

# National Roundtable Report

## The National Roundtable on the Mental Health of People with Intellectual Disability: A Summary.

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A first National Roundtable on the Mental Health of People with Intellectual Disability (PWID) was held in Canberra on 22.5.13 organised by the NSW Council of Intellectual Disability (CID) in partnership with the Department of Developmental Disability Neuropsychiatry University of NSW (3DN), Australian Association of Developmental Disability Medicine and the Queensland Centre for Intellectual & Developmental Disability (QCIDD), with the funding and support from Department of Health and Ageing. The meeting included a focused consultation with 95 recognised leaders in mental health and intellectual disability from consumer and advocacy representatives, health, mental health, disability, education and non-government organisations to develop 'a guide for providers' on 'accessible mental health services for people with intellectual disability', which will be shortly released for wider consultation.

The day was an extra-ordinary gathering, capturing the level of problems and of practical potential developments from significant leaders in the field, which received general recognition by the participants. This is not a minor problem with an estimated 56,000 people with intellectual disability and mental health problems (PWIDMH) in Australia. The day was grounded by the appalling and traumatic personalised experiences of consumers with intellectual disability and their carers, and their accounts of how the services systems failed to provide an understanding or diagnosis of their mental health problems, let alone effective treatment over many years (which may be published elsewhere). Rosemary Huxtable, Deputy Secretary Department of Health and Ageing, emphasised the importance of the National Disability Strategy. One key performance target is for PWID to be able to obtain the highest possible health and wellbeing throughout their lives, and be able to contribute to their community. This policy direction will require all health service providers to meet the needs of this special need population, including timely prevention and early intervention. Universal health reform must address PWID, their families and carers. There is a potential for further funding with the Roadmap for National Mental Health Reform. Professor Allan Fels the Chair of the National Mental Health Commission validated the consumer experiences as common, with poor access to mental health

care and frequent errors in diagnosis. This is in the context of a massively underfunded mental health system, and the broader context of this country's failure to provide an appropriate mental health service for the burden of health need. In the context of the National Disability Insurance Scheme (NDIS) now called DisabilityCare Australia, strategy to up-skill all services, with clear service pathways plus a focus on prevention and promotion of mental health provides a vision which has a capacity to enable all PWID to lead contributing lives and with potential to lower government budgets in disability and health.

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Jim Simpson a lawyer from CID has been an articulate and passionate lead figure in bringing this agenda to wider attention. He identified the components of challenge and the need for change:

1. mental health problems in PWID are difficult to diagnose, with communication problems, atypical presentations and the need to look at the underlying causes of challenging behaviour.
2. PWID have poor access to mental health services, and psychiatrists report self-perceived lack of training and poor quality of care in mainstream services. Thus far funding for the PWIDMH has not been adequately considered.
3. The mental health of PWID also needs to be considered in schools, general practice and paediatrics. All mental health services should provide equitable access, and one service indicator could be the rate of the 'diagnostic cop out' of just 'behaviour problem' instead of careful assessment to recognise mental health problems and identify their treatment.
4. There is a need to recognise a national network of specialists in mental health and intellectual disability and training to back up mainstream services. ACT has a viable model of a small multidisciplinary team of specialists in mental health and intellectual disability that provides both a community based service and supportive in-reach to mainstream mental health services and collaborative relationships with disability services.
5. There should be joint planning between mental health, education and disa-

bility services with clear pathways to service provision and early access to multidisciplinary teams, which is currently a rare experience.

6. Training is required in mental health of intellectual disability in all services.
7. Data is needed on the service provision specifically for those with intellectual disability.
8. There needs to be a focus on multiple disadvantage, including those in poverty, in the criminal justice system, from Indigenous backgrounds and from backgrounds of cultural and linguistic diversity.
9. The NDIS is required to provide appropriate supports, including behaviour support and behaviour therapy, but does not provide clinical mental health services. In April the Council of Australian Governments documented the requirement for all state and territories governments to have inclusive services, specifying inclusion of PWID. They are also obligated to improve interagency interactions with mental health systems as part of the national Roadmap for Mental Health Reform. The NDIS may not fund health and mental health services, but does create an opportunity for change of the health and wellbeing of PWIDMH. The NDIS launch sites will need to develop principles for world standard practices of managing NDIS packages. They must also establish partnerships with health and mental health services, as these may be the most readily changeable contributions to disability.

Currently specialist mental health services for PWID are driven by a few individuals and their vision needs to be ramped up to develop a concerted action in mental health to share a vision of a decent life of PWIDMH.

Prof Nick Lennox, President of the Australia Association for Developmental Disability Medicine and QCIDD has been researching on primary health care for PWID for 21 years. He started by saying that this country, by international standards, has a good primary health care system of equity of access and cost effectiveness. However a focus on the empowerment of PWID will still require system change. Research, including three randomised controlled trials shows that annual health assessments of PWID improve their health. Awareness of the Medicare item of annual health assessments needs to be improved, and reintroduction of the intellectual disability specific Medicare item would allow us to monitor general practice access for PWID. The annual health care assessment also improves relationships with and reduces fear of the health service for PWID. In his research,

general practitioners were extremely motivated to be involved in the health care of PWID, recognising their special responsibilities, and the benefits of continuity of care in general practice. Electronic health records will provide measurable benefit for the complex health issues of PWID. He advocates establishing a website of '60 million health stories' from across the globe to enable consumers and carers to learn from each other, because of the diversity of health and mental health problems for PWID.

Emeritus Professor Bruce Tonge Child Psychiatrist of Monash School of Psychology and Psychiatry reported on some findings from their 25 year longitudinal epidemiological study of the mental health problems of children and youth with intellectual study. Of people with intellectual disability, children and adolescents have 3-4x rates of serious mental health problems compared to mainstream young people, adults 2-3x and the elderly have 2x. The scale of the burden of their mental health problems is greater than that of schizophrenia. Yet less than 10% receive appropriate mental health services as their needs fall between the silos of disability and mental health.

These mental health problems are a key barrier to their problems of social inclusion and participation. These problems start early and persist, therefore we need early intervention. These problems do not follow the same trajectories as mainstream mental health problems because they are substantially biologically driven, as illustrated by our knowledge of behavioural phenotypes. Parents need education of these developmental problems and parenting skills as these behaviours don't respond to intuitive skills. Mostly the causes, such as genetic factors, can't be prevented. Although geography and socio economic factors are important, these problems are escalated by disadvantage such as Indigenous background and are more severe where this is remote. These are associated with additional health difficulties for example epilepsy but this is only where epilepsy is not treated or controlled which is common in remote communities.

PWIDMH are frequently excluded from school, post school options, and employment and where they are employed are subject to injury and worker's compensation. Their mental health problems place an inordinate burden on their families. The services are poorly coordinated. Early intervention is required for all children with developmental disorders, not just for ASD! The evidence base shows this should start with parent education followed with teaching special parenting skills, and additional support for transi-



tions: into school and high school and then into post school placements. We need significant up-skilling of the workforce for PWIDMH, including psychiatrists, psychologists and developmental paediatricians and all front line staff that deal with PWID.

A/Prof Julian Trollor, Chair of Intellectual Disability Mental Health, 3DN, funded by Ageing Disability and Home Care NSW Family and Community Services, presented on his department's initiatives: they aim to build workforce capacity with an on-line educational resource for mental health workers; this includes a survey of mental health staff attitudes and competencies. Since training initiatives aren't coordinated in this country, a national approach is required and the establishment of a virtual network of mental health workers with a special interest in intellectual disability. They are looking at a data linkage study between disability and mental health services to build the evidence on access, inclusion and outcomes of PWID in mental health services. If a human rights foundation provides the right of access to mainstream mental health services, then data will drive the reform.

Maria Tomasic, President of the Royal Australian and New Zealand College of Psychiatry (RANZCP) emphasised the forensic mental health issues: PWID and mental health problems are over-represented in those that commit offences, and also come from socio economic disadvantage, have communication difficulties, are highly suggestible, more likely to be caught, and also more likely to be victims of crime. Intellectual disability,

mental health problems and involvement in the criminal justice system is the triple disability: they are not prioritized, not likely to access appropriate treatment, more likely to be imprisoned and less likely to get remand. They need specific treatments and rehabilitation which needs to be culturally sensitive and involve mainstream mental health services. RANZCP has thus far not included PWID because of the service divide created by the social model of disability services. We have relied on British graduates to bring the specialist psychiatric skills to these shores. In 2011 a college special interest group for PWID was established and the college has introduced a new competency based fellowship that will require all psychiatrists to have training in ID. The college plans that the special interest group should progress to subspecialty status, with the expansion of subspecialist research and services. Developments will depend on funding, but the mainstream services already have responsibility to demonstrate that they provide for this population. The Federal funding through the Health Education Training Institute for Specialist Training Positions in priority areas is ripe for use for developing services for PWID. Initiatives for PWID are overdue in RANZCP and it is the responsibility of the college to meet the needs of community and advocate for needs of PWID. Eddie Bartnik is the first of the Mental Health Commissioners and has been working in Western Australia for two years. He aims to develop community psychiatric services with a transfer of funding from the hospital based services with a greater emphasis on person centred approach, optimism and recovery. Collaboration between

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disability and mental health services needs to be a two way process with shared vision and values and mutual accountability. One problem is that mental health is not a single system, but responses vary according to service and hospitals. The psychiatrist carries so much responsibility for making the decision to admit or discharge, without alternatives of where to discharge patients to. There is no standardisation of admission and discharge processes. All this is underpinned by a mental health service that only has 50% of required funding to function adequately. There is a need for greater involvement by families and carers. With 100 different priorities in such a system, where do you start? The health system priorities are currently driven by the four hour limit rule of admission to an emergency service, waiting lists for surgery and Activity Based Funding, so it is difficult to get PWIDMH on a district health service agenda. There is data confirming that intellectual disability is a significant cost driver to health care, both for in and out patients. If Activity Based Funding is not going to ignore the needs of PWID, then it will need refining with an additional cost fraction for ID as happens for rural and remote and indigeneity. How do PWIDMH with complex needs, whose presentations are getting younger, get a service? How do you scale up the specialist skills of mental health and intellectual disability? It is important to start with those who get stuck in psychiatric hospital for 10 years and bring the best available expertise in. This will involve psychiatric leadership, helping one person at a time!

'The guide for providers of accessible mental health services for PWID' is designed to be suitable for general practice, community health, public and private hospitals, all age mental health services including community, outpatient and inpatient services, criminal justice services, drug and alcohol services and specialist intellectual disability health and mental health services. The principles of service provision focused on: rights, inclusion, person-centred approach, promoting independence, and recovery-orientated practice. The key components of accessible mental health services for PWID included: access to mainstream services, access to specialist ID mental health services, identification of care pathways, training and education for practitioners, interagency collaboration and partnerships, data collection and evaluation and inclusion in policy development. Break out groups specially considered primary care and general health services, public and pri-

vate mental health services, prevention, promotion and early intervention across the life span, with particular attention to practical steps in the education system to meet the needs of PWID. These principles were broadly endorsed. There is still time for fine tuning and wider consultation with a range of important stakeholders. The draft will be made publically available.

The day was summed up by further key lead figures: Liz Marles President of RACGP said that PWID are vulnerable and have additional access problems if they are Indigenous or come from a culturally and linguistically diverse background. GPs need to develop long-term relationships and direct access to and coordinate different resources. Medicare locals with their additional allied health staff may be able facilitate this coordination. The to-do list requires a network of professionals with an interest in ID, increased resources, better education through medical media and promoting the ID Medicare Annual Health Assessment, including social and emotional wellbeing.

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Keith McVilly of the Australian Psychological Society and Principal Research Fellow of Deakin University reiterated the need for a lifespan perspective, from early intervention and education initiatives, to multidisciplinary team collaboration with joint policy statements, from general practice, nursing, psychology, allied health and psychiatry. Progress will be driven by evidence based practice. Behaviour Support is rocket science, in that it needs to be allowed to fly to make a difference. Data on process and outcomes should drive finance and human resource investment.

Frank Quinlan of the Mental Health Council of Australia questioned how do we develop local systems of PWIDMH when we 'don't have a mental health system'? There are a raft of services and programs that only relate to each other sometimes. The mental health system is tremendously overloaded and only one in three people getting the access to the expertise they need. There will be improved efficiencies, but mental health will need to attract new resources through advocacy, politics and evidence. Service integration will only hap-

pen if we get the connection between policy, funding and service integration. So many PWID report that they got better despite the mental health system. Ultimately it depends on consumers determining what services they need. Western Australia has the best data linkage on PWID. There are plenty of examples of good practice. We need to use optimal case studies to drive guidelines and look for highlights and expertise in the system. Action will arise from a combination of aspiration and cause for complaint. This is the moment to take initiatives forward for PWIDMH.

In conclusion, the historic achievement of the NDIS has brought the needs of PWID into the national conscience. The 'guide for service providers' will give new direction for benchmarking the standards of health and mental health services for PWIDMH. The important contribution of individuals who have specialist MH&ID skills was recognised, who need to develop a stronger voice with the establishment of a national multidisciplinary professional network for specialists in MH&ID. The importance of cross agency collaboration was emphasised and the need to develop specialist approaches to prevention, promotion, and the special role of schools and education. Specialist mental health services for PWID will need to be developed. In addition, every mental health service needs to identify clinicians from within their workforce with a special interest in PWID. All mainstream mental health staff will need additional training in MH&ID.

This was a landmark event in the history of services for PWIDMH. A number of important challenges were voiced and pathways forward proposed, with the expectation for stepwise continuing improvements in the services for PWID in the next five years. These will be reviewed and reported on by consumer advocacy groups and should be included in the regular report cards of Federal and State Mental Health Commissioners. PWIDMH as a marginalised and disadvantaged minority special need population can no longer be ignored as a priority area for mental health reform and service development. A national agenda was set for a new direction, with a need to work at how progress can be implemented locally.

Further background reading about the roundtable is available at the NSW CID website: <http://www.nswcid.org.au/images/communique.pdf>