

Conference Report: The Second Annual ACI Intellectual Disability Health Network Forum

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The Disability Network of the NSW Agency of Clinical Innovation (Dossetor, 2013) has been established for 2 years and the second Annual Disability Health Forum was held on 7.3.14. This was a valuable coming together of a range of interested parties and significant partners concerned for the health and welfare of people with Intellectual Disability (PWID).

To achieve better health outcomes for PWID, who usually have complex and chronic health needs, improvements in equity of access to health services, is vital. The pressing challenge is for mainstream services to have greater understanding of these health needs. This was illustrated by the recent Rare Disease Day: as Steve Waugh said "400,000 people have rare diseases but few people know about them". Maria Heaton, Co-Chair of the Disability Network Executive and parent of a child with Lissencephaly reminded us that "PWID come as a package with their carers". This was a passionate forum with a strong sense of the inequity that PWID face both in the health and disability service systems in NSW. This report is not intended to provide a comprehensive summary of the day's presentations, which are available on the ACI website (<http://www.aci.health.nsw.gov.au/networks/intellectual-disability/ID-forum-2014>). However presentations from key invited speakers expanded our horizons.

Kerri Lawrence, Manager of the Mental Health Strategy and Policy unit for the NSW Mental Health Commission, presented on behalf of John Feneley, the Commissioner. The Mental Health Commission was founded as an independent statutory body in July 2012 as agent of change and person centred reform in mental health to 'improve the mental health of all people in NSW'. At least one deputy commissioner must have 'lived experience of mental illness'. There is also an advisory council of 16 members representing a diversity of the community. The question remains of how can the commission have an impact on PWID when there is no new funding for mental health services. There remains a disconnect for the mental health of PWID with the transition to NDIS, as much of the mental health problems are related to a lack of services and a lack of recognition of their needs.

Mary Hawkins, Branch Manager of National Disability Insurance Scheme presented on the rapidly adapting structure of the NDIS pilots which were launched 1.7.13. The aim of the NDIS is to limit cost but achieve good outcomes: by investing in things that help early, giving choice and control of services, demand driven not funding restricted, delivered

locally working to national coverage. The brokering will be through individual plans through setting goals, defining other supports and NDIS funded support. The provision of 'reasonable and necessary support' has to show a reduction in disability and increased functionality, particularly through employment, which in turn reduces a need for support. Practitioners will have to demonstrate change, and the NDIS will be developing an algorithm of the evidence and effectiveness of different interventions. There will be different funding package levels for different levels of disability, using supported and substituted decision making for a child. The Hunter New England pilot already employs 76 staff, including 32 planners, 8 coordinators, 13 regional support officers and 22 support staff. There are 55 registered disability Non-Government Organisations, 357 registered service providers, and another 1500 eligible. 1221 plans have been completed. The scheme has been described as building a plane while flying it, emphasising the continuing modifications, including establishing an evidence base.

While the NSW Disability Services provided by ADHC will cease to exist as this funding is transferred to the NDIS between 2015-18, a range of functions provided will need to be provided within an NDIS context. This was a key message of the presentation from David Coyne, Executive Director of the Clinical Innovation and Governance Directorate of ADHC (CIG). This includes certain discrete services: the Integrated Services Program for people with a range of complex support needs and challenging behaviour, the Community Justice Program as a substitute provision to imprisonment, Regional Behaviour Intervention Teams, and Tertiary Behaviour Support as provided by the Statewide Behaviour Intervention Service. There will still be a requirement for policy development, practice leadership in the disability professional skills of occupational therapy, dietetics, speech therapy, physiotherapy, psychology and behaviour support. There will still be a need for practice development and research, adapting interventions for PWID, such as interventions (Dialectical Behaviour Therapy) for Borderline Personality, and Complex Management Review Panels for cases that are failing to progress. In Queensland and Victoria there are equivalent functions and some similarities of service as found in CIG in NSW.

Further the CIG has also funded some specific mental health initiatives such as the Chair of Developmental Neuropsychiatry and the Chair of Positive Behaviour Support at University of NSW, advanced training fellowships in MH&ID, and the memorandum of understanding between health/

mental health and ADHC. Negotiation with NDIS/A will need to occur in order to ensure these important initiatives continue to support the disability sector. David has summarised 6 key functions which are required in a new NDIS environment: Safeguarding; Practice Leadership, research and development; Innovation; Access to specialist tertiary consultation and support; Workforce capability and development; and monitoring and review. One proposed solution is that consideration be given to the establishment of 'centres of excellence' or hubs which have regional capacity to deliver and contribute to tertiary clinical consultation, capability development and practice leadership. The NDIA could build on the exiting work in CIG but also in Queensland via the Chief Practitioners Office.

Kathryn McKenzie, Director of Systems Reviews at the Ombudsman's Office (OO) presented on their role in disability, such as the review of deaths of PWID in care (100/year) who die on average 30 years younger than the average population. The OO is concerned about access to medical treatment: behavioural problems prevent access for routine checks of blood pressure, teeth, eyes or breast cancer. There are problems of informed care and consent, a dislike of hospitals, an aversion to touch or a fear they wouldn't cope leading to missing out or refusing examination or treatment. PWID need special support for admission and discharge arrangements and planned and coordinated transfer of care from hospital back to their home. The OO hear of easily avoided system failures. They have problems of lack of access to community care for chronic ill-health and referrals to specialists to prevent recurrent acute admissions with chronic lung disease or diabetes. They also need greater support over lifestyle risks from obesity, reduced activity and smoking. They need coordination between Medicare Locals and mainstream services. Disability Reform is placing greater pressure for mainstream services to meet the needs of PWID. The NSW Disability Inclusion Bill 2014 has given the OO increased powers and they will be working to ensure appropriate and minimum safeguards over health provision, working in conjunction with the Australian Human Rights Disability Discrimination Commissioner, to resolve complaints.

Melissa Clements, Director of Disability Learning and Support in NSW Department of Education and Communities (DEC), presented on the education reforms of the last 5 years. The medical model has had a big impact on identifying and defining disability, but there is a need to move to measures of functional need, rather than diagnosis. The increased recognition of disability has required education to look at improving teacher skills to support special needs in a mainstream setting. Gonski will provide additional school funding based on the measures of disability. At present there is no national dataset but 24 different disability datasets. The legal framework requires DEC to treat all students with disability on the same basis as their peers, making reasonable adjustments, in consultation with parents and carers. Of 740,000 students, 12% (90,000) have additional learning needs, of which 80% are supported within regular mainstream classrooms.

Barbara Lewis and Jackie Small (Co-Chairs of the Network's Access and Equity subcommittee) presented on the mapping process of access to NSW Health for PWID. This provided evidence on the need for Local Health Districts to improve processes to enable greater equity of access for PWID. For example, most LHDs lack a specific point of contact for PWID or provide specific information or supports for them. There are few mainstream staff trained in the special health needs or routine processes to support PWID. The Forum saw snapshots of the videos developed by the Network to raise awareness and hear from clinicians about the health of PWID. There is little doubt that the 3 pilot Tier 4 Intellectual Disability Health teams have had a big impact both in specialist provision but equally through building awareness, partnerships and pathways into mainstream health services. With the attention on the NDIS in Hunter New England, there is an opportunity to enable the specialist health services for PWID at Stockton Residential Centre Clinic to be funded and remodelled as a Tier 4 Specialist ID Health Service,

Chris Shipway Director Primary Care and Chronic Services Agency for Clinical Innovation described the ACI methods of supporting consumer and clinician led change based on the experience of the patient's journey, to enable LHDs to respond to best practice models of care, using the skills of the health economics team and enhanced evaluation and research capacity. The Intellectual Disability Health Network needs to articulate a single approach to enable improvements across the whole spectrum of health from primary and community care to specialised and in-patient care. Not only is there a constraint on new funding for health, but more can be gained through building capacity and skills in mainstream services to improve access and quality of health services for PWID. Les White Co-Chair of the Network and the Chief Paediatrician for NSW led the discussion that promoted the notion that LHDs be required to show 'reasonable adjustment' for PWID which would pull together much of the work done by the Network to improve the awareness and special processes that need to be considered for PWID.

Reference

Dossetor D. 2013, Better Health Services for People with Intellectual Disability in NSW: the Agency of Clinical Innovation Disability Network. CHW School Link Newsletter Volume 4, Issue 1 Pp. 2-5, www.schoolink.chw.edu.au.

