who have training and experience in intellectual disability.

(Justice Health and Forensic Mental Health Network NSW)

Step down hospital units

Victorian government initiative to develop 2 new 10 bed units step (one at The Austin Hospital and the other at Monash Medical Centre) for people with complex mental illness combined with ID or acquired brain injury. Focusing on a long term therapeutic and recovery focused residential environment and providing an avenue for long term staged progression for rehabilitation into the community.

Special working group of GPs with an interest

Being established as a first step towards a possible Chapter in the RACGP.

Regular dual disability group meetings in SA

(Reported by SA CID)

WA proposed model of care

Includes a small specialist team.

(Reported by Developmental Disability WA)

Element 5 - Collaboration between disability, schools, health and other agencies

Interface between health services and the NDIS

The Commonwealth Department of Health continues to work with the Department of Social Services and the National Disability Insurance Agency in relation to the interface between mental health and the National Disability Insurance Scheme. Similar work is occurring with State/Territory health agencies.

Positive review of partnership tertiary service in NSW

Joint service of Children's Hospital at Westmead, Statewide Behaviour Intervention Service of Ageing, Disability and Home Care and Department of Education - Very complimentary external stakeholder review, recommending enhancement of funding to have a more significant statewide impact.

(Reported by David Dossetor)

Stepping Stones Pilot

Collaborative project between Ageing, Disability and Home Care NSW, the Department of Education and Communities and the Children's Hospital Westmead. The Stepping Stones pilot involved the roll out (and evaluation) of the *Triple P Group Stepping Stones Program* across a number of Schools for Specific Purposes in NSW. This program aims to decrease problem behaviours through a positive behaviour support approach and is co-delivered in each school by practitioners from DEC and ADHC or DEC and Health.

(Response by Ageing, Disability and Home Care NSW)

Cross departmental working group Qld

Education, Health and Disability - Joint action team to identify referral and treatment pathways and framework and capacity for collaborative responses to the needs of people with ID and mental disorders. (Response by NDS Qld)

WA Disability Health Network

The Network is establishing working parties to improve outcomes in relation to workforce development, care co-ordination, and transitioning from youth to adult services.
(Response by Mental Health Commission WA)

NDIS trials in WA

The needs of people with ID and mental illness have been considered in the planning and implementation of the Western Australian My Way and NDIS initiatives. This has increased the focus on people with ID and mental health problems.

(Response by Mental Health Commission WA)

Outreach specialist psychiatry in Tasmania

The outreach service is a joint initiative of disability and mental health services and provides services to both sectors.

(Response from RANZCP)

Interagency working group in SA

Conducted workshops and consultations on issues for people with ID and mental health issues. Report to government mental health and disability executives.

Rural and Remote Education blueprint NSW

Set out planned actions over 2014-2016. These include establishment of networked specialists to improve support for schools in meeting the needs of students with complex needs, including mental health.

www.det.nsw.edu.au/media/downloads/about-us/our-reforms/rural-andremoteeducation/randr-blueprint.pdf

(Dept of Education and Communities)

Principles for Collaboration, Communication and Cooperation between Mental Health Service Providers

Outlines general principles to support referral and the sharing of care between services in the private sector.

(Written by the Private Mental Health Alliance and approved by the RACGP.)

Giant Steps Autism School specialist paediatric and psychiatry clinic

This has demonstrated the essential partnership between education and medical specialists to meet the needs of children with extremely high needs in Sydney.

(Reported by David Dossetor)

Establishment of partnerships in St George area of Sydney

Regular ID mental health meetings involve disability, mental health and ID health services and police to discuss mutual clients. Similar partnership is being developed in the Illawarra.
(Kogarah Developmental Assessment Service)

Extension of school based clinics

MH clinics in schools have been extended to more SSPs as well as to mainstream schools with special classes.

(Kogarah Developmental Assessment Service)

School kit

In partnership with the Dept of Education and Community, a website has been developed to inform people of available health services. (Kogarah Developmental Assessment Service)

Element 6 - Workforce education and training

Launch of IDMH e-learning platform

E-Learning for mental health and other professionals

Modules cover:

- Introduction to ID
- Living with ID
- Changing perspectives on ID
- Mental Disorders in ID
- Communication: the basics
- Improving your communication
- Assessment of mental disorders
- Management of mental disorders.

Further modules will follow. The platform has had very high uptake and user satisfaction.
(Department of Developmental Disability Neuropsychiatry UNSW)

Development of IDMH Core Competencies Manual for NSW mental health staff

This Manual aims to enhance professional development and workforce capacity. The Manual will build on existing core competency/capability frameworks to describe the essential skills and attributes required for the mental health workforce to deliver accessible, high quality mental health care to people with an ID.

(Department of Developmental Disability Neuropsychiatry funded by NSW Health)

Health and ID Symposium and Seminar Series WA

A four day series was held in August 2013 and included one day focused on the mental health of people with intellectual disability to identify the key themes relevant to this cohort.
(Response by MHC WA)

Development of dual disability core capability framework

The framework will support good practice, service collaboration, workforce development and improved service delivery for people with ID and mental health problems. There will be a training program for service providers to develop skills in ID mental health. In November 2014, Dr Mike Kerr, Professor of Learning Disability Psychiatry, Cardiff University, will visit Perth to deliver seminars on mental health and intellectual disability to a range of audiences including families, carers and mental health professionals.

(MHC WA)

Development of the GP mental health education standards 2014-16

Includes new provisions for training providers to develop educational activities that focus on mental health services for specific populations such as people with ID.

(General Practice Mental Health Collaboration which is facilitated by the RACGP)

Development of online modules for GPs on care for individuals with ID

This program will be offered through the online portal GPlearning. Topics related to mental health include managing complex health problems, communication strategies, care planning including GP Mental Health Treatment Plans, challenging/problem behaviours and prescription of psychoactive medications.

(RACGP and Centre for Developmental Disability Health Victoria)

GP Active Learning Module

A ten week module available to GPs around Australia. Has been developed with NDS and Queensland Centre for Intellectual and Developmental Disability.
(Response by NDS Qld)

Learning Modules on the RANZCP website

Increases the profile of people with ID and emphasises the role of psychiatrists.
(RANZCP)

Mental health capabilities project

Health Workforce Australia undertook a mental health capabilities project to assist the mental health workforce to have consistent skills and work to a high standard.

Collaboration between nursing associations

Professional Assn of Nurses in Developmental Disability Australia and the Australian College of Mental Health Nurses – Includes exploring a joint conference and greater sharing of information and knowledge.
(PANDDA)

Education conference for disability nurses

Annual conference of PANDDA had a major focus on mental health.

Training in the Disability Standards for Education NSW

More than 42,000 teachers and staff in more than 2,000 NSW public schools have completed training in the Disability Standards for Education since Term 3, 2013. This training is complimented by a range of professional learning options for teachers in identifying and responding to students' diversity.
(Dept of Education and Communities)

Training program for teachers in neurodevelopmental disorders Vic

An increasing number of public and private school teachers have skills in managing children with ID and/or an ASD and in initiating transition plans. (Response by Bruce Tonge)

Expanding training in ASD intervention

Involves emotion based social skills training.
(Dr Dossetor, Children's Hospital at Westmead)

Disability support worker health literacy education

Training package for disability support workers to increase health literacy which includes information about ID and mental health.
(NDS Qld)

Training activities in justice health NSW

There has been a range of activities including education for doctors and disability awareness training for clinical nurse educators and the mental health nurses forum. A survey of all staff identified the education, training and employment backgrounds of staff in the area of ID and is informing an education strategy to improve disability awareness and expertise.
(Justice Health and Forensic Health Network NSW)

STP funding to Tasmania

This funding allows for interstate ID psychiatrists to travel to Tasmania for a teaching session with Tasmanian trainees.

(Response from RANZCP)

CPD sessions for psychiatrists in Tasmania

(RANZCP with federal funding)

ID Mental Health First Aid Manual

An updated version is being prepared along with the development of a young persons' version.

(Ageing, Disability and Home Care NSW)

Pilot of MH First Aid in schools for special purposes

(NSW Health)

Education activities of ID Health Network of Agency for Clinical Innovation NSW

- Sponsorship of local initiatives within LHDs
- Producing four expert opinion videos for, one features a talk on IDMH.
- 2 day course on ID Nursing run with the College of Nursing.

NDS NSW conference 2014

Symposium on ID mental health organised by The Disability Trust.

Element 7 - Enhanced data on mental health needs, access and outcomes

ID mental health data linkage projects NSW

- Project linking the NSW Disability Services- Minimum Data Set with the NSW Ministry of Health Admitted Patient Data Collection and the mortality datasets maintained by the Australian Bureau of Statistics and the NSW Register of Births, Deaths and Marriages, 2005-2012. The objectives were: to use linked data to build a detailed profile of the mental health of people with ID and the interaction between the mental health and disability service systems; to examine mortality rates of people with ID; and to compare these to people without an ID. This project has recently reported to NSW Health and its findings are expected to be published in peer reviewed journals.
- Analysis of linked disability services/ NSW Health data - Will illustrate the mental health profile and service use of people with an ID and allow a comparison with people without ID.
(Department of Developmental Disability Neuropsychiatry UNSW)

NHMRC Partnerships for Better Health Project Grant

This project is led by Department of Developmental Disability Neuropsychiatry UNSW and jointly funded/supported by the NHMRC and various NSW agencies (NSW Health, Ageing, Disability and Home Care, Justice Health and Forensic Health Network, Mental Health Commission, Ombudsman, Public Guardian, NSW Council for Intellectual Disability, Mental Health Review Tribunal NSW and Department of Education and Communities), plus Inclusion Australia and National Disability Services.

The project aims to:

1. Create an annualised linkage of administrative minimum datasets 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 ID, and to enable comprehensive development of ID mental health services in NSW.
2. Analyse Commonwealth and State mental health policy to determine the current representation of people with ID and to establish strategies which will enhance ID mental health policy.
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 ID across the lifespan.
4. Progress to maturity a partnership which develops and applies an evidence-based approach to ID mental health service development, policy and reform across the lifespan.

Project gathering data on in-patients with ID

(Children's Hospital at Westmead, reported by David Dossetor)

Further research on annual health assessments and health diaries in Qld

Research in relation to comprehensive health assessment program (CHAP) and ASK health diary to collect data around mental health needs, access to services and outcomes.
(Queensland Centre for Intellectual and Developmental Disability)

Consumer engagement mapping for mental health services

Brisbane North Medicare Local engaged Health Consumers Queensland to gather data on mental health consumers' engagement with their health services.
(Reported by NDS Qld)

Data collection in Justice Health NSW

Investigation of ways to more accurately and consistently record disability information about its clients.
(Justice Health and Forensic Health Network NSW)

Element 8 - Addressing contributors to multiple disadvantage

Education and Aboriginal students

The Connected Communities strategy and the Rural and Remote Education blueprint include activity that focuses on improved educational outcomes for Aboriginal students, through a strong focus on collaborative partnerships with community and other agencies.
(Dept of Education and Communities NSW)

NHMRC foetal alcohol trial

(Reported by Stewart Einfeld)

ACT Government sector wide dialogue on multiple disadvantage

This is an attempt to reduce the number of individuals sentenced as a result of mental health issues.
(Reported by Gerald Franks)

Correctional services seeking advice on care plans SA

First time advice has been sought consistently on a range of client care concerns.
(Reported by Dept for Communities and Social Inclusion SA)

Liaison with indigenous health and migrant health organisations

Aims to ensure communication channels, inform them of the support available for people with ID and mental illness and make services culturally safe.
(Centre for Disability Health SA)

A specific forensic ID unit in SA

Unit being developed within the forensic inpatient facility, with input from the specialised ID mental health service.
(Reported by Maria Tomasic)

Continued development of Aboriginal mental health workforce

(NSW Health)

Aboriginal Housing and Accommodation Support Initiative (HASI)

Provides community-based accommodation and support throughout NSW for 100 Aboriginal people experiencing mental illness and associated psychosocial disability.
(NSW Health)

2. Are there other significant actions planned for 2014 -2015

Blueprint for Improved Health Services for People with an Intellectual Disability in NSW

(ID Health Network of the Agency for Clinical Innovation, NSW Health)

Continued reform in state schools NSW

Work to better support schools to take proactive, holistic, strengths based and inclusive approaches to the wellbeing of all students. In addition, in 2014 more than 1,700 NSW public schools have taken part in the second stage of the implementation of a new approach to collecting nationally consistent data on school students with disability. The data collection will provide better information about the adjusted learning needs of students with disability.
(Dept of Education and Communities NSW)

RACGP actions

- Continued policy advice to the Commonwealth on matters related to mental health and ID.
- Review of the ID online learning activity offered through GPelearning.

Qld actions from State Roundtable

These include:

- NDS to improve uptake of disability support worker mental health module.
- NDS to work with QCIDD to support CHAP tool being considered as part of intake for NDIS.
- NDS with University of Sunshine Coast – To develop ID module within teaching and develop a clinic.
- QUT to incorporate more ID knowledge in social work program.
- Public Advocate to work with Privacy Commission to develop protocols to share information.
- Participant readiness work for NDIS in Queensland to target and support people with dual disability.
- QCIDD to undertake national advocacy .

- QCIDD anxiety disorders kit.
- Systemic cross sector plans for 2015-2016 for Mental Health and Disability to be submitted to CEOs of HHS.

www.ndsqldprojects.net/mental-health-roundtable.html

Continued action on clients with ID in correctional or forensic services

(DCSI SA)

Development of WA Mental Health, Alcohol and Other Drug Services Plan 2015-2025

Will consider people living with co-occurring conditions as well as those with exceptionally complex support needs.

(MHC WA)

New position in Forensicare Victoria

Nurse Practitioner for people in prisons who have complex mental health needs (including intellectual disability).

(Reported by Aust College of Mental Health Nursing)

ID mental health service regular visits to a major rural region in SA

(Centre for Disability Health SA)

RANZCP initiatives

- The College Congress continues to have a stream on intellectual disability. In 2014 Professor Chris Oliver was Keynote Speaker nominated by the ID Special Interest Group.
- The SIG is represented on the editorial board of Australasian Psychiatry.
- Plans for papers on clinical practice to support the implementation of clinical competencies in the new syllabus for psychiatry trainees.

Department of Developmental Disability Neuropsychiatry UNSW

Projects (funded by NSW Health):

- Launch of the IDMH Core Competencies Manual
- Release of additional modules of IDMH Online learning

3. Has there been any change that is likely to worsen the mental health of people with ID?

Participants listed the following:

Actions of the Commonwealth Government

- Tightening of social security entitlements.
- Medicare co-payment
- Reduced health funding
- Changes to Medicare Locals
- Freeze of Commonwealth funding for Cooperative Research Centres
- Withdrawal of Department of Health funding commitment towards UNSW Partnerships for Better Health project.

Actions by State Governments

- New mental health legislation in Victoria may make it less likely that people with an ID will receive mental health services.
- Termination of some ID mental health facilitator positions in Queensland.

Activity based funding

This may reduce access to health services unless there is a loading for intellectual disability.

NDIS implementation

- Some senior ID psychiatrists had major concerns about the NSW Government's intention to cease being a disability service provider once the NDIS is implemented. The psychiatrists emphasised the expertise in complex challenging behaviour in Ageing, Disability and Home Care (ADHC) and its structures to meet the needs of some people with complex needs. NGOs have limited skills in this area. There is a danger of long term hospitalisation if disability services are not able to meet individual needs. Also, what will become of the mental health partnership between ADHC and NSW Health set out in the Memorandum of Understanding and Guidelines on IDMH, and the structures for implementation of these? NSW Health shared various of these concerns.
- With NSW contracted to hand over all its disability budget to the Commonwealth, what will happen to important mental health initiatives currently funded by ADHC, including the chair in ID mental health and other ID psychiatry clinics?
- Across Australia, the period of transition to the NDIS carries dangers including downsizing of existing disability services.

Vulnerability of academic units in ID health

Vulnerability to escalating costs of operating within a university. One unit has lost a senior psychiatrist and much of its capacity to provide clinical care, education, research and advocacy.

4. Please list any factors that have been key contributors to positive initiatives

Participants listed the following factors:

- **Enhanced collaboration** – At a range of levels and between a range of relevant players including: consumer and family advocacy groups; professional associations; universities; ID health specialists; disability, health, education and justice agencies.
- **Enhanced awareness and visibility of the need** – For example at senior levels of politics, health agencies, amongst psychiatry trainees.
- The **human rights profile** now given to the issue.
- **National Disability Insurance Scheme**
 - The NDIS “has raised the profile of people with disabilities in our community, and confirmed their right to equal access and opportunities in the community” (RACGP)
 - The delineation of responsibilities of the NDIS and of health and justice agencies.
- **Government funding** – For example, for training initiatives, research, leveraging of flexible funding such as the STP program and Rural Outreach Program.

- **Some specific initiatives**
 - The momentum created by the round table
 - The creation and activities of the chair in intellectual disability mental health at UNSW including The Guide and the online education modules.
 - Professional Special Interest Groups
 - The 'Review of the Admission or Referral to and the Discharge and Transfer Practices of Public Mental Health Services within Western Australia' - One of the recommendations related to dual disability and this led to the development of the Dual Disability Core Capability Framework.

- **The commitment of champions** – “A long hard slog by many people over many years” (RANZCP)

The inclusion of people with ID in training activities ensures the relevance of the activity, and reinforces their ability to add their expertise and experience to our understanding and so their ability to contribute to society.
(RACGP)

The creation of the Chair of Intellectual Disability Mental Health at UNSW, funded by Ageing, Disability and Home Care since 2009, has been a key factor, due to the considerable expertise residing in the team at UNSW. The Chair has leveraged other resources into intellectual disability mental health initiatives.

There is a growing awareness of the importance of intellectual disability mental health among people in leadership positions within NSW Health and of the need to better equip the health workforce to work more effectively with people with intellectual disability and mental health problems.
(NSW Health)

5. Please list any factors that have prevented more being done in the last year

Participants listed the following:

- Continued problems with **values, attitudes, skills and demarcations**
- **Funding cuts**
 - The decision to freeze or restrict funding to certain mental health programs such as the GP Psych Support program, a service for GPs through which they could seek the advice of a psychiatrist to assist them to manage complex mental health problems.
 - A national trend towards smaller government.
- **Uncertainty surrounding Commonwealth Review** of Mental Health Services and Programmes.
- **Rate of change** within the disability and health sectors
 - The NDIS impacting upon the capacity of many to give adequate attention to ID mental health.
 - The overwhelming speed and scope of widespread reform tends to count against integration of the needs of people with ID.
- **Increased numbers of people** in the criminal justice and forensic mental health systems.
- **Uptake of the IDMH Online Learning** program in public mental health services – This has been limited with contributing factors possibly being technical infrastructure, time available for professional development and low exposure to people with IDMH on a regular basis. The need for further promotion and to link module completion to continuing professional development points has been flagged. (NSW Health)

6. Do you have any other comments?

There are gains, important gains, but major gaps in care remain. In particular there is a lack of multidisciplinary services (and that includes multi medical disciplinary e.g. psychiatry, general medicine, neurology, in combination with psychology, neuropsychology, speech and language specialists etc). The use of 'othering' language continues. There is a general failure to understand the meaning of equity and reasonable adjustment as well as what constitutes discrimination on the grounds of disability and this is enshrined in some protocols that deny people with ID access to services. This is especially so for people with age related conditions such as dementia who are denied access to mainstream service because they have a disability. (RANZCP)

The Australian Government recognises that mental health is important for the Australian community and is committed to ensuring that mental health services are delivered as efficiently and effectively as possible. It has tasked the National Mental Health Commission to assess the effectiveness of all existing mental health programmes across the government, non-government and private sectors. This process will ensure services are being properly targeted at patients, are not being duplicated, and are not being unnecessarily burdened by red tape. It will also identify any obvious service gaps.

The Commission's deliberations and its final report will inform the Government's future decisions on mental health, including funding arrangements. The Commission's report is due to be provided to the Australian Government on 30 November 2014.

(Commonwealth Department of Health)

The issue of mental health and ID in our criminal justice system is at breaking point. The criminal justice system is being utilised by both the disability system and the mental health system as the default provider of specialist accommodation and care for people who may be declared mentally impaired. This small but significantly important group are being indefinitely detained via the legislatively defined mental impairment process under state based criminal codes. This is a breach of a number of articles under the ICCPR and the CRPD framed around access to justice. There is a larger problem however relating to the numbers of people with dual disabilities in our gaols and psychiatric units who have not come under the mental impairment provisions of the criminal codes and have been dealt with through the criminal justice process as having capacity when in fact they do not. They may have not been identified as having a disability and are not receiving appropriate treatment and support whilst detained and exit prison having not understood what brought them to that place in the first place or have the necessary community supports to prevent them returning to detention.

(Aboriginal Disability Justice Campaign)

APPENDIX A - Key elements of an effective system

1. The needs of people with an intellectual disability and a mental disorder are specifically accommodated in all mental health initiatives.
2. People with intellectual disability and their families receive education and support to prevent mental disorders and to obtain early and timely assistance for mental disorders.
3. All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.
4. A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services - by provision of consultancy and training, and through research.
5. Ongoing joint planning by disability services, schools and mental health and other relevant services including:
 - a. Identification of referral and treatment pathways.
 - b. A framework and capacity for collaborative responses where intellectual disability and mental disorder co-exist.
6. Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.
7. Collection and analysis of data which measures mental health needs, access to services and outcomes of people with intellectual disability.
8. All of these elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, CALD backgrounds and contact with the criminal justice system.

APPENDIX B – Survey questionnaire

NSW COUNCIL FOR INTELLECTUAL DISABILITY National Roundtable on the Mental Health of People with Intellectual Disability Audit on action 12 months on

This survey aims to establish what action has occurred to improve the mental health of people with intellectual disability since the May 2013 Roundtable.

The survey seeks a report on actions on the eight key elements of reform identified in the Roundtable Communiqué. The Communiqué also provided a menu of recommendations for action on each element. www.nswcid.org.au/images/communique.pdf

In your answers to the following questions, please provide information in dot point format including, where possible, web links or references to programs or initiatives you refer to.

1. What initiatives have occurred in your sphereⁱ since May 2013 to improve the mental health of people with intellectual disability?

This question is asked in reference to each of the eight key elements of reform identified in the Communiqué.

Element 1 - Inclusion of people with intellectual disability in all mental health initiatives

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 2 - Prevention and timely intervention

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 3 - Equitable access to, and skilled treatment by, mental health services

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 4 - Specialist ID mental health services to support mainstream mental health services

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 5 - Collaboration between disability, schools, mental health and other agencies

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 6 - Workforce education and training in health, disability and education services

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 7 - Enhanced data collection on mental health needs, access to services and outcomes

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

Element 8 - Addressing contributors to multiple disadvantage, eg Indigenous status and contact with the criminal justice system

Has there been incremental progress on this element in your sphere? **YES/NO**

If yes, list each action on this element in your sphere. For each action, specify how it is a significant reform.

2. Are there other significant actions planned for 2014 -2015 in relation to any of the eight key elements of reform? Please list planned action.

3. Has there been any change that is likely to worsen the mental health of people with intellectual disability? Please list.

4. Please list any factors that have been key contributors to positive initiatives

5. Please list any factors that have prevented more being done in the last year

6. Do you have any other comments?

ⁱ Your sphere' is your agency and others with which you work. The boundaries of your sphere may be imprecise.

However the following examples may assist you:

- The sphere of a State mental health agency would include it and other local agencies with which it needs to collaborate in seeking to meet the needs of people with mental disorders.
- The sphere of a statewide advocacy group is the State in which it is operating.
- The sphere of a national paediatricians group would include itself and the practice of paediatrics around Australia.