

The NDIS and MH & ID Services: Two Conference Reviews

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This report follows from my attendance at two recent conferences: (1) "Designing & Delivering Mental Health Services within the NDIS", organised by Criterion Conferences 21-22/10/15 and (2) "NDIS and Mental Health Services Forum" organised by the Mental Health Commission of NSW, 5/11/15. My aim was to gain greater understanding of the implications for the client group of this journal: children and adolescents with intellectual and developmental disabilities. In fact the 2nd presentation represented a government/agency view, whereas the 1st represented an academic, clinician, mental health service manager, NGO and consumer perspective. The experience involves understanding a significant culture change of service provision and I think no one knows what the final impact will be, or what modifications to services for those with complex needs still need to be during the rollout.

Janet Schorer, (2) Executive Director of the NDIS Reform Group of NSW Department of Premier and Cabinet Office described this as the greatest social reform since the introduction of Medicare: 'its about the human right of choice' and 'will shape the future of helping people'. In NSW 140,000 will access help (funding packages) which is an increase of 45,000 from current service provision. It will

create 25,000 jobs and in 2018/19 will rise to \$6.4 billion with a 2 year roll out starting on July 1016. Current ADHC clients will be the first to receive assessments. It is a provision based on need and not rationed or capped. The NDIA has to develop/provide the implementation. NDIS Act 2013 provides a framework for 'reasonable and necessary support', with rules of support. It will be based on what might be a novel question for many of 'what is your goal (in life)'. She predicted that market forces will move clients away from specialist services to more generic services eg from hydro therapy to joining a gym. Further, earlier intervention will prevent more complex problems developing. Support does need to consider value for money and the responsible role of families. The Disability Inclusion Act 2014 will drive Disability Inclusion Action Plans of all mainstream services to be more inclusive. James Dunne (2) Director of Social Policy Implementation, Government Relations Branch, described the changes in terms of a growth of the deinstitutionalisation/rehabilitation model of mental health and talked about the cluster group meetings of Family and Community Services (FACS), Education, Transport, Housing and Health organised by the Department of Premier and Cabinet Office to coordinate this partnership between NDIS and the cross government services. He reported that the Department of Health will be monitoring and evaluating the framework being introduced. The main distinction is between health and NDIS: health is based on the diagnosis and treatment of a medical condition, whereas NDIS is based on a person's functional impairment. Some of the interface issues include: when is allied health intervention disability support and when is it a health intervention? In NDIS, therapy has a role in maintaining function. But what if a health intervention is needed because of a disability, such as cerebral palsy surgery for contractures, or psychotropic medication to minimise chronic psychosocial disability? When is a goal reasonable and should you be allowed to choose an intervention that isn't evidence based? Will health and the justice system be the provider of last resort? Tracy Wright and Monika Koetzke Macdonald (2) from FACS talked about the impact on 450 people with intellectual disability in large residential homes (institutions) in the Hunter New England. Success depends on partnership with mainstream services eg GPs, but these people will still need access to day programs. Some have readapted well. There are 69 with complex needs often with a criminal justice background which will require access to mental health and other specialist skills. There are currently 12 who are struggling and under their client monitoring and review process: 4 with behaviours of concern or MH problems, 2 because of



placement problems, 1 where no provider can be identified and 1 with problems of continuity of care.

The strengths of large residential care provision is: skilled and knowledgeable staff, strong management and clinical leadership, skilled multidisciplinary teams, access to specialists, consistent staff, early intervention for problems and coordinated integrated management plans. Can any of this be reproduced under the NDIS? How do you transit to the NDIS a 15 year old, graduate of the criminal justice system, with mental health problems, intellectual disability, self-harm, aggression to staff who has already had 15 placement breakdowns? They are looking to develop an intensive support framework with 18 key initiatives which will also need to build capacity in the health sector. There needs to be an agreement not to allow the blocking of beds in acute care in health or mental health or in the criminal justice program. We look forward to hearing more details on service development for those with complex needs. This account brings to mind that the closure of institutions of people with intellectual disability in UK in the 90s was balanced by the maintaining some of the funding for building of specialised ID psychiatry services. I see this as an essential part of any modern model of community care for people with ID.

Leanne Johnson (2) General Manager gave a general mental health perspective on lessons learned from the Hunter Trial Site. It has taken significant time to clarify the confusion between what is NDIS and what is Mental Health. The benefits have been increased funding and range of services, new models of accommodation, increased flexibility of support, resulting in staying well for longer and shorter MH admissions. An advocate to support the application to access NDIS has a higher success rate, and the average length of time preparing for and applying is 60 hours of professional time.

However 76 long term patients have been accepted into the community. Challenges remain with: clinical governance, guidelines and procedures for staff, barriers for the most complex, vulnerable patients, access to safe, secure, affordable housing, not knowing the NDIS status of a patient, minimal service for non-NDIS consumers and a lack of data. New services have needed mental health training and education and should that be at the cost of the mental health services? Monitoring and safeguards of complex vulnerable clients; Health is part of the cost of support; increased need for the public guardian in decision making; the service capacity of NGO sector; ensuring choice and control for consumers. Progress has required: clear health governance, documentation of disability and disadvantage, a centralised database, appointment of NDIS champions, project manag-

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ers and access coordinators, active engagement with the NDIS, regular interface with NDIA, and organising the coordination of the NGOs. The NDIS website is a font of developing information.

Conversely Conference (1) was not attended by a NDIS/NDIA representative. The response to an invitation was: the NDIS does not provide services, just provides an economic market place in which NGOs provide the services. ‘Market failure’ is the term used to describe the failure to provide services to those in need: this particularly focuses on those in ‘small markets’, such as regional and remote populations, clients with complex care needs and clients with high levels of mental health issues.

Sarah Pollock (1) from Mind described the NDIS is a transfer of power from the government to the individual, recognising the citizenship of individuals despite their disability, but also how ‘choice’ can be used to limit entitlement, if there are no options. Many people struggle with ‘outing themselves’ and declaring their disability. The NDIS gives a business imperative to make a service that is meaningful to people. Judy Harper (1) from NSW Council of Intellectual Disability spoke directly to my concerns when she talked of the problems of mental health problems in people with an intellectual disability. In Australia 120,000 of the 400,000 people with an intellectual disability have a mental health problem. However diagnosis is challenging and she cited a case where 5 different psychiatrists said there was no problem until they saw a specialist psychiatrist in intellectual disability, which led to treatment that kept the person out of prison. How does the NDIS work to support access to the expertise? The concept and label of ‘challenging behaviour’ prevents recognition of a mental health diagnosis. Both GPs and general psychiatrists are under-skilled and we are a long way behind the development of a subspecialty compared to the UK. We need multidisciplinary approaches for challenging behaviour, looking at the behaviour through ‘multiple lenses’. Sometimes medication for behaviour is inappropriate and sometimes it is essential.

The National Canberra Roundtable on MH & ID established consensus for the need for subspecialty mental health skills. However the \$115million for the NSW Mental Health Strategy provides no money for intellectual disability. Prevention of these mental health problems needs attention such as with skilled parenting programs such as Stepping Stones. She cited the needs for: inclusion into mental health services, equity of access, prevention, specialist ID MH services, collaborative models, workforce development and data to address the multiplicity of disadvantage. Tier 2 NDIS services need linkage engagement and the \$140million allocated will not be sufficient. How does NDIS support access to mainstream services? We will not survive the loss of the ADHC specialist services. It remains unacceptable that the NDIS has not even considered the assessment of the combined disability of Intellectual Disability and Mental Health Problems.

Leanne Dowse (1) Chair of Intellectual Disability Behaviour Support, UNSW, a speech therapist by background, talked about her 10 year life course research study on those with

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complex needs in the criminal justice system with 2700 in the study, most of whom don't have the personal capacity to access NDIS. An example case was a woman called 'Natalie' in her 20s with multiple psychiatric disorders, substance abuse and asthma. Her psychiatric diagnoses included ADHD, Dissocial, Schizoid and Histrionic Personality Disorders, and Psychosis in the context of substance abuse. She was subject to child abuse, had problems at school at 12, a brother with mental health problems, 22 contacts with the police by the age of 15 including 7 periods of custody, multiple out of home care home and residential placements which broke down because of her behaviour. She had minimal therapy of little impact; had 3 high risk pregnancies by the age of 22 who were all taken into care. She had charges for malicious damage to property, was a victim of domestic violence, had multiple AVOs against her and was under the Guardianship Board, yet no one identified her intellectual disability or psychosocial needs. The cost for her support and surveillance and control has already cost the state \$960,000 without considering her personal and the community costs. Complex support involves the relationship between simultaneous, intense and multiple needs in health, disability, social disadvantage, risk, justice and legal issues including decision making capacity. Domains of intervention change over time. Her individual needs have both a breadth and depth which are interconnected. Her environment lacks natural or informal supports to meet her needs. The services lacked a unity of capacity to provide support, often providing no service response because of service gaps and silos. Complexity theory, like a symphony orchestra, determines the input is greater than the sum of its parts. Access to NDIS may be a human right, but care is deferred to the criminal justice system. NDIA also requires voluntary engagement, proving eligibility, needing support for planning, gathering information and making decisions. Natalie will be deemed ineligible because NDIS is only about the ID, not the rest of her psychosocial disability.

How can those with the most complex needs not be eligible?

1. NDIA will fail to reach its target audience because of the lack of and access to documented information.
2. How could she take up voluntary engagement with her history of trauma and lack of trust of professionals? This also needs a self-awareness of need.
3. Eligibility gets altered based on cost control and advocacy.
4. Support Planning requires the planners to identify both the ID and the mental health disability but then

what products are available to purchase to support such complex needs?

5. Getting the information and making the decision involves: need, interest, literacy, transport to attend an appointment, and a capacity to think of goals and aspirations.

At a minimum, a case like Natalie needs intra & inter agency collaboration, which is proactive, not reactive, with comprehensive case management, specialist MH and prescribing, and trauma focus. It also requires mainstream support, which has a focus on inclusion not their lack of capacity. Key ingredients include: best practice guidelines, services with training, supervision and mentoring. It takes time and leadership. 'Market failure' is a failure to address the needs of an individual. Building market capacity may take 20-30 years, as found in UK. Market deregulation led to competition from large scale overseas providers such as Serco with a profit motive that can kill competition, diversity, and niche capacity and connection. Leanne suggested the NDIA is retreating from complexity. There is no ID working group in NDIS. Self-determination is a middle class idea for those with supportive families. In complexity theory small steps all help, e.g. starting with a visit to the dentist, but most of the work needed will not be 'billable'. Legally the state government still has responsibility for the welfare of its population and mainstream service provision.

Two mental health consumers Simon Swinson and Erika Gelzinnis talked of their experience of the Hunter Pilot Study: the problems of meeting the criteria of need; the need for advocacy skills, the need for professional assistance in application and skills in describing problems. Erica described the bureaucracy failures of documents lost, misinformation between agencies, lack of direct communication and the lack of MH expertise in Assessors. Her aim was to get out of poverty. Her exceptional GP helped guide her through the maze dysfunctional services and helped her believe she had a right to a quality of life. It was frustrating that she had money allocated but no functional service to provide for her needs. She felt that the NDIS is incompatible with a recovery model of support. She concluded: "I would like to be able to contribute to society but will probably always need support". Simon summed the dilemma as "you need to present yourself in your worst state and with the assumption that diagnosis is permanent". Ben Mathews, a NDIS transition manager with a lived experience, also talked of the problems of helping customers apply, quoting Bob who needed 5 hours of meetings to get him to even consider an application. He also talked of the loss of MH Rehab funding reducing supported employment capacity. Michelle Massey, Team Manager of Mental Health Services for the Salvos in the South Australia Pilot, talked of the problems of changing their service structure from block funding to NDIS funded fee for service and the business processes that have to be set in place. They can only provide what NDIS has funded, not what the clinician feels is needed. Despite tailoring their service they are running at a loss at the current support fee of \$45/hour, with increased client loads and less time to give. In fact the financial loss had to be subsidised by the National Salvos organisation.



They risk the loss of collaboration with MH services, because as NDIS providers they are not allowed access to clinical information including client risk profiles. Paul O'Halloran, Director of Mental Health International Networks for Developing Services, presented on the growing evidence on Recovery models of intervention in MH and its overlap with the Psychosocial Disability Models of NDIS.

Debbie Hamilton, a doctor with the lived experience, talked of how you need an advocate to get a package, and without such support you will fail. You may have the name of a service, but it is difficult working out what it does. It is difficult to articulate what your goals for life are, especially if you have been 'in a difficult place'. Up till now NDIS has not been proficient in substitute decision making. David Meldrum from Mental Illness Fellowship Australia talked of the epidemiology of NDIS for people with mental illness. 4 million Australians have a mental illness a year. The NDIS is designed to provide assistance for 56,000 with mental illness and complex needs requiring support from multiple agencies. But there are 103,000 with persisting severe mental illness (SMI) and 321,000 with episodic mental illness. Peer workers are skilled in recognising who will become long term care cases. The National Mental Health Service Planning Framework identified 65,000 who had SMI, with severe psychosocial disability requiring assistance or severe disability in 2 or more dimensions. This 2 year project and report has been ignored by NDIS. He is concerned that many of the most needy will miss out. In actuarial terms it is predicted that 80% of those with disability will have an NDIS package by 2020, but that for those with Mental Health Psychosocial disability, this will be only 20%. He is concerned that to provide funding for 56,000 mental health NDIS packages, the states will transfer funding to NDIS which would otherwise have provided for the other 80% with SMI but receiving no NDIS package. He ad-

vocated that for the better good of people with SMI that it would be preferable to fund NDIS MH packages for a fewer number eg 40,000 so that the states funded NGOs could still provide services to the other 200,000 with SMI not receiving a NDIS package. Such a mixed model of funding is the only way to get a balance. The 5th MH Plan also focuses on Prevention, Promotion and Early Intervention, Suicide Prevention, Primary Care, Hospital Admission Avoidance, and Research. Vanessa Kirk, Lead Case worker from Mission Australia talked of some Hunter Valley MH Cases, such as 'Amber' a 28 year old with intellectual disability, schizophrenia and challenging behaviour, who was considered too hard for any NGO to provide a service, and therefore none was given, even though she had a package.

Peter Gianfrancesco, NSW State manager for Neami National talked of his experiences in UK of developing the business model, mechanisms, jargon and hype of NGO Insurance service provision: focusing on the 5 Cs: Cultural competence (who are we here for), Customer service (90% is your relational and engagement skills, only 10% is technical skills: 'have we wowed you?'), Capability (often to do with hidden skills and what distinguishes you from your rivals), Capacity (not to be overcome by demand, work out debt recovery and cash flow systems), and Costs (need to know own costs and flexibility in cost for service provision). The idea is that NDIS should be disruptive in the market place with innovation, like Uber has been in taxi provision. They extended their service provision into schools, public services and private companies. Each employee needs 26 billable hours per week. But financial viability is support fees of \$75/hour to enable 20% profit for growth and enhancement, (a commentator at conference (2) described this as market making). The primary survival motive of services is profit.

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Jane Henty and Jonathan Harms from MH Carers ARAFMI Australia presented a carer’s perspective: Australia has 2.7million carers with increased rates of health, mental health and disability themselves. For example carers of people with a personality disorder have the same rates of PTSD as Afghanistan veterans. Holistic assessment should take account of the carer’s needs, for example providing respite. NDIS should take some pressure off carers, but they are often expected to manage the packages. The Information, Linkages and Capacity Building (ILC) is the new term for Tier 2 of NDIS and a Framework that is planned to lead to a new organisation (probably another NGO) designed to guide carers and clients where to go for services, that will publish (name and shame) the services that do not provide appropriate inclusive services, as a governance process of linkage between the NDIS to other government and non-government services http://www.ndis.gov.au/sites/default/files/documents/ILC%20Policy%20Framework_0.pdf.

In conclusion there is a diversity of information, experience and concerns. There will no doubt be winners in this reform, but the challenge is how many losers will there be and how

big the losses. In fact, prompt action can still prevent such an important social reform ‘inadvertently’ causing such losses. Some people involved in the pilot studies are aware of the concern about the mental health needs of children and adolescents with intellectual and developmental disabilities. There is a real risk of disintegration of service provision with privatisation and privacy destroying collaboration and the sharing of clinical information and expertise. Who will manage the children and adolescents who find themselves abandoned into the care of health and the justice system? Business novelty and hype is a limited substitute for interdisciplinary expertise. With these seismic social changes the maintenance of the essential centralised roles of ADHC remains critical: practice guidelines and policy, interdisciplinary practice leadership, workforce development especially in Positive Behaviour Support and MH (including the MH fellowships in ID), tertiary interdisciplinary expertise and treatment partnerships (Statewide Behaviour Intervention, Integrated Services Program and the Community Justice Program), innovation through research and partnership (including the University Chairs of Intellectual Disability Mental Health and Positive Behaviour Support) and complex client monitoring and review (clinical governance including Restrictive Practice Authorisation). We still need a special focus on those with additional disadvantage such as Indigenous and CALD populations, and those with multiple sensory disabilities, behavioural phenotypes and FASD.

A current review needs to resolve this by July 2016. May be this ADHC resource is what could provide the impetus/funding to enhance specialist ID MH and 1st world health/MH practice and remodel the hub and spokes of interdisciplinary expertise based from health? There are also significant funding concerns about the maintenance of services for those with severe mental illness who will not qualify for an NDIS package.

