



What will the NDIS do for subspecialty expertise and the multidisciplinary services for complex mental health problems of young people with intellectual disability?

Implications from the Centre for Disability Study's review of the Developmental Psychiatry Clinic.

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Introduction

Over the last 10 years, a specialist mental health (MH) service has developed for children and adolescents with intellectual and developmental disabilities (ID), based on the establishment of the Developmental Psychiatry Team (DPT) at the Children's Hospital at Westmead, and the growth of partnerships with the Children's Team of the Statewide Behaviour Intervention Service (SBIS) of Ageing Disability and Home Care, NSW Family and Community Services (ADHC) and the NSW Department of Education and Communities (DEC). From the genesis of the monthly interagency tertiary Developmental Psychiatry Clinic (DPC), the growth of the Developmental Psychiatry Partnership (DPP) has spawned a range of collaborative activities. This partnership has recently had an independent stakeholder review led by Professor Patricia O'Brien and colleagues from the Centre of Disability Studies of the University of Sydney. This article reviews this best practice model of multidisciplinary multi-agency subspecialty MH for ID and its future in the context of the uncertainty of tertiary disability skills under the National Disability Insurance Scheme (NDIS). The review highlighted the importance of multi-disciplinary cross-agency MH and ID expertise. Investment in such services can help minimise the adverse impact of this chronic dual disability impairment and make major savings in the cost of provision care and support. The transition to the NDIS and the transfer of specialist disability service delivery out of NSW government raises questions around how, and with which agencies, this will occur in the future. The various agencies are currently working together to identify ways that safeguards can be built into a free market model of care and support to address the risk of losing access to specialist tertiary services and the potential negative outcomes for individuals and their families.

Context and recent history of MH for children and adolescents with ID.

Forty percent of young people with ID have severe and persisting MH problems (Einfeld & Tonge, 2006). It is a primary factor influencing the quality of life of these young people and their families. Historically these behaviour disturbances were seen as part of the ID, what is now known as 'diagnostic overshadowing' and it was often these behaviours that led to people with an ID being institutionalised. The large institutions have been gradually phased out over

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the last 30 years since the Richmond Report (1983). This was in keeping with the development of the philosophy of normalisation and the recognition of the human rights of people with ID, but motivated by the public scandals of mistreatment and abuse in some institutions. Thus 'community care' of people with ID was born. The intention was about providing "normal accommodation" with access to a community supported by a community team, albeit at greater cost on the public purse. In many cases the care, custody, control and cost was transferred to families. Normalisation also reframed the severe emotional and behavioural problems as "challenging behaviour": a functional communication in the context of limited communication skills and limited power to manage one's own world. People with severe mental illness have had a similar journey, with the closure of the institutions starting from the 1950s, partly with a shift in social attitudes to people with a mental illness and partly due to the development of psychotropic medications and other treatments. This has been in parallel to the massive development of the science of medicine, with the development of classification and treatment of health disorders, including MH problems in the community, reducing the need for hospitalisation of MH problems to those who are unsafe and those needing further assessment and stabilising of treatment.

Service provision for those with ID was managed by the health service in NSW until 1987, when this funding was transferred to the welfare sector of government, in keeping with the social model of care, which avowed that de-institutionalisation would relieve some of the emotional and behavioural disturbance but recognising that new challenges would arise in the community setting. In keeping with this approach, in 1990 the Training Resource Unit of the NSW Disability Services was funded to provide state of the

art intervention in behavioural approaches to “challenging behaviour”. Paediatric developmental services were also transferred to NSW Disability Services, and eroded over the subsequent years till the remaining diagnostic services were handed back in 2008.

In Australia MH services have been funded to provide services for the seriously mentally ill, and those with acute mental disturbance with a risk of self-harm or harm to others. This accounts for 2-3% of the population, whereas those with MH problems are between 11% of adults and 26% of youth population, at any one time (Mental Health in Australia: A Snapshot, 2004-05; www.abs.gov.au/ausstats/abs@.nsf/mf/4824.0.55.001). For those with ID, in the absence of significant research on the MH problems of those with ID, a false dichotomy arose, that if the problem wasn't a severe mental illness, then it was a “challenging behaviour”. Hence there were barriers due to the service access gaps between disability services and MH services and hence difficulties in ensuring appropriate supports were provided. However, research into the MH of adults with ID shows that of the 40% have severe challenging behaviour, of which over 50% also have a significant MH problem (Cooper et al, 2007).

Child MH epidemiology described a MH problem as any emotional and behavioural disturbance that impacted with significant impairment which includes all ‘challenging behaviour’, but with the increased demand and cost restraint, and management by adult MH, services are largely restricted to severe mental illness or acute mental disorder, or presentations that may be prodromal.

Study of childhood development has transformed our approach to mainstream child MH problems, with the recognition that children could have serious depression and anxiety disorders and appreciation of developmental disorders in particular ADHD and ASD. In Australia most child MH assessment and treatment is provided by paediatricians with behavioural and developmental interests. This also applies to the MH problems of young people with an ID, but challenging behaviour has been managed by specialist disability services.

Comparisons with UK.

In UK, a subspecialty of the psychiatry of ID survived from the institutional era, and the Faculty of ID of the Royal College of Psychiatrists (RCPsych) is as almost big as the Faculty for Children and Adolescents. In the late 80s and 90s the Royal College of Psychiatrist promoted the integration of children and adolescent with ID into mainstream child and adolescent MH services. Integration meant recognising the necessity of subspecialty skills and over the next 20 years every CAMHS Service had to provide a specialist MH service for those with ID. Epidemiology indicates that the MH of children and adolescents with ID is 14% of the burden of MH in children and adolescents (Emerson & Hatton, 2007). Add to that: it is estimated that the MH service needs of children and adolescents with ASD is a further 10%. Based on human rights and the Disability Discrimination Act 1995 and 2005, the Royal College of Psychiatrists (UK) recently argued that specialist ‘Learning Disability’ (LD) CAMHS services were necessary to provide appropriate services for young people with ID and recommended 5-6 CAMHS LD specialist clinicians per 100,000 general population, plus 8

Delineation of the spectrum from Mental Illness to Mental Health & Wellbeing, describing the allocated service, level of disturbance or impairment and examples.				
Term	Service	Disturbance	Severity	Examples
Mental Disorder/Illness 3% (3rd National Mental Health Plan)	Diagnosable Illness from DSMV Priority for Mental Health Services	Cannot fend for self Managed in community with short assessment IP admission Risk of stigma and social exclusion	Significant impairment and high risk of harm to self or others Major Problems of reliability and validity of diagnosis	Major Depression Bipolar Disorder Schizophrenia Acute Mental Disorder
Mental Health Problem (3rd National Mental Health Plan) 20-40%	Diagnosed from DSMV but seen as a developmental disorder (not a serious mental illness) Rx by Paediatrics & disability Service, +/- specialist ID MH. Not MH Priority	Emotional/Behavioural disturbance is as severe as impairment from ID. The combination makes for complexity and severity	Severe impairment, risks to caring framework esp in acute exacerbation Needs high expertise multidisciplinary subspecialty collaboration of disability and health	ADHD ASD ODD/CD Depressive Symptoms Anxiety Disorders, OCD, etc Lability of Mood Panic disorder, Dissociation Trauma based problems Usually several disorders
Challenging Behaviour (Emerson 2001) 40-60%	Culturally Abnormal Behaviours Disability Services, ABA approach	The Physical safety of the person/others is placed in serious jeopardy	Significant impairment, high intensity, frequency or duration Still big impact on Quality of Life	Aggression Self harm Behaviour Disturbance Stereotypy Habits, Pica
Mental Health and Well-being (3rd National Mental Health Plan) 100%	A state of emotional and social wellbeing. Needs PPEI across family, school, community & interagency leadership, collaboration and research on approached in special population	Promote individual resilience to cope with the normal life stressors	Chronic moderate severe EDBD problems. Aim to achieve potential and Quality of Life	Risks of poor attention, restlessness, reciprocity, relationship connection, self esteem, autonomy, skills, participation, employability

specialist LD CAMHS in-patient beds/million population (RCPsych CRI163, 2010). This includes a network of approximately 60-100 subspecialty trained child psychiatrists in learning disability plus associated multidisciplinary teams and dedicated LD in-patient CAMHS Units. This is a model of significant leadership to close this gap of disadvantage for young people with ID.

“Reasonable Adjustments” in UK.

In UK there was a cost of mainstreaming ID without recognising their special needs and in 2009, a Parliamentary and Health Service Ombudsman and Local Ombudsman Enquiry reported following the deaths of people with ID in hospital which the families felt were avoidable. All health services were placed with a legal obligation to develop processes of “reasonable adjustments”, which include processes to create systematic changes, some of which should be available before a person with ID visits, to run a truly effective service (www.improvinghealthandlives.org.uk/projects/reasonableadjustments). These processes of 'What extra things do we need to do, so people with LD can get health services as good as other people' includes information adapted for people with ID, working in partnership with families, processes for assessing capacity, enabling consent and advocacy, specially modified service delivery eg with special arrangements pre, during and after appointments or admissions. It includes nurses with special skills to look out for people with ID; giving people more time with doctors and other clinicians; monitoring and reporting information on access and effectiveness of the health service for people with ID; patient and public involvement; and employment of people with ID. These processes are regularly audited and made publically available. Central to this is collecting information specific to people with ID through all health systems, including rates of annual GP health checks and preventative health interventions. Data on the health, MH, and measures on community access and participation is audited in every borough in UK through the Learning Disability

Public Health Observatory which has now become part of Public Health England (www.improvinghealthandlives.org.uk/). The Observatory also enables a People’s Parliament for people with learning disability as part of a participatory advocacy process. Based on the UK experience, we have the opportunity to act to prevent such a systems failure if we act now. These experiences show the necessity of recognising the special needs of people with ID, both in the active integration into mainstream services and the building of subspecialty CAMHS Services.

What is the Australian Model?

At first glance it is difficult to make comparisons with the British mental health system, where LD (intellectual disability) MH is a well-established Faculty in the Royal College of Psychiatry, and the voice of subspecialty child and adolescent psychiatry is also stronger. This may partly be because Australia has a more developed ‘free market economy’ of health (MH) private/Medicare services and a relatively less developed Public MH service system. Also Australia has 40 paediatric trainees for every child psychiatrist. Most psychotropic prescribing in Australia has been done by behavioural and developmental paediatricians including for children and adolescents with ID and/or ASD. The ‘Neurodevelopmental and Behavioural Paediatric Society of Australasia’, representing both public and private paediatricians, is a growing group who are looking for partnership with the expertise of child psychiatrists with a special interest ID. The Royal Australian and New Zealand College of Psychiatrists has no subspecialty in ID, although in the last 3 years it has recognised a national special interest group in ID, and Maria Tomasic, the past president of the college suggested that the college needed to progress to developing subspecialty training and recognition. Indeed the Canberra National Roundtable on Mental Health and Intellectual Disability (May 2013) confirmed that recognising and supporting the development of subspecialty services in MH



and ID was necessary if there was to be equity of access to meet the MH needs of people with ID. Further, whereas the model of care in UK is that all young people with ID and emotional and behavioural problems need a multidisciplinary MH assessment, in Australia services have worked on an assumption that most of these problems are 'challenging behaviours' and therefore should be managed by allied health staff in the disability services. This is the heart of the dichotomy of the service provision.

Local Arrangements:

In the last 4 years a Memorandum of Understanding between ADHC and Health (Mental Health) (2010) has brought a modicum of greater collaboration between the 2 services (both poorly funded sectors in OECD tables). In July 2018 ADHC will no longer exist and the challenging behaviour (mental health) allied health expertise in dealing with these complex cases will need to be transitioned to the rest of the sector. A number of initiatives are currently underway to develop models of service provision and funding options that will enable this to transition successfully. There is a risk of a loss of expertise and collaboration in the service system with the move to a 'free market economy' of disability NGOs if this is not planned for carefully. The key will be for the NDIS funded 'care and support' agencies to develop strategies to maintain multidisciplinary subspecialty expertise and an acute response capacity to collaboratively with health or MH. Such considerations are being included in planning from the local Districts, to statewide approaches, and at a national level through the NDIS Quality and Safeguards work. This is critical to ensure that families unable to cope with the behaviour of their child or adolescent with ID do not expect emergency paediatric and MH services to provide safe haven in the absence of alternatives and to minimise the likelihood of such complex young people being cared for in hospitals and by Community Services (FACS).

Further, some private practitioners do not have experience in supporting such disruptive and often dangerous young people, and will require support and guidance to encourage them into the field. This can be a particularly difficult undertaking if there is no back-up capacity in the state CAMHS service to manage them safely. ADHC is currently working with private and NGO practitioners across the state to help them prepare for the transition to the NDIS. In recent years, start-up funding for developing MH service for people with ID has come from Ageing Disability and Home Care (ADHC) (part of NSW FACS). In particular ADHC provided funding for 8 MHID Psychiatry Fellowships and 5 years funding for an Academic Chair in IDMH. ADHC is currently undertaking work to identify potential future funding options for these significant initiatives as it is not yet clear how, or whether, the NDIS will fund such services. It is ADHC that has taken the lead in advocating that the MH of people with an ID is the primary welfare concern and acted to work to help build subspecialty skill development in their service and certain partners in order to maintain family and community placements. All other government agencies are also preparing for the transition to the NDIS as there will be a greater expectation that people with ID access mainstream services where

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appropriate which is a key part of the underpinning philosophy.

While the recently launched “The Guide: Accessible Mental Health Services for People with an Intellectual Disability” (2014) will require all MH services to ensure human rights principles and equity of choice and access be applied to people with an ID, state MH systems are constrained as to the extent of service development possible because of fiscal constraint in state health and mental health. The NSW and National Mental Health Strategic Plan, prioritises growth funding to the Non-Government Sector with a focus on Care and Recovery. There has been additional Commonwealth funding for MH through Medicare and the Better Access to Mental Health scheme but no targeting of needs for the MH of people with ID.

At the Children’s Hospital at Westmead alone, there are several cases in the last year, where breakdown of care in a family or a care-home and long term hospitalisation was averted through the partnership between subspecialty child psychiatry and emergency funding, training and professional intervention from ADHC. The CHW does not have the capacity to provide a bed for all those difficult cases who are kept in Emergency Departments for a week. However our outpatient intervention would appear to be dramatically cost effective in enabling young people with ID to return to living with the family preventing additional millions of dollars on fulltime out of home care. Without a disability agency with responsibility for complex cases, this best practice model of community practice will decline (Centre for Disability Studies; 2014).

Similarly Wurth and Brandon have published on the experience of a small ID/MH team in ACT providing a quality of care through working in partnership with both disability services and mental health services (Australasian Psychiatry, 2014) in which he provided a detailed overview of the ACT Mental Health Service. In both services the use of psychotropic medication for reversing the level of disability from emotional behavioural disturbance is critical. The severity of impairment from emotional and behavioural disturbance is the reversible component of their disability, yet there is no investment in this medical expertise to improve disability (Dossetor, 2014).

Core elements of the Developmental Psychiatry Partnership (DPP)

Over the last 10 years there have been significant international developments in the MH of people with ID. We have moved from seeing all disturbance as 'challenging behaviour', to diagnostic manuals which accept they have a similar spectrum of mental disorders to a mainstream popula-

tion. The lack of research holds up international consensus, but research shows that they have much higher rates of MH disorders, with much higher rates of multiple disorders, and these advances in community MH diagnosis and intervention can have a dramatic impact on outcome. Yet evidence shows that a large proportion of community professionals feel untrained to understand and treat these MH problems. One of the key strengths of the DPP comes from the work to build a multidisciplinary curriculum on MH & ID for children and adolescents based on evidenced based approaches and practiced based evidence. The resultant multi-author book “Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: a framework for professional practice” (Dossetor et al, 2011) has 4 main elements:

1. Foundations: understanding the issues and integrating scientific approaches. This includes a focus on enabling a quality of life for the child and family, and an appreciation of developmental concepts to the developing mind, which provides a universal language for families and all professional disciplines to understand the developmental delay inherent in ID and difference.

2. Focus on carers and family and the impact of disability on family well-being involves anticipating the threats to family breakdown and designing services to promote better adaptation to the difference of ID: i) promoting adjustment to a special of different child, especially with specialised parent training; ii) managing the main handicap of increased burden of care, enabling wider family and community acceptance and support. This includes the addition of diverse specialist approaches to providing carer respite. iii) understanding and promoting delayed and uneven development is the main challenge in improving MH. iv) maintaining the wellbeing of family members and the coherence of the family for every member.

3. Interventions to promote skill development and mental health. Behaviour and emotions need to be seen in a developmental context, especially emotional-social skills needed for social integration. MH prevention and promotion needs to focus on building skills and competencies. Psychological treatment is also modified to focus on skill building in addition to limiting maladaptive approaches. Psychopharmacology is also critical in severely impaired cases where skill promoting approaches cannot engage. The full range of skills for an effective multidisciplinary team for complex MH problems include:

a) **Medical and psychiatric skills** to review health and MH features contributing to a multidimensional formulation and review of medication needs.

b) **Multidisciplinary allied health skills each with subspecialty expertise.** Clinical Psychology, Occupational Therapy, Speech Therapy, Special Education, Pharmacy, and case management who contribute to skill building approaches to intervention; enabling sharing of specialist skills with less experienced members of the treating teams; specialised or modified therapies eg Emotion based Social Skills Training,

play therapy, dialectical behaviour therapy or trauma focused CBT.

c) **Family and system skills** which are different to mainstream families, including the cultural expertise. The system issues can refer to family systems but equally to service systems in the way complex cases cause problems in the family and in service systems. The need to match environment to developmental/psychiatric need.

d) **Legal assessment of child protection**, with concerns for abuse and neglect; an interface with Family and Community Services and Intensive Support Services for young people in out of home care; human rights/child protective legal elements eg when service systems that are failing.

e) **A high level of interagency collaboration:** To influence each other’s service systems for the needs of the child and family; to match service provision with clinical need versus business models of funding formulas; level of mutual respect from efforts to help with each other.

4. Integration of service systems. The framework in Figure 1 needs to be integrated across families, schools, community settings and in clinical practice. MH Clinical practice has to integrate primary general practice and community health care, secondary specialist disability support and hospital services, and tertiary multidisciplinary, multiagency support including special education, neurodevelopmental paediatrics, CAMHS services, and the new Tier 4 specialist health services for people with ID. No agency has all the disciplinary skills needed for MH & ID cases of any complexity, which means that the more complex the problem, the more multidisciplinary/multiagency partners need to collaborate. There are limited Tier 5 (or quaternary) services which include a brief admission to a CAMHS in-patient service, emergency services, and informally recognised Tier 5 subspecialty MH services for young people with ID. Ultimately, care in the community models are about a final common pathway for Tier 4 where funding models and the best available clinical advice need to work together to provide for the long term needs for care and recovery of the patient. This could be supported by a ‘best endeavours’ mechanism, as exemplified by FACs entitlement to ask health to provide a priority response.

If the NDIS is to prevent the abandonment of young people with ID and complex problems to long term hospital care and/or out of home care under the care of the minister for FACs, they need to be at the centre of Tier 4 integrating multidisciplinary care and support with the departments of education, health and MH. The NDIS philosophy of putting the patient at the centre of service provision creates a challenge of educating clients and families on the complexity of need as described above. Maybe a modified version of the book on the framework for MH and ID (Dossetor et al 2011) needs to be rewritten for consumers. The Agency of Clinical Innovation ID Network has provided descriptions of pathways to care for children and adolescents with ID, which presents a longitudinal view of this pyramid model of service over the first 20 years of life. In truth however, parents

Tier 5: Acute short/medium term interventions that inform Tier 4
 Includes: Emergency departments, MH in-patients assessments, other residential behaviour services; and **Specialist/Tertiary MH in ID clinicians** from mental health & disability services.

The Tier 4 Circle: The Final Common Pathway

Complex case management decision making; 'best endeavour' obligations including decisions about out of family community placements.

Tier 3: Multidisciplinary and Multi-agency Collaboration

Disability Service: ADHC behaviour clinician, speech pathologist, OT, other specialist psychology service;
Health: GP, paediatrician or neurologist; MH Psychologist, SW, family therapist, psychiatrist; and
Education: teacher, aide, school counsellor, principal, behaviour support specialist.

Tier 2: Community Disability Services providing case management and specialist parent training. Mainly from ADHC but can be MH or other agency or non-government organisations.

Tier 1: Generic Health Provision for families
 Includes: GPs, community nurses, child community teams, Families NSW, Triple P

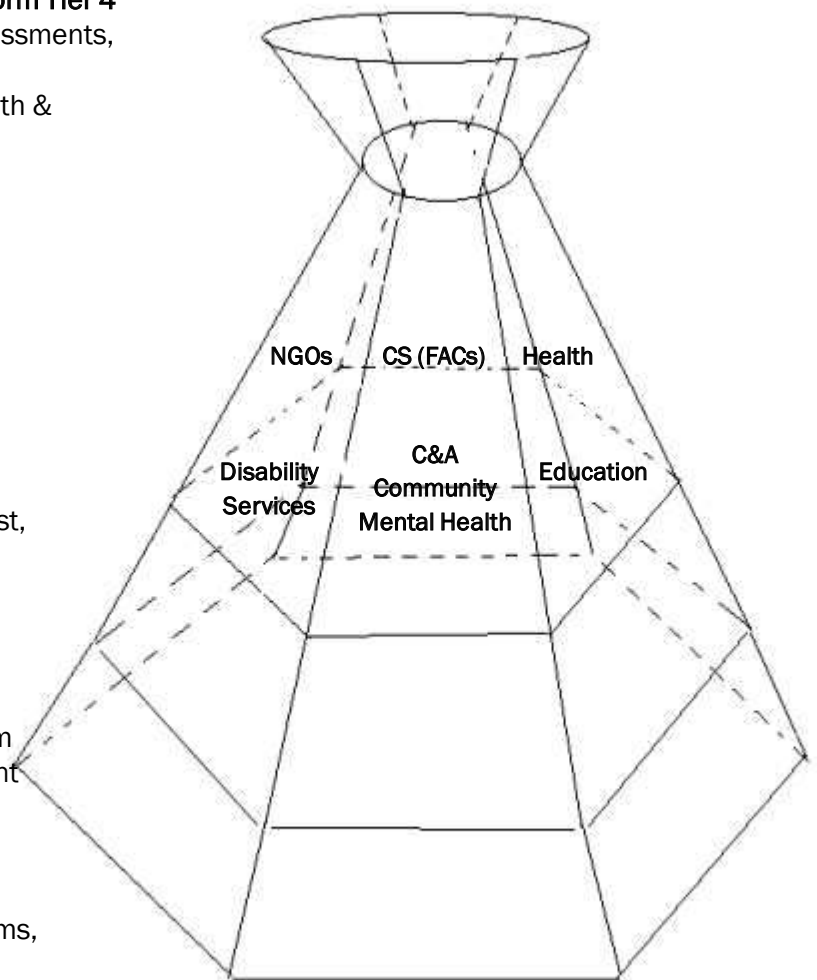


Figure 1 3D Model provides for **all other human services** to be part of the pyramid

and clients are not in a position to follow the progressive growth on knowledge or fund clinical research to improve cost effective approaches to intervention in addition to understanding the complexity. (See Figure 1).

Findings of the Review of the Developmental Psychiatry Clinic (DPC).

The Centre of Disability Studies review of the DPP found that the service was responsive, with a cohesive team approach and high levels of cross agency collaboration. It was seen by clients as a beacon of hope in the context of abject despair of the lack of specialised services, and had a visible presence, with cross cultural sensitivity, and was responsive to NSW Disability Standards. Areas of future growth and development included expansion of the model to be more widely accessible as a statewide service, increase the infrastructure support with marketing, research and education of what can be done, and to promote ID and MH as professional area.

The Centre for Disability Studies recommended a hub and spoke model of a Centre of Excellence of Tier 5 expertise providing support for and promoting spokes of local and regional expertise. Can the NDIS fund an enhanced Centre of Excellence with continuing capacity for training disability staff, developing MH prevention and promotion initiatives?



The Centre for Disability Studies reports the DPP provides a best practice service for complex cases with their partners that integrates the best of multidisciplinary disability skills with subspecialty MH skills. This world class, cost saving model needs to be supported and replicated in different settings such as the effective developments in special

school clinics, rather than to fail from the loss of multidisciplinary disability support for subspecialty MH for young people with ID. If 20% of 200 complex MHID cases seen a year are prevented from family breakdown, this saves \$10Million of residential care costs (\$200,000 each) every year at a cost of \$1 million or \$5000/case. The cost: return on the care of these cases alone of approximately 10:1, without including the benefit in education and family costs from improved physical, emotional and employment functioning. Can the NDIS afford not to prevent and escalation of such costly family breakdown, and maintain the subspecialty ID professional capacity? Currently there is little sign that Disability NGOs are disposed building capacity to managing 'challenging behaviour' and some are overt in excluding such cases to assign them as a problem for MH. These are the tell tale signs of collaboration failure, at the expense of the individual. The simplest precaution to prevent this public crisis would be to transfer essential multidisciplinary expertise in 'challenging behavior' to mental health to establish subspecialty IDMH multidisciplinary expertise.

The Future of MH ID Services for children and adolescents.

Can the NDIS fund an enhanced Centre of Excellence with continuing capacity for training disability staff in challenging behaviours and MH problems, growing MH prevention and promotion initiatives and enabling clinical research intervention? Such a Centre of Excellence could be a virtual hub across a number of sites, with both clinical and academic components. The Centre for Disability Studies review reports that the DPP provides a service model for complex cases with collaborative partnerships to the wider service sectors that integrates the best of multidisciplinary disability skills with subspecialty health and MH skills. Probably NSW needs something similar for adults with ID as well. The Agency of Clinical Innovation ID Network has focused on the health structure of ID health services, but also needs to incorporate the MH tier structure, as MH is approximately 50% of the health needs seeking assistance at Tier 4 ID health services.

Components of Child and Adolescent MH ID Service Development

Components of Child and Adolescent MH ID Service Development will require both better access to mainstream health and MH and support for the further future development for subspecialty skills. The growth of ID child multidisciplinary MH will need to nurture the seedlings of expertise and training through building partnerships with the stronger associated services. This will depend on future developments in:

1. Building the MH skills in paediatrics and their partnership with general practice/Medicare locals (Tier 1-2).
2. Building partnerships between specialist paediatrics and mainstream CAMHS to advocate for the acceptance of young people with ID access to their tertiary services. Such a partnership would benefit from a service agreement between NSW Kids and Families and CAMHS. It is not clear that the state health system is ever likely to fund full time positions in CAMHS ID (Tier 2-3).
3. Each LHD will need to identify a single contact of a clinician with interest in ID as part of reasonable adjustments as part of developing processes equivalent to "reasonable adjustments", from which to grow expertise in the 'spoke' of each LHD (Tier 2-3).

4. Specialist ID paediatrics will also need to build partnerships with the nascent subspecialty of child psychiatrists in public and private practice. Specialty ID paediatric services will need to fund their own child psychiatry positions. The Neurodevelopmental private paediatricians will need to cultivate partnerships with private child psychiatrists (Tier 3-5).
5. Child Psychiatrists with an interest in ID will need to continue to grow the status of the subspecialty in the RANZCP. There is value in neurodevelopmental and behavioural paediatricians and the Community Faculty of Paediatrics in RACP building a professional partnership with the Special Interest Group in ID in RANZCP (Tier 5).
6. Paediatricians, CAMHS and subspecialty child psychiatrists will need to develop local partnerships with a few of the larger disability NGOs and private practitioners to build capacity in the complementary allied health professions necessary for multidisciplinary collaboration. There may be opportunities for innovative public-private partnerships to enable funding for capacity building, while ensuring the highest quality of professionalism (Tier3).
7. The adolescent forensic MH population with mild or borderline ID, and multiple other disadvantages, such as abuse, neglect, out of home care, homelessness, substance abuse etc are a population that overlaps the population that is the focus of the NDIS, who are not well catered for, but require partnership with Paediatrics, Social Services, and a different group of NGOs. Some of this population is catered for by the AHDC funded Community Justice Program which will transition to the NDIS model (Tier 4-5).
8. There remains a need to build clinical research evidence and innovation in subspecialty ID MH. This will need to include prevention, promotion and early intervention, which will require further partnerships with NSW Department of Education and Independent Schools, NSW FACs, NGOs, research organisations and universities. Data collection and exchange between agencies will be necessary to demonstrate need and improvement. Arguably establishing and orchestrating evidenced-based whole of government PPEI is likely to be the most cost effective intervention, which underlies the principles of NDIS (Tier 2&5).
9. The special needs of complex patients with ID, MH problems, challenging behaviour, law breaking behaviour and family breakdown remains an area that has not had any organised approach and would benefit from the establishment of a Centre of Excellence in NSW and probably in every state. Such a centre would require cross sector/agency support, steering committee and collaboration. This centre might link with a network or local services in a hub and spoke model of service and wider workforce development. Such a Centre could provide the nexus for further world class growth of expertise and services in the future and provide workforce development across NDIS funded NGOs. Such a centre

should have a fully-fledged integrated multidisciplinary team of subspecialty clinicians including psychiatry, paediatrics, clinical psychology and neuropsychology, social work, family therapy, behaviour support, occupational therapy, speech therapy, and probably play therapy, music therapy, and physiotherapy (Tier 5).

10. Establishing a comprehensive tiered service framework for the MH for children and adolescents with ID within the broader health and disability services will enable “pathways to care” to be developed to guide children and adolescents with ID and their families to access the help they need for their children and provide a roadmap across the lifespan for improving their quality of life (ACI Network, 2013; Dossetor, 2011).

In Conclusion

Any model of care for the MH of children and adolescents with ID requires significant developments in mainstream health and MH and the funding of subspecialty MH capacity. Human rights, equity of access, consumer demands and data on ID MH publicised by the Mental Health Commissioners are likely to be the drivers of the development of MH services for children and adolescents with ID. In the current political climate, business modelling and market forces may be the means that need to be harnessed. There is a clear role for professional leadership in the different professional organisations. Partnership is the key to capacity building, including through a model such as a Centre of Excellence, particularly with the NDIS and the care and support providers NDIS will fund. Progress in improving the severe and often chronic MH problems of people with ID is likely to be the most cost effective component of intervention to improve their participation, economic contribution and reduction in impairment.

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