Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:
An Educational Resource

Contents

The aim of this Journal is to improve the mental health of children and adolescents with intellectual and developmental disability through enabling academic debate, research and commentary on the field.

Description and purpose
This journal is a modification of the previous newsletter; a vehicle of expertise about mental health information of children and adolescents with intellectual and developmental disability. As a product of CHW School-Link, this journal is supported by School-Link and a collaborative effort with a multi-agency editorial group from the Statewide Behaviour Intervention team of the Department of Aging Disability and Home Care, NSW Family and Community Services, and NSW Department of Education and Communities. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

On our Website:
www.schoollink.chw.edu.au
The website will be playing a crucial role in the information that CHW School-Link can provide to you.
- *The collection of previous and current editions is located there with the ability to download articles separately.*
- *An invitation for contributions can be found on the website with instructions for authors.*
- *Upcoming training at conferences, workshops and other professional development opportunities will be continuously updated.*

Editorial

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Welcome to the first edition of the Journal for 2015.

We are thrilled to announce that The Children's Hospital at Westmead School-Link staff will be visiting every local health district over the coming months to facilitate a workshop on mental health, intellectual disability and autism in the classroom. A venue timetable and registration page will be distributed shortly and we look forward to visiting your local community.

Autism and the number 10 feature in several articles in this edition. Louisa Carroll writes about the implication of ASD **changes in the DSMV. Ellen Notbohm shares her "10 things every child with autism wishes you knew" whilst** David Dossetor suggests 10 components of child and adolescent MHID service development in this editions feature article about the role of NDIS and complex mental heath of children and adolescents with ID. Rachel Rowles and Lesley Whatson from ADHC- FACs share an insight into their Client Monitoring and Reporting System (CMRS) which aims to improve the effectiveness of support provided to complex and high risk clients. Their article highlights that referrals to this system gather pace at age 10.

Our chief editor Hebah Saleh asks Professor Julian Trollor, Chair of Intellectual disability and Mental Health at UNSW,

10 questions and Michelle Montgomery from Niland School writes 10 paragraphs about her experience in creating a holistic school environment through the establishment of a Community Room. Judy Longworth writes a Medicine Cabinet article about allergies and anaphylaxis highlighting that up to 10% of children and adults can experience adverse effects from antibiotics that resemble allergic reactions.

Enjoy reading this edition of the journal and please send any feedback or your own contributions to schoollink@chw.edu.au

Happy reading!

Jodie Caruana

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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 multiagency 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

> ## "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 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 Wellbeing (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** exampled 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
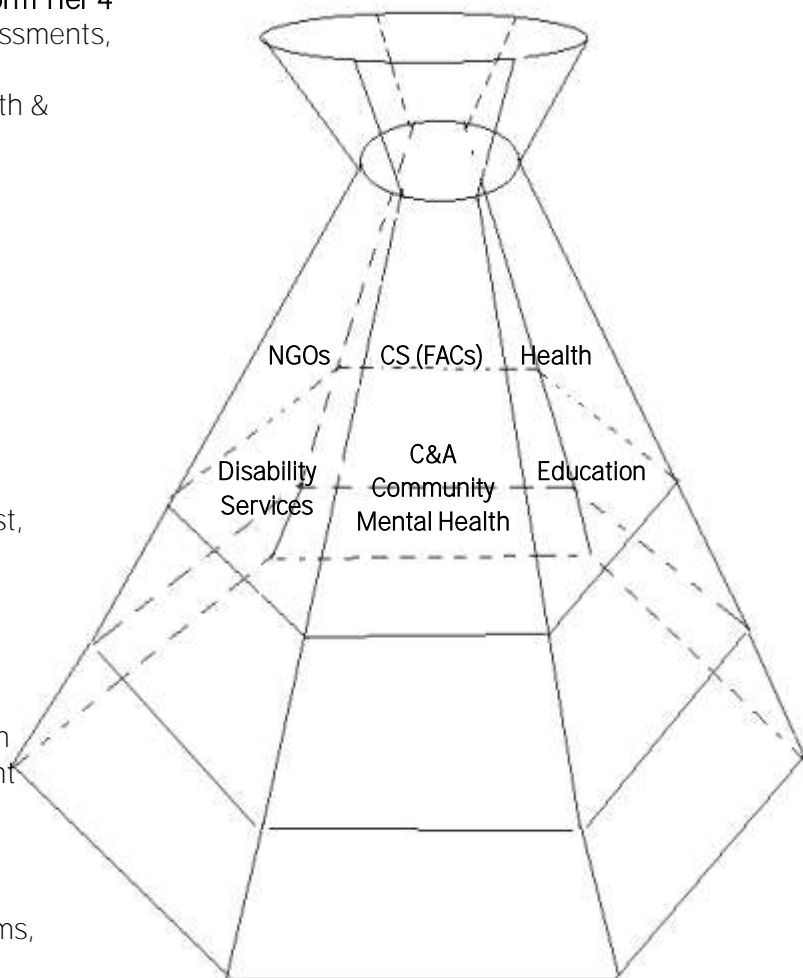
Figure 1
*3D Model provides for **all other human services** to be part of the pyramid*

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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> ## "Partnership is the key to capacity building, including through a model such as a Centre of Excellence..."

Autism Spectrum Disorders: Implications from the changes in DSM-V

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The Diagnostic and Statistical Manual of Mental Disorders Volume 5 DSM-5 was released in May 2013, and with it came some significant changes to the conditions formerly classed as pervasive developmental disorders. Most notably, the diagnosis of Autism Spectrum Disorder (ASD) was formally recognised in the DSM for the first time (finally catching up to clinical practice in the field, which has long recognised and used this terminology descriptively). The 'new' ASD is an umbrella diagnosis that subsumes the former classifications of Asperger's disorder/syndrome and Autistic disorder/childhood Autism, as well as the very clunky "Pervasive Developmental Disorder Not Otherwise Specified" (PDDNOS). Childhood Disintegrative Disorder is retained under the Autism spectrum umbrella, while Retts Syndrome is no longer considered a part of this cluster of disorders. So far, so straight forward – the general consensus was that such changes made good sense, and basically just brought the manual in line with clinical practice.

However, in addition to changing the terminology (ie essentially replacing PDD with ASD), the DSM-5 also introduced some criterion changes that subtly but significantly (arguably) alter the construct of the disorder – by changing the combinations and thresholds of clinical features required to make a diagnosis.

One of these changes was the collapsing of the 'triad of impairments' to a dyad; that is, the previous notion of distinct social deficits, separate to communication deficits, has been replaced by the collective "persistent deficits in social communication and social interaction". Again, the murmurings amongst clinicians on this count seem pretty favourable– if you've ever tried to form a social relationship with someone without communicating with them (verbally or non-verbally) in some way, or if you can imagine any scenario where you might purposefully plan to 'communicate' something to nobody – then you should make your case! – because otherwise it seems evident that 'social interaction' and 'communication' are pretty inextricably intertwined. As an aside, in the DSM-V, any degree of *language* impairment has become a separately coded 'specifier' (where previously it constituted one of several possible examples of a core communication impairment) – which is a further nod to the differentiation of language *as a means of*, rather than as *being*, communication.

Another significant change to the criteria is the relaxing of the age-of-onset criteria (which previously for Autistic Disorder was 3 years), and the option for the behavioural criteria to be met on history (rather than necessarily currently manifest)

Probably most controversial of the changes are the alterations to the 'pick-and-mix' equations that existed in DSM-IV; where individuals were required to have "at least two" from category A (social) + "at least 1" from category B (communication) + "at least 1" from category C (restricted and repetitive interests/behaviours) for a total of "at least 6" altogether to diagnose Autism (and at least 2 from 'A' and 1 from 'B' for Aspergers). This resulted in a myriad of possible combinations of symptoms. Rather, the DSM-V requires ALL of the social-communication deficits to be present, for that criterion to be met. In addition, individuals must present with AT LEAST 2 features from the restricted and repetitive interests and behaviours section to meet that

> "The DSM-V requires ALL of the social-communication deficits to be present, for that criterion to be met..."

criterion. And this is where things have started to get contentious, because in refining the definition to mandate restricted and repetitive interests be present, and to further require that there be evidence of at least 2 qualitatively separate components to how this presents (e.g. an insistence on sameness AND presence of stereotypic motor movements would meet criteria, but an insistence on sameness and ritualised patterns of behaviour would not), there emerge a significant number of individuals who would meet DSM-IV criteria for PDDNOS (and an even a smaller but existent number who would meet criteria for Asperger's or Autistic Disorder), but who do not classify as presenting on the Autism spectrum when considered in terms of the DSM-5 criteria. To capture this group, the DSM-5 also saw creation of a new condition, Social (Pragmatic) Communication Disorder (SCD), which is classified as a language disorder, rather than part of the Autism spectrum.

Those in favour (the purists?) would argue that these changes make sense; that they don't truly alter the underly-

ing construct of the Autism spectrum, they just define it better (ie those who would no longer meet criteria were always on the cusp, and perhaps were given a technical diagnosis when in practice they probably never 'really' presented with the triad/dyad of impairments that constitute Autism). For example, individuals diagnosed with PDDNOS who have never had any restricted or repetitive interests or behaviours.

Those at the coalface of supporting children and their families (and/or those who are just more practically minded) may also recognise, though, that the functional value of a diagnosis is mostly about access to and guidance around what constitutes the best intervention and care. Most families I can think of would be less concerned whether it's called Autism Spectrum or Aspergers, and more interested in how to help their loved ones achieve the best possible outcomes. And when a diagnosis of ASD opens doors to funding and intervention services, but a diagnosis of Social Communication Disorder offers pretty much nothing (the current state of play); there can be no question of 'subtlety' in the re-drawing of the diagnostic boundary that has taken place – the impacts are potentially chasmic. Though it is important to emphasize that this is neither a stipulation nor an intention of the DSM-5; it is a product of how governments and other service providers have opted to interpret and respond to the new diagnostic criteria. The other group that may potentially fall-through the cracks with the revised criteria are those very young children whose full range of symptoms have not yet emerged. In the past, these children might have received an initial diagnosis of PDDNOS later revised to Autism or Aspergers; but in the DSM-5 there is not this flexibility – so for example, a pre-schooler who does not (yet) present with two symptoms from the "restricted/repetitive interests/behaviours" will not meet criteria for

ASD (even though with time further restricted interests etc may emerge, and they may receive the ASD diagnosis at a later date). This has implications for service access, particularly for early intervention, where on the one hand the recommendation is to intervene as early as possible, but on the other there is a risk that age of diagnosis may be delayed.

The other major issue with the introduction of the singular ASD diagnosis was the potential loss of differentiation as compared to having separate Autistic Disorder, Asperger's, and PDDNOS categories. For many, these served as markers of severity. To address this issue, within the diagnosis of ASD the DSM-5 has introduced separate 'general' and 'severity' specifiers, that are intended to be included as part of any formal diagnosis.

The general specifiers are intended to capture any comorbidities, and so require indication of presence and degree of any intellectual disability, presence and degree of any language impairment, association with any known medical conditions, association with any other neurodevelopmental, mental or behavioural disorder, and presence of catatonia. The severity specifiers are intended to communicate the level of support required by the individual *specific to* that ASD criterion. Level 1 equates to 'requiring support', Level 2 'requiring substantial support', and level 3 'requiring very substantial support'. The clinician is required to rate SEPARATELY the degree of severity of social communication impairment, and the degree of severity of restricted and repetitive interests and behaviours.

The use of severity specifiers, while conceptually laudable, seems fraught with challenges. First is the paucity of guidelines and the resulting degree of subjectivity and potential

inter-rater discrepancy in terms of what is meant by the support levels. Arguably even more fundamental is the expectation that clinicians will have read the DSM-5 in close enough detail to know that "Severity of social communication difficulties and restricted, repetitive behaviours should be separately rated.". In the vast majority of DSM-5 diagnostic reports that I have come across, the individual has only been given one, collective severity rating (eg "ASD, severity Level 3"). Finally, the (potential) misuse of the severity specifiers by funding bodies, and educational and intervention services, is concerning. For example, the NDIS, in their operational guidelines around access to that scheme, specify a minimum Level 2 (Requiring substantial support) to be eligible. That is, despite a diagnosis of ASD with one or both areas classed as "Requires support" (Level 1), the NDIS is effectively deeming that these individuals do NOT require support (or not government funded support, anyway). And this is distinct from the fact that the DSM-5 is explicitly clear that the severity level specifiers "should not be used to determine eligibility for and provision of services"

The DSM-5 is very careful to emphasise that the severity specifiers are NOT intended to be static, rather, can "vary by context and fluctuate over time". That is, depending on an individual's personal circumstances, health, environment, and so on, the level of support they will require around either their social communication needs or the management of their restricted or repetitive interests or behaviours – may change. This is again, conceptually, a really important, valuable recognition of the experience of many individuals with an ASD and their families, and goes some way to acknowledging the socially- and environmentally- determined aspects of disability. For example, a young person who has a lot of difficulty coping with transitions and change may have relatively low support needs in this area during a stable period of primary school enrolment between Year 4-6 – but their support level may increase significantly around the point of transition into High School.

Looking to the future, it will be interesting to see what developments emerge in areas related to the revised diagnoses and criteria in the DSM-5.

First of all, evidence is needed around the reliability and validity of SCD as a clinical diagnoses, and the criteria used to define it – particularly, how it is different from ASD, and whether those differences are meaningful (e.g. in regards to things like prognosis and response to treatment), or if the distinction is arbitrary. The reliability and stability of the criteria over time will also be important to track; particularly,

whether there is an impact on the age of diagnosis and access to early intervention services for pre-schoolers who are 'subthreshold' when younger, but later go on to manifest symptoms for an ASD diagnosis.

Table: Summary of key changes to Autism spectrum diagnostic criteria in DSM-5

- 'Autism Spectrum Disorder' subsumes/replaces the previous diagnoses of Autistic disorder, Asperger's disorder, Childhood disintegrative disorder, and PDDNOS
- 'Social-' and 'communication-' impairments combined into one 'social communication' category within which ALL features must be present to diagnose ASD
- Restricted and repetitive behaviours MUST be present (where previously not required for PDDNOS)
- General specifiers introduced to capture any degree of intellectual disability, language impairment, and other comorbidities
- Severity specifiers now included/required; SEPARATE ratings for social-communication, and restricted repetitive interests/behaviours
- Behavioural criteria can be met on history (do not have to be currently manifest)
- Sensory issues now included as an (optional) behavioural symptom rather than just an associated feature
- Functional impairment must be present
- Comorbidities (such as ADHD) can be formally recorded (where previously these were excluded)
- Individuals with a 'well-established' DSM-IV diagnosis of Autistic Disorder, Asperger's Disorder or PDDNOS retain the diagnosis of ASD (even if they do not fully meet the new DSM-5 criteria)

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"The DSM-5 is very careful to emphasise that the severity specifiers are NOT intended to be static, rather, can 'vary by context and fluctuate over time'…"

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Kahane, L. and El-Tahir, M. (2015). Attachment behaviour in children with Autistic Spectrum Disorders. Advances in Mental Health and Intellectual Disabilities. Vol 9, Iss 2, Pp. 79-89.
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This article supports the hypotheses that although children diagnosed with ASD and ID require substantial support their developmental needs are still not being met by their current treatment and services.

The Medicine Cabinet:
FAQs for Allergies and Anaphylaxis

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What is an allergy?
Allergy occurs when there is an immune modulated response to an environmental substance that to some has no response or a therapeutic response. These substances are then called *allergens* and these can include house dust mite, pets, pollen, insects, moulds, foods and some medicines. Some people have inherited a tendency to be allergic and thus are called atopic.

Mast cells in the body (gut, skin, lungs and eyes) are designed to kill worms and parasites. These mast cells are filled with irritant chemicals including histamine. Mast cells are also armed with proteins called IgE antibodies which act to detect allergens in the local environment. When the mast cells recognise the allergen then they can dump the irritant chemicals such as histamine into the surrounding body cells.

What does an allergic rhinitis look like?
Allergic reactions also known as allergic rhinitis occurs in 1 in 5 Australians. Symptoms include runny nose, rubbing a nose, itchy nose, sneezing, itchy and irritable eyes, blocked nose and snoring at night. Many people with asthma also have allergic rhinitis.

These symptoms are usually treated with over the counter preparations from the community pharmacy such as non-sedating antihistamines and limiting exposure to the allergen if possible. If these symptoms persist, longer term management with immunomodulating medications such as nasal steroid preparations may be used.

What is allergic conjunctivitis?
Allergic conjunctivitis is inflammation of the thin membrane on the inside of the eye and this can be itchiness, redness and watery eyes. Mostly these are mild symptoms and usually occur with allergic rhinitis but can be severe and involve **the eye's cornea and then be sight threatening.**

What is eczema or allergic dermatitis?
This is the most common form of dermatitis and occurs in 15-20% children but only 1-2% of adults. This usually occurs in people who are atopic i.e. have inherited the tendency such as family history of allergic rhinitis, atopic dermatitis, and asthma. There are both environmental and genetic factors in play. How the eczema looks varies with age of the child

The skin in people with eczema is more brittle and does not absorb and retain water levels as effectively as other people due to reduced ability to make fats and oils in the skin. Thus people with eczema have a less effective barrier to the environment than those without eczema and although might not have patches of dermatitis the skin is never normal.

Treatment can involve years of moisturising and other topical treatments including topical steroids but for some more complicated treatments involving the immune system are necessary.

What is urticaria or hives?
This is an intensely itchy rash that can occur in children and adults. It may occur by itself or as part of a generalised allergic reaction. This is frequently the first symptom to a food, sting or medication. Acute urticaria can occur as a one off event or the episode can continue for 2-3 weeks. It is often caused by an allergy and the most common cause is food or medication. In children this urticaria can also be associated with infection and it not an allergic reaction. Treatment is often with antihistamines.

What is food allergy?
Food allergy occurs in 1 in 20 children and 2 in 100 adults. **The majority of food allergies are not severe and will 'grow out it' in time. But not all food reactions are due to allergies,** some can be due to intolerances or even poisonings or toxic reactions.

Symptoms of food allergy can be urticaria (hives), swelling around the mouth, vomiting and usually within 30 minutes of eating the food. Other symptoms include runny or blocked nose, abdominal pain or diarrhoea.

But food allergies can also be very SERIOUS and dangerous. Symptoms of severe allergic reaction can occur affecting the breathing and heart. These can include difficult and/or noisy breathing, swelling of the tongue, swelling or tightness in the chest, difficulty in talking or hoarse voice, wheeze or persistent cough, persistent dizziness and/or

"It is very important when starting new medications that the prescribing doctor and pharmacist know all the medications that are being taken..."

collapse. Young children are often described as floppy and pale.

What about medication allergy?
Allergies can occur to complementary and alternative medicines (CAM) both by interacting with conventional (western) medicines in how they respond in the body and just to the substance itself. CAM is often considered very safe as it can **be advertised as 'natural' or 'organic' but allergic reactions** such as allergic rhinitis and /or are common. People with other allergic conditions are often sensitive to many allergens and these can include herbal medicines.

It is very important when starting new medications both CAM and conventional for the prescribing doctor and pharmacist know all the medications that are being taken. This helps identify adverse effects from allergies when a reaction does occur.

Antibiotic hypersensitivity (adverse effects from the antibiotics that resemble allergic reactions) is reported to be as high as 10% in children and adults, are often dose independent, particularly noxious and unintended result of a normal dose given to humans.

- Only when there is a distinct immunological response should these reactions be called allergies.
- Immediate hypersensitivity reactions are usually IgE mediated occur within 1 hour and these are usually urticaria, angioedema, conjunctivitis, rhinitis, bronchospasm, gastrointestinal symptoms and anaphylactic shock.
- Non immediate reactions occurring over 1 hour from taking the medication are often associated with delayed T cell dependent type of allergic mechanism.
- The most common nonimmediate reactions are maculopapular exanthemas and delayed-appearing urticaria and/or angioedema; more rarely, fixed drug eruption, exfoliative dermatitis, acute generalized exanthematous pustulosis (AGEP), Stevens-Johnson syndrome (SJS), and toxic epidermal necrolysis (TEN) can be elicited. These can be life threatening.Assessment of hypersensitivity reactions can be complex with the final diagnosis needing skin test. These can be used for IgE mediated reactions (immediate) using drug provocation testing. Nonimmediate reactions are evaluated by several laboratory tests after delayed reading skin pricks, patch tests and drug provocation testing. In some cases, intradermal testing is not used due to the previous severity of the reaction.Penicillin is the most common drug allergy occurring in 5-10% of adults and children. In people with well documented hypersensitivity reactions there is a potential for cross sensitivity particularly amongst penicillins and cephalosporins. Thus these people should avoid the causal penicillin and related penicillins as well as other β lactams – cephalosporins.

What is anaphylaxis?
A serious allergic reaction that should be considered as a medical emergency, this occurs after exposure to an allergen which the person is extremely sensitive. Anaphylaxis signs include difficult or noisy breathing, swelling of the tongue, swelling and/or tightness of the throat, difficulty talking and/or hoarse voice, wheeze or persistent cough, loss of consciousness and/or collapse, pale or floppy in young children. In some cases there are preceding symptoms such as swelling of face and/or eyes and lips, hives or welts on skin, and abdominal pain or vomiting.
When seeking medical help for anaphylaxis, it is important to be able to identify the allergen causing the anaphylaxis so a series of questions will be asked. Once recovered, a series of tests to formally identify the allergen may also be done. It is important that these are done by a referral to a qualified immunologist or allergy specialist.
Adrenaline (US name epinephrine) is the first line treatment. This may be administered using an autoinjector or an intramuscular or intravenous injection. For more information and videos about how to use the autoinjectors :-
Epipen http://www.allergy.org.au/images/stories/anaphylaxis/multinew/ENG.How_to_give_EpiPen_2011.pdf and Anapen http://www.allergy.org.au/images/stories/anaphylaxis/how_to_give_anapen_2011.pdf .

Helpful websites
www.allergy.org.au - website for Australasian society of clinical immunology and allergy.

www.allergyfacts.org.au - website for the charitable organisation Allergy and Anaphylaxis

http://www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/#cat10 for paediatric centred factsheets on allergy.

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The Community Room: Connecting schools, support agencies and families and transforming lives

Michelle Montgomery

School Counsellor
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"Schools can ignore what lies beyond their gates but they cannot escape it. Students bring with them … everything that has happened to them elsewhere in their lives." (Cummings, Dyson & Todd, 2011, p. 231)

School-based wraparound programs which provide social, financial and mental health support for students and their families are not new. Often known as Full Service Schools, Extended Schools, Community Schools or Community Hub Schools, they recognise that academic achievement is affected by numerous factors outside the academic domain. Such programs focus on the student within a wider social context in order to reduce obstacles to learning and enhance educational outcomes. The negative impacts of chronic stress and poverty on learning are well established (e.g. see Perry, 2001; Haig, 2014). Much has been written about the educational, social and philosophical justification for community school projects (e.g. Dryfoos, Quinn, & Barkin 2005; Dyson, 2011), as well as their effectiveness (e.g. Moore, Caal, Carney, Lippman, Weilin, & Muenks, 2014; James, St Leger & Ward, 2011). This article offers a first-hand perspective of one such project in practice.

In 2012, Niland School initiated a wraparound Community Room Project to ameliorate chronic needs in our community and improve learning outcomes for students by increasing family access to support agencies and strengthening family-school partnerships. The Community Room is a practical space – a large room just next to the main playground area-where family, community agencies and school staff can connect. More importantly, it represents a philosophical commitment to provide holistic care for our students.

The school context
Niland School is a School for Specific Purposes servicing Western Sydney schools and catering for students who have a dual diagnosis of a Mild Intellectual Disability (IM) and an Emotional Disturbance (ED). The school also has an Early Intervention class that caters for Primary aged students with an Emotional Disturbance. Classes at Niland range from Year 3 to 12 with eight IM/ED classes and one ED class.

Niland is a low Socio-Economic Status, equity funded school. It is also a National Partnerships Program School and ESES (Every Student Every School) site. At Niland there is a focus on community engagement to improve the attendance of our students as well as the role the parents and carers play in their child's education. Unfortunately, Niland has long been stigmatised and community involvement has historically been very low. Our families struggle with complex social and educational support needs and this is often exacerbated by parents' own negative school experiences. Indeed, parental involvement and cooperation with school was so poor that many parents refused to even answer school phone calls.

In an attempt to start shifting school and community culture, Principal Renee Culgan used ESES funding to establish the Community Room Project in her first year of leadership. She sees the process as twofold: "The community room serves our families by helping them access services and this helps builds rapport with school staff. But it also helps connect parents and students with opportunities to help themselves long after students leave Niland." By facilitating connections with support agencies such as Mission Australia, Disability Services Australia, and Centrelink, parents are provided with the tools to access ongoing support. Parenting skills, transition to work, social and TAFE outreach programs can also help to increase a family's capacity for positive change and aspirations for employment or further study.

Making changes
Billy's* story is a powerful example of the community room's success as a hub for holistic support. Billy is a year 6 student in his Aunt Rachel's care. Rachel and Billy had arrived in Australia 3 years earlier. They had been living with Rachel's sister-in -law in a violent and precarious situation with no external support or knowledge of her entitlements as Billy's carer. In her first visit to the Community Room open day, Rachel was connected with Centrelink, Mission Australia and Graceades Community Cottage, a local community group. Centrelink arranged for financial support and back pay so Rachel could become independent. Mission Australia worked to find her and Billy a new home, helped furnish it appropriately and provided individual counselling for Rachel. She was also connected with social support groups through the Graceades Community Cottage and made new friends. Billy has participated in a number of school programs aimed to build his self-worth, resilience and self regulatory skills. His home life is much more settled these days, and he is succeeding in class. The school and Rachel have established a strong positive relationship and work together to support Billy to reach his potential.

"School culture is shifting to greater inclusiveness and shared decision making between school staff and carers..."

Other parents have also reported meaningful improvements from Community Room Programs. One parent participated in a parent support program run by a visiting Occupational Therapist. She reported that the work helped her to clarify relationships and meaning in her personal life, increased her feelings of hope, and gave her positive coping strategies. Community Room Coordinator Kisane Wilson says, "The great thing we do is help connect families with the right support. Many of these people have tried to seek help before, and that's such a big thing, to ask for help. So when it's not the right agency, they get so defeated and take it so personally. It's a kick in the guts and they stay down. They don't get up again. Our job is to care for people and the Community Room helps us do that in a way that works for them."

The results have been positive. School culture is shifting to greater inclusiveness and shared decision making between school staff and carers. Parent participation at meetings, school open days and presentation days has tripled. Inter-agency collaboration has begun to occur. Through their partnering work at Niland, Mission Australia and Disability Services Australia have now established joint programs in other local schools. Coreen School has employed our Community Room Coordinator to help establish their own Community Room Programs.

Principal Renee Culgan attributes Niland's Community Room success to 3 main factors: careful planning and commitment to long term change rather than 'quick fixes'; dedicated resources such as the ESES funding and personnel; and all staff sharing a common purpose of supporting students and their families beyond the school gate. Looking ahead, Niland School will further develop its focus on holistic care of students by implementing trauma informed practices in classrooms. Staff will receive training on how adverse childhood experiences affect learning and behaviour, as well as strategies to help students achieve socially and academically. Once known as the "last stop on the line", Niland's future as a place of learning and success is bright.

*Names of students and their families have been changed for privacy reasons.

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Developmental Disabilities, Challenging Behaviour and Mental Health: Research to Practice and Policy – Conference Review

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The *Developmental Disabilities, Challenging Behaviour and Mental Health: Research to Practice and Policy* conference was held at the Footbridge Theatre at the University of Sydney on 7/11/2014. There was an enthusiastic turnout representing the full gamut of the Intellectual Disability (ID) workforce. The topics were diverse and catered to medical professionals as well as those working in allied and non-clinical roles. This was the third annual one day conference on challenging behaviour with a great line up of speakers.

The day's events were divided into four sessions, each with a distinctive theme related to ID: (1) population perspectives, (2) brain functioning in developmental disability, (3) interventions for challenging behaviours, and (4) advancing policy.

1: *Population perspectives*

Eric Emerson began with 'Challenging behaviour: A community issue'. The talk grappled with the definition of what 'challenging behaviour' actually is and also what it is not: it is not an illness or health condition but rather something of a 'catch-all' term. In this regard, the exact prevalence of challenging behaviour in the community depends on where one draws the line. It is believed that around 10% of children with an ID and 5-15% of adults with an ID who use or who are known to services have challenging behaviour. However, there is an unknown 'hidden majority' of adults with mild ID who do not use or who are not known to services. Some groups are more vulnerable than others: people with certain specific syndromes associated with ID

(such as Autism), people with more restricted opportunities to control their environment, and children in families exposed to environmental adversity (such as poverty). Addressing challenging behaviour is a matter of social justice but also a significant clinical issue and it was suggested that the way we approach challenging behaviour might be a good litmus test of our services.

Kerim Munir discussed 'Autism in human populations' which began with an overview of the development of the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) in its approach to Autism and the new term of Autism Spectrum Disorders (ASD). This provided space for historical reflection and it was noted that the first edition of the DSM had no description for Autism or even Pervasive Developmental Disorder; rather, 'Schizophrenic Reaction (childhood type)' was the closest diagnosis. In fact ASD is currently viewed as a set of complex neurodevelopmental health conditions that vary enormously in their presentation from severely impaired individuals at one end of the spectrum to verbally fluent and academically gifted individuals at the other. However, there are difficulties in trying to encapsulate this in the current classification system and the much broader 'Autism phenotype' has not been included in the DSM-5 despite growing evidence on its existence and relevance. The comment was made that the new diagnosis of 'Social Communication Disorder' does not adequately capture this. Mention was made of the Autism and Developmental Disability Monitoring Network (ADDMN) and the current prevalence rates for ASD of 1 in 42 boys and 1 in 189 girls. However, there is clearly a need for
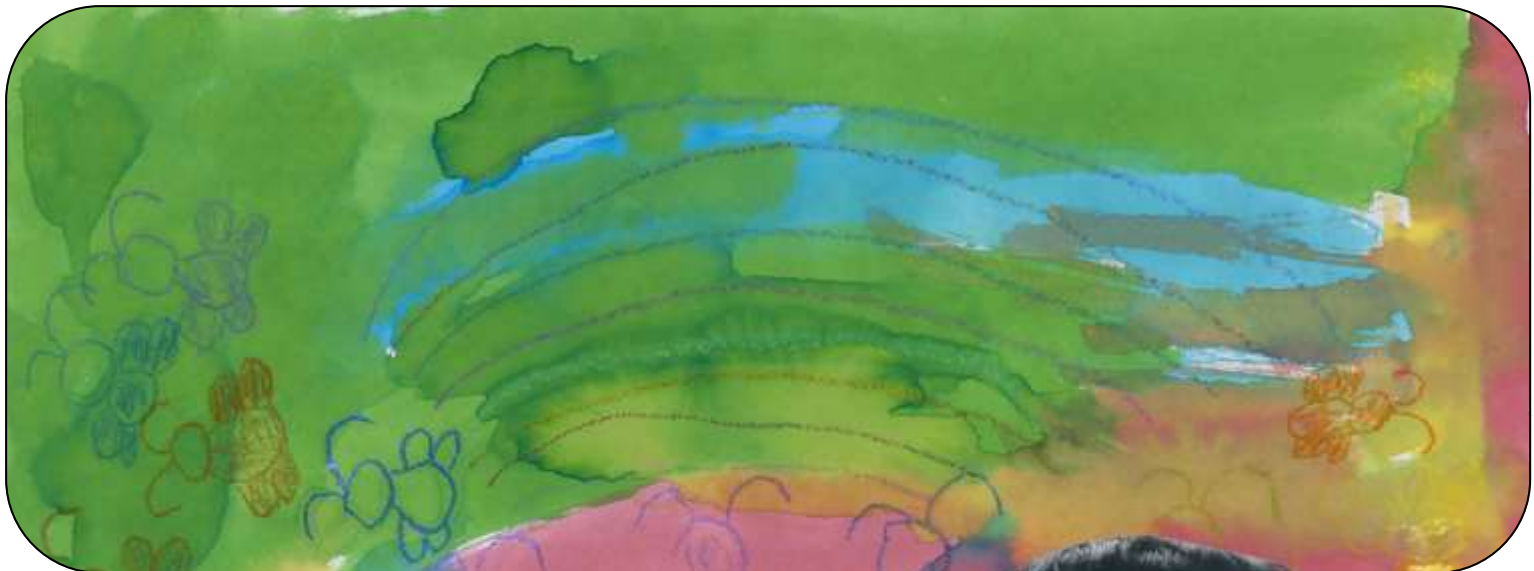
more prospective representative epidemiological studies.

To conclude the first session, Pat Howlin provided a brief overview of the new book *Communication in Autism* which is edited by Joanne Arciuli and Jon Brock. The book appears to be a sophisticated tome discussing this highly variable domain in ASD.

2: Brain functioning in developmental disability

Michael Brammer began this session with 'Developments in brain imaging in developmental disabilities'. This was a medically oriented presentation which evaluated traditional ('univariate') versus more modern ('multivariate') approaches to neuroimaging in ID. In essence, the traditional voxel-based approach has remained the standard to date and more than 95% of the literature refers to this method of imaging. Data is generally easier to understand but the clinical usefulness is debatable. For example, despite having access to univariate modalities such as fMRI for many years, it is rarely used in a day-to-day clinical context. The more modern approach tends to view the brain as a whole and may be able to provide far more detailed information. This way of approaching neuroimaging has only been available for the last five to ten years and as a result researchers are much less familiar with it. 'Maps' of the brain can be created but are not easy to produce and localisation information may not be readily understood. The focus of such multivariate methods presently is on diagnosis: brain scans from a neurotypical group can be compared with a group of patients with ASD and a computer can be trained to separate the two groups and later to apply these learnt rules to other individuals in order to predict diagnosis. Such an approach has already been licensed for assisting in the recognition of Alzheimer's dementia in the USA where early small structural changes can be detected and processed. The method is being used in the diagnosis of Depression, Schizophrenia, Autism, and Attention Deficit Hyperactivity Disorder (ADHD) with a reported accuracy of 75-95% although it is still obviously in its infancy and is expensive. Some concluding cautionary remarks were made about possible ethical, insurance, and family issues associated with computer diagnoses as well as current limitations concerning specificity and sensitivity.

Roshel Lenroot presented on 'New treatment approaches for behavioural problems in developmental disabilities' which began with a discussion on 'synaptopathies' (neuronal synapse abnormalities) and the imbalance between excitatory and inhibitory neuronal activity which is proposed to be at the core of developmental disabilities. Down syndrome was reviewed in this context where synaptic plasticity has been explored in animal models and potential treatment targets subsequently identified, including GABA$_A$ antagonists such as pentylenetetrazole. This medication has a history of use in humans and is available as a cough syrup for children in Europe; however, its usefulness in Down syndrome is only just beginning to be explored with clinical trials underway across Australia. Fragile X syndrome was also reviewed in light of the possible benefits of GABA agonists such as arbaclofen and acamprosate and mGluR5 negative modulators such as fenobam. Developments in the treatment of tuberous sclerosis have been marked and rapamycin (mTOR inhibitor) has had favourable results in humans. The 'Autisms' are also being increasingly explored and the above treatment pathways are being translated, although it remains difficult to account for the significant heterogeneity and pathophysiology associated with ASD. Timing of any intervention is an important consideration and it is generally thought that the earlier the treatment the better the outcome. However, neurodevelopmental disorders can become apparent at different ages and thus treatment effects may vary depending on the stage of development. This is interesting given that most current studies focus on adults and then attempt to translate the findings onto younger age group- trialling medications in children presents an ethically challenging hurdle. However, with the conceptual possibility of prenatal treatment for Autism on the therapeutic horizon, it is apparent that exciting progress is afoot.

> "Parent-mediated treatment programs may improve outcomes for infants and toddlers at high risk of developing Autism…"

Roger Stancliffe presented on 'Mental Health support for older people with developmental disabilities' and reviewed some of the experiences of adults with ID. These included the high rates of depression, loneliness, and adverse life events as well as low levels of employment and participation in domestic and community activities. Observational studies have found that 33-42% of residents in group homes have very low average levels of participation which is vastly atypical compared to the general population where 99% of adults spend their waking time engaged in activities. Low participation levels have been correlated with poorer physical and mental health. With this in mind, the *Active Support* interventional approach was explored. This aims to increase staff support, resident participation, and adaptive behaviour and decrease levels of depression, self-injury, stereotyped behaviour, and withdrawal. *Transition to Retirement* is a program which applies these concepts to mainstream communities and involves facilitating individuals to participate in the community group of their choice where they can receive support from volunteer mentors. In the program, mentors are trained to provide effective social support and ensure activities are available. The approach is very much person-centred and there is generally one person with a disability per group. Video clips were shown which followed an individual engaging in a group and demonstrated these principles well.

3: Interventions for challenging behaviours

Pat Howlin commenced the third session for the day with 'Effective interventions for Autism: what does the latest evidence show?' This talk began by warning of internet-

promoted therapies that are often unsupported, expensive, and dangerous. The central theme of the talk was on psychosocial interventions for families with autistic children. The focus on the early years (one to six years) holds relevance given the plasticity in early brain development. Here the goal is to avoid the development of maladaptive behaviours (in parents and children) and set children off on more 'normal' trajectories. Preliminary evidence has suggested that parent-mediated treatment programs may improve outcomes for infants and toddlers at high risk of developing Autism. Specifically, early intensive behaviour intervention (EIBI) is an intensive strategy with moderate to large effect sizes in most. Behaviourally based training for parents varies in its results but can lead to significant improvements in parents' stress, mental health, knowledge of Autism, ability to carry out the program, perception of control, and quality of life.

James Harris's presentation on the 'DSM-5 and ICD for people with developmental disabilities' provided an involved and informative overview of the DSM-5 categorisation of neurodevelopmental disorders and the co-occurrence of certain diagnoses, for instance ASD and ADHD. The current DSM criteria for ID (deficits in both intellectual and adaptive functioning with onset in the developmental period) were detailed, as were the inherent problems associated with trying to subcategorise these disorders meaningfully, given their profound heterogeneity. Another problem is the strict age limit definitions of the 'developmental period' given that the brain continues to mature well beyond the previously accepted and rather arbitrary 18-year-old cut-off. In ASD, the transition from three core criteria to two in moving from DSM-IV to DSM-5 was highlighted. Further, the recognition of Autism being a spectrum of disorders (in favour of

the older classification which attempted to segregate out Asperger disorder) is seen as an important step in improving the accessibility of services in the USA.

Stewart Einfeld concluded the session with 'Community-wide approaches to interventions for behavioural problems'. This began with the statistic that children with an ID have a three- to four-fold increase in behavioural and emotional problems. The *Australian Child to Adult Developmental Study* found that only 10% of children with severe behavioural and emotional problems received expert help and most do not gain access to appropriate evidence-based treatment. The *Stepping Stones Triple P Program* was reviewed and there appears to be growing evidence for its efficacy. The creation of carer resources for seven specific behavioural phenotypes (Down syndrome, Fragile X syndrome, Foetal Alcohol Spectrum disorders, Williams syndrome, Prader-Willi syndrome, ASD, and Velo-cardio-facial syndrome) represents an impressive advance in the field.

4: Advancing policy

Holly Proddis offered the final session with 'Supporting families affected by developmental disabilities'. Holly spoke about the Luke Priddis Foundation, of which she is the Director and co-founder. The Foundation emphasises the importance of social support for families of children with ASD. This was quite a personal talk, as Holly's own son was diagnosed with ASD in childhood. Holly spoke of how the family struggled with limited information and support. Stories were shared about young people and their families who had attended the Foundation's various activities which provided an individualised context to people living with disabilities.

Julian Trollor prescribed 'The need for a national guide' and provided an overview of the sociopolitical context of challenging behaviours, services, and supports as well as funding and policy considerations. Historically, a disconnect has existed between health and disabilities funding but ideally care will start to move towards more individualised, multidisciplinary services which are not based on funding boundaries. The talk addressed progress with ID being incorporated into mental health policies in recent years, as well as the recognition of elevated rates of mental health problems in ID. However, the translation into practice is far from complete. The development of ID mental health educational resources and research at 3DN was outlined.

The day's events concluded with the NSW launch of *The Guide: Accessible Mental Health Services for People with an Intellectual Disability (A Guide for Providers)* which was very well-received by all. *The Guide* is a landmark document (available in print and online at www.3dn.unsw.edu.au) which offers a framework for mental health professionals to improve the accessibility and quality of mental health care for people with an ID. Julian Trollor, Holly Priddis, and the NSW Mental Health Commissioner, Mr John Feneley, spoke at the launch which provided both an enjoyable and optimistic finale to the day.

Book Excerpt: Ten things every child with Autism wishes you knew.

Ellen Notbohm

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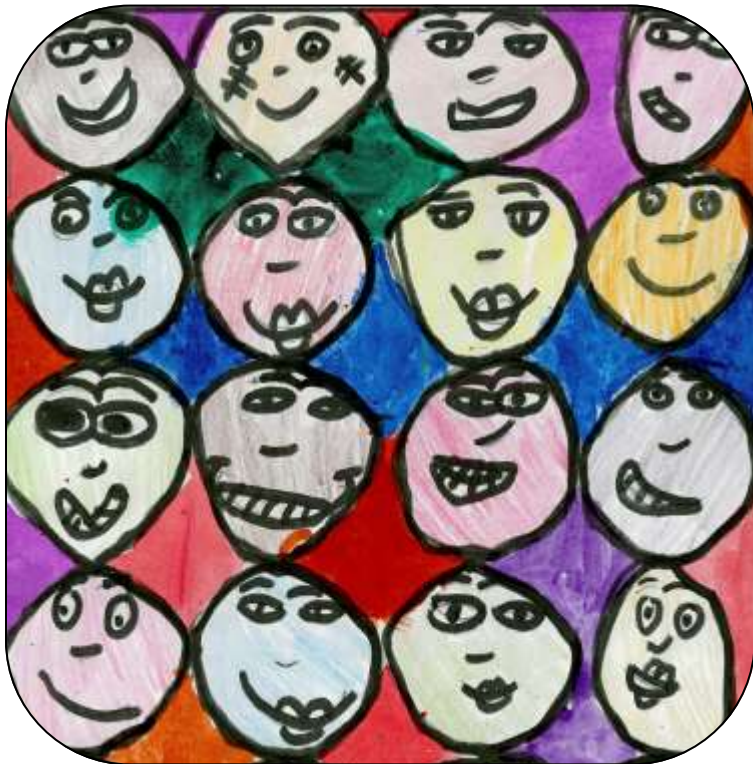
Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute—the inconsistency. Autism can be baffling, even to those who spend their lives around it. The child who lives with Autism **may look "normal" but his behaviour can be perplexing and** downright difficult.

Autism was once labelled an "incurable disorder," but that notion has crumbled in the face knowledge and understanding that increase even as you read this. Every day, individuals with Autism show us that they can overcome, **compensate for and otherwise manage many of Autism's** most challenging characteristics. Equipping those around **our children with simple understanding of Autism's basic** elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is a complex disorder but for purposes of this article, we can distil its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. Although these four elements may be common to many children, keep front-of-

"Autism was once labelled an "incurable disorder," but that notion has crumbled in the face knowledge..."

mind the fact that Autism is a spectrum disorder: no two (or ten or twenty) children with Autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly, every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with Autism wishes you knew:

1. I am a child.
My Autism is part of who I am, not all of who I am. Are you just one thing, or are you a person with thoughts, feelings, preferences, ideas, talents, and dreams? Are you fat (overweight), myopic (wear glasses) or klutzy (uncoordinated)? Those may be things that I see first when I **meet you, but you're more than just that, aren't you? As an** adult, you have control over how you define yourself. If you want to single out one characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. If you think of me as just one thing, you run the danger of setting up an expectation **that may be too low. And if I get a sense that you don't think** **I "can do it," my natural response will be, why try?**

2. My senses are out of sync.
This means that ordinary sights, sounds, smells, tastes, and touches that you may not even notice can be downright painful for me. My environment often feels hostile. I may **appear withdrawn or belligerent or mean to you, but I'm just** **trying to defend myself. Here's why a simple trip to the gro-**cery store may be agonizing for me.

My hearing may be hyperacute. Dozens of people jabber at **once. The loudspeaker booms today's special. Music blares** from the sound system. Registers beep and cough, a coffee grinder chugs. The meat cutter screeches, babies wail,

"It's hard for me to tell you what I need when I don't have a way to describe my feelings…"

carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy nappy, they're mopping up pickles on aisle three with ammonia. I feel like throwing up.

And there's so much hitting my eyes! The fluorescent light is not only too bright, it flickers. The space seems to be moving; the pulsating light bounces off everything and distorts what I am seeing. There are too many items for me to be able to focus (my brain may compensate with tunnel vision), swirling fans on the ceiling, so many bodies in constant motion. All this affects how I feel just standing there, and now I can't even tell where my body is in space.

3. Distinguish between won't (I choose not to) and can't (I am not able to).

It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, I hear "*&^%$#@, Jordan. #$%^*&^%$&*." Instead, come over to me, get my attention, and speak in plain words: "Jordan, put your book in your desk. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.

4. I'm a concrete thinker. I interpret language literally.

You confuse me by saying, "Hold your horses, cowboy!" when what you mean is, "Stop running." Don't tell me something is "a piece of cake" when there's no dessert in sight and what you mean is, "This will be easy for you to do." When you say, "It's pouring cats and dogs," I see pets coming out of a pitcher. Tell me, "It's raining hard." Idioms, puns, nuances, inferences, metaphors, allusions, and sarcasm are lost on me.

5. Listen to all the ways I'm trying to communicate.

It's hard for me to tell you what I need when I don't have a way to describe my feelings. I may be hungry, frustrated, frightened, or confused but right now I can't find those words. Be alert for body language, withdrawal, agitation or other signs that tell you something is wrong. They're there.

Or, you may hear me compensate for not having all the words I need by sounding like a little professor or movie star, rattling off words or whole scripts well beyond my developmental age. I've memorized these messages from the world around me because I know I am expected to speak

when spoken to. They may come from books, television, or the speech of other people. Grown-ups call it echolalia. I may not understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Picture this! I'm visually oriented.

Show me how to do something rather than just telling me. And be prepared to show me many times. Lots of patient practice helps me learn.

Visual supports help me move through my day. They relieve me of the stress of having to remember what comes next, make for smooth transition between activities, and help me manage my time and meet your expectations.

I need to see something to learn it, because spoken words are like steam to me; they evaporate in an instant, before I have a chance to make sense of them. I don't have instant-processing skills. Instructions and information presented to me visually can stay in front of me for as long as I need, and will be just the same when I come back to them later. Without this, I live the constant frustration of knowing that I'm missing big blocks of information and expectations, and am helpless to do anything about it.

7. Focus and build on what I can do rather than what I can't do.

Like any person, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need fixing. I avoid trying anything new when I'm sure all I'll get is criticism, no matter how "constructive" you think you're being. Look for my strengths and you will find them. There is more than one right way to do most things.

8. Help me with social interactions.

It may look like I don't want to play with the other kids on the playground, but it may be that I simply do not know how

to start a conversation or join their play. Teach me how to play with others. Encourage other children to invite me to play along. I might be delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to read facial expressions, body language, or the emotions of others. Coach me. If I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know what to say. Talk to me about Emily's feelings and teach me to ask, "Are you okay?"

9. Identify what triggers my meltdowns.

Meltdowns and blow-ups are more horrid for me than they are for you. They occur because one or more of my senses has gone into overload, or because I've been pushed past the limit of my social abilities. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, and activities. A pattern may emerge. Remember that everything I do is a form of communication. It tells you, when my words cannot, how I'm reacting to what is happening around me.

My behaviour may have a physical cause. Food allergies and sensitivities sleep problems and gastrointestinal problems can all affect my behaviour. Look for signs, because I may not be able to tell you about these things.

10. Love me unconditionally.

Throw away thoughts like, "If you would just—" and "Why can't you—?" You didn't fulfil every expectation your parents had for you and you wouldn't like being constantly reminded of it. I didn't choose to have Autism. Remember that it's happening to me, not you. Without your support, my chances of growing up to be successful and independent are slim. With your support and guidance, the possibilities are broader than you might think.
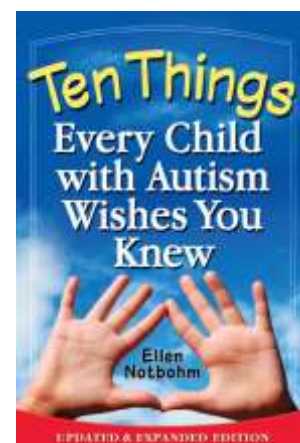
Three words we both need to live by: Patience. Patience. Patience.

View my Autism as a different ability rather than a disability. Look past what you may see as limitations and see my strengths. I may not be good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, or pass judgment on other people?

I rely on you. All that I might become won't happen without you as my foundation. Be my advocate, be my guide, love me for who I am, and we'll see how far I can go.

Equal before the Law: Towards Disability Justice Strategies

Reviewed by Terry Sarten
Previous CHW School-Link Coordinator

The release in February of 2014 of the Human Rights Commission report 'Equal Before the Law: Towards Disability Justice Strategies', is a crucial and timely document. This report draws a significant line in the sand. It is both critical of the current inequalities affecting those with disabilities when engaging with the justice system and simultaneously optimistic that a strategic response can create change, while providing a realistic measure of how far there is to go before equal justice before the law is achieved.

Built on wide consultation and submissions from key stakeholders gathered in 2013, it provides a clear picture of the inequities that interaction with the justice system currently present for those with a disability, whether victims of or perpetrators of crime.

These inequities include the lack of access to effective justice as a further layer of disadvantage. It notes the exposure of those with a disability to further risk due to a lack of protection, and acknowledges that some victims, can become caught in a cycle of offending. The relatively high risk of being imprisoned can led to repeated involvement with the justice system, compounding the already existing inequities.

"The lack of access to effective justice is a further layer of disadvantage..."

The report highlights the difficulties of identifying disabilities and responding with the appropriate supports which are often lacking. The report mentions the unknown impact of NDIS on disability support services and its potential effect on access to justice.

The issue of communication and misunderstanding about the legal competence of those with disabilities is highlighted along with barriers created by the perceptions that they will be unreliable, not credible or incapable of being a witness. This can be compounded by a questioning style by police, lawyers, courts and custodial officer that can confuse those with disabilities. The Commission heard that those with disabilities often experience prejudicial assess-

ments of their competence to give evidence.
Professor Martine Powell spoke to the Commission about research that shows people with an intellectual disability **can provide accurate and reliable testimony but** "poor interviewing practices negatively influences the quality of evidence elicited" noting the decline in accuracy from inappropriate questions is greater for vulnerable witnesses.

The variation in relevant legislation between states is noted as an issue. The Uniform Evidence Act has been enacted in NSW, Victoria, Tasmania and ACT but not in Queensland, South Australia, Northern Territory or Western Australia. The Act provides a clear legal framework for consideration of disability in Court proceedings. The testing of such legislation, as explained by South Australia Chief Justice Kourakis, is however reliant on the issues coming before the High Court but in the current situation this rarely happens. The report noted this as an indication that people with disabilities and their advocates are not aware of the potential legal pathways.

The Commission heard that diversion measures were not well utilised, not available or were ineffective without appropriate supports and services. People with disabilities were less likely to get bail and then have difficulty understanding and complying with the conditions.

The report places considerable emphasis on safety, freedom from violence and the importance of access to services that can provide the necessary level of support. This is linked to the 2013 ABS Personal Safety Survey which found that those with a disability or long term health conditions experienced higher levels of violence than the wider community, with higher rates for women with disability. There is also a higher risk of violence for those with disability within the criminal justice system.

The issues and challenges are evident in the profiles of disability for Aboriginal and Torres Strait Islander people. The 2009 Australian Bureau of Statistics found this population were 1.7 times more likely that non-indigenous people to be living with disability. For indigenous children aged below 14 yrs, the rate was 14.2% compared with 6.6% for their non-indigenous peers. Coupled with a rate of imprisonment 15 times higher than average, there is a high risk trajectory for this population to be involved with the justice system .

This picture of disadvantage in so many aspects for those with disabilities and the need for change is clearly stated in the foreword to the report by the Disability Discrimination Commissioner Graeme Innes. It acknowledges the Australian criminal justice system is complex but that equal treatment irrespective of difference is fundamental and that the **report will 'begin the work of redressing inequality experienced by Australians with disabilities, particularly those with complex support needs and communication challenges".**

The report does not make specific recommendations but has focused on barriers, services, programmes and proposing actionable steps towards a Disability Justice Strategy.

"It emphasises the importance of partnership with people with disabilities in the development of a justice strategy…"

The report proposes that each jurisdiction develop an holistic overarching response to the challenges presented with a strategy that focuses on the safety of people with disabilities. The strategy should describe effective justice that is non-**discriminatory and reflects a respect for the** "inherent dignity and individual autonomy including the freedom to **make one's own decisions with full and effective participation and inclusion in the community".**

The report emphasises the importance of partnership with people with disabilities in the development of a justice strategy alongside the coordination of services, with actions embedded in operational practice that is monitored and adjusted as experience progresses.
Crucial to this process is accountability via the parliamentary democratic process and public administration.

Summary
In its conclusions, the Commissions report notes that equality before the law for those with disabilities will not be easily achieved. It encourages governments around Australia to consult, work and learn together to remove barriers to accessing justice.

The report includes the economic consequences of inequality in access to justice in considerable detail. This may be of importance to policy makers, politicians and economists but these are a sideline to the ethical and human rights questions of equity in access to justice highlighted by the Commission.

Link to paper and reference https://www.humanrights.gov.au/sites/default/files/document/publication/2014_Equal_Before_the_Law.pdf

(Access to justice in the criminal justice system for people with disability. Issues Paper 2013)
https://www.humanrights.gov.au/publications/access-justice-criminal-justice-system-people-disability-issues-paper-april-2013

The Client Monitoring and Review System (CMRS)

Rachel Rowles *(A/Senior Project Officer, CMRS & TBP)*
Lesley Whatson *(Team Co-ordinator, Children's Team, Statewide Behaviour Intervention Service)*

Background and Overview:
The CMRS was established within Ageing, Disability and Home Care (ADHC) in 2011 to facilitate the identification; escalation and independent review of those clients of concern to the (now) ADHC Districts/Program Areas. At the time, there was no single system across the state that identified complex cases that ADHC was involved with, nor articulated what ADHC responses should be. Similarly, there was no single system for monitoring and measuring change.
This initiative was designed to improve the effectiveness of support provided to people who present with high risks and complex support needs through:

- The development of enhanced strategies for managing complexities and risks in the context of a person centred approach
- Identifying systemic strengths and gaps within individual cases and developing state wide solutions where required
- Improving the quality of life for identified clients
- Ongoing, proactive monitoring of cases, and
- Identifying trends/patterns across the initiative and creating systems responses to these.

Figure 1: CMRS Governance

The CMRS comprises a set of three complementary projects designed to improve clinical governance and client risk management. It is essentially an internal quality assurance and clinical support mechanism for ADHC staff and senior management.

1. Reporting and data analysis:

Districts and identified Program Areas are required to provide quarterly updates regarding all Tier 1 and Tier 2 clients. The Quarterly reports are provided to and analysed by Clinical Innovation and Governance (CIG).
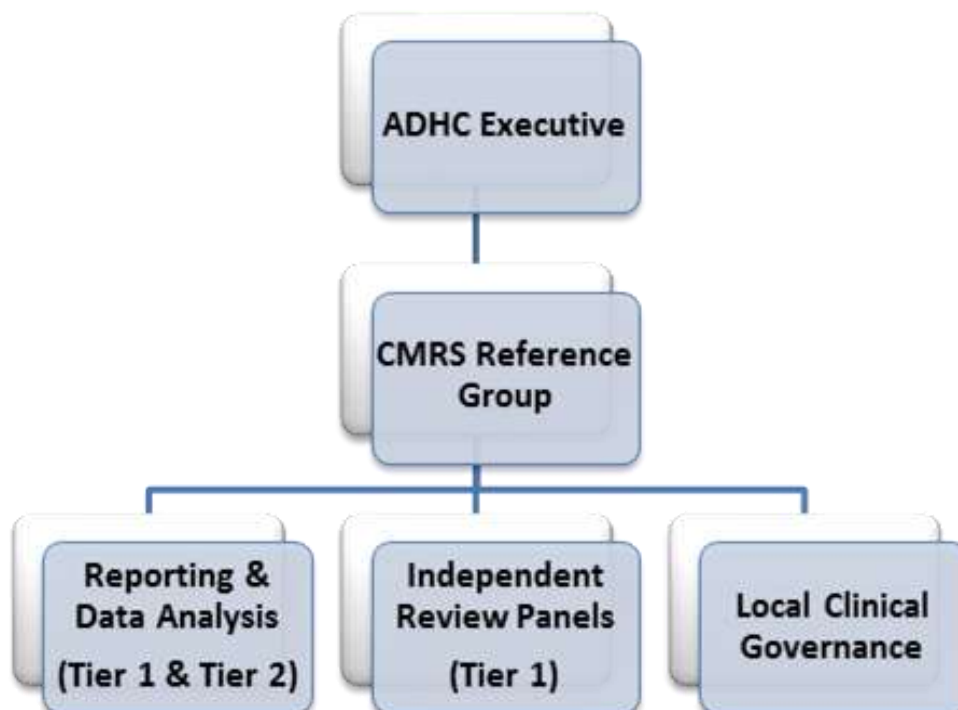
It should be noted that the language of "Tiers" pre-dated the NDIS and has not relationship to the NDIS "Tiers".

Tier 1 Register
People listed on the Tier 1 register are those individuals of immediate concern because Districts:

- have been unable to resolve complex individual or system-related issues, and/or
- do not have the capability to deliver the complexity of support required
- have identified a significant risk which would benefit from external review to determine whether other strategies than those proposed are warranted.
- individuals who, on the basis of clinical judgment, would benefit from external review or escalation.

Tier 2 Register
People listed on the Tier 2 register are those for whom the District has identified significant issues of concern and:
- who are or should be subject to monitoring by senior District management
- for whom a serious adverse outcome is likely but may be prevented due to the current provision of additional resources and/or specialist level support
- whose circumstances do not require or would not benefit from external review or further escalation at this point in time.

2. Independent Review Panel:

A specialist Panel which conducts independent reviews of the ADHC services being provided to clients on the CMRS Tier 1 register.. This is not a clinical assessment of the client therefore they are not present but rather it is a review of the support provided by the local ADHC team in order to provide guidance in relation to future supports.

Internal members of the panel include the Executive Director or his delegate, CIG (Chair), senior Behaviour Support and Case Management specialists from different Districts/Programs Areas to those presenting their cases. There are also four external specialist areas that are routinely represented i.e. Psychiatry, general medical/paediatrics, behaviour support, and advocacy. Other internal and external specialists may be called as required. All panel members are acting as consultants for ADHC and have signed Confidentiality and Conflict of Interest disclosure agreements.

3. Local clinical governance systems:

ADHC has developed an approach to improve responses for vulnerable individuals with complex support needs. This has been referred to as the Client Monitoring and Review (CMR) Approach. It identifies how each component of the system interacts with the wider organisational, cultural and behavioural factors that can impact on achieving good practice. Each District/Program Area has developed a localised approach to this component of the system. The aim is to minimise the numbers of people on the statewide Tier 1 and Tier 2 register over time due to more effective local clinical supports and governance.

There is a Reference Group for the CMRS which provides overarching advice and input into CMRS projects. Meetings
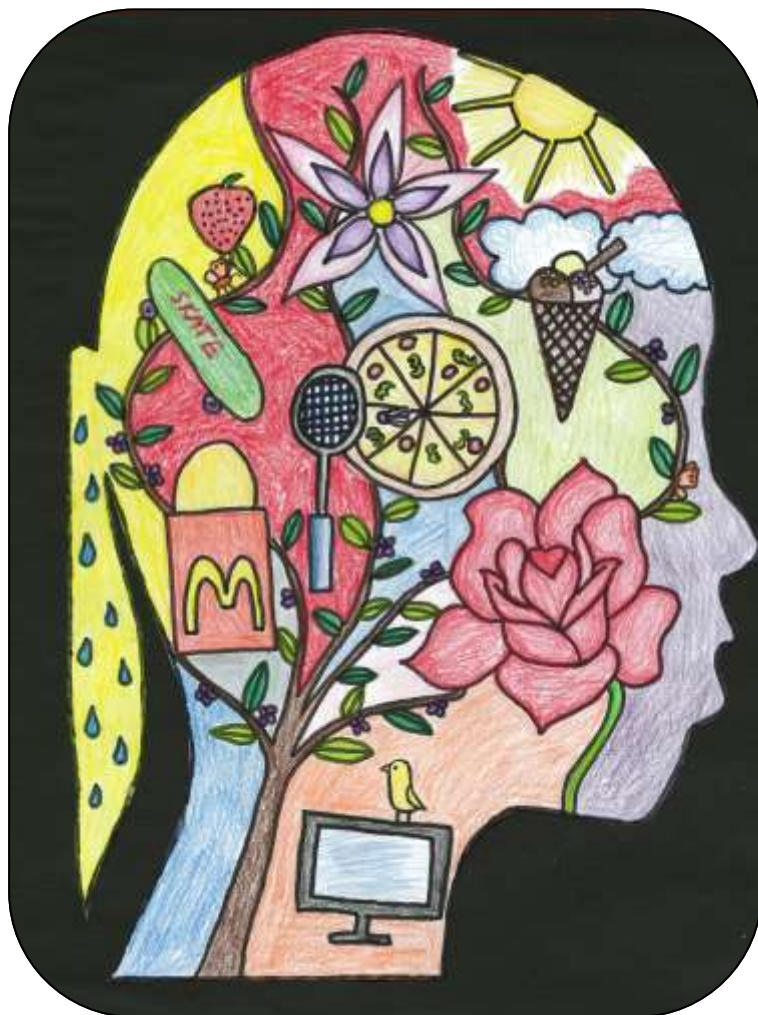
At the end of the December 2014 reporting period, there were 218 clients (across the age range) registered in CMRS, 73 on Tier 1 and 145 on Tier 2. To date, the total number of children, young people and adults who have been registered with CMRS since it's inception in 2011 is 618.

Children and Young People in CMRS (18 and under at the point of referral)
Table 1 displays the number of children and young people (18 and under at the point of referral) registered with CMRS since 2011 and the age at which they were referred. A total of 233 children and young people have been registered with CMRS, comprising 39% of all referrals.

Table 1: Number of children / young people referred to CMRS

Age at referral	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Total
No. of referrals	2	1	3	7	2	4	5	4	10	12	16	8	19	25	30	32	53	**233**

are co-ordinated by CIG with representation from each District and Program.

CIG provides regular confidential Status Reports to the ADHC Executive providing information regarding all three CMRS components to support strategic decision-making.

Children and young people represent 38% of the overall referrals to CMRS.
Source Status Report 7, November , 2014 (ADHC– Internal Document only)

From the available data we can see that referrals to the CMRS begin to gather pace at age 10, with the number of

"Maintaining connections between child and family was a critical factor in restoring relationships..."

referrals for each age point steadily increasing; except 13 year olds where we see a drop.

Reason for nomination of children and young people (18 and > at point of referral)

When individuals are nominated to Tier 1 or Tier 2 the reasons for nomination are divided into three categories: client, carer, and system issues. Multiple concerns are usually identified for each client. Analysis of current data relates that these issues include:

1. Issues Relating to Clients:
- Behaviours of Concern
- Complex health, medical and/ or physical needs
- Decline in service, does not consent to service or refuses mandatory services
- Deteriorating mental or physical health
- History of placement breakdown or inappropriate models of support
- Inappropriate placement or accommodation
- Impact of dual diagnosis, e.g. Mental health, drug and alcohol
- Perceived reputation of client impacts on ability to identify suitable provision
- Receiving services from multiple providers without con-tinuity of care
- Young male (under30) with Autism Spectrum Disorder

2. Issues relating to Carers:
- Ability to manage support which places the client, carer or family at risk of harm
- Age and support needs of other family members, including two or more people in the home with a disability
- Conflict with current or future support arrangements
- Considering relinquishment
- Exhaustion, stress, depression or mental illness
- Family/Carer unable or unwilling to support the person with a disability
- Financial impact on carer/client/family due to carer not being able to work due to caring responsibilities and cost of equipment/therapy/aids
- Health diagnosis/condition that impacts on ability to manage challenging behaviour and/or complex health/physical needs
- Limited access to informal supports, or nature of disability impacts on informal supports
- Recent death or diagnosis of terminal illness that impacts on ability to maintain current care arrangements

3. Issues Relating to the system supporting the individual:
- Community Concern
- History of service systems being slow to respond
- Multiple agencies or programs involved without a shared view about what is required
- Restrictions on what support will be provided by formal support system
- Suitable option unavailable due to gaps, capacity or waiting times
- Suspension from program/services

- System has previously provided high cost/high level services which are not sustainable with no alternative defined
- Transition points mean reduction in available support to family

Issues of significance

The percentage of clients affected by particular issues is reasonably similar across the two Tiers. Notable exceptions include the higher proportion of clients on Tier 1 where **"impact of dual diagnosis e.g. mental health, drug and alcohol" has been cited as a reason for nomination. Increasingly, Districts are utilising Tier 1 to explore questions relating to specific medical/clinical supports.** From the data, the predominant issues currently impacting carers of clients registered with the CMRS include health diagnoses and exhaustion / stress / depression. Risk of relinquishment and the limited range of options in residential support for children outside of the family home is also a significant theme for this high risk and high needs group.

Panel recommendations

Panel recommendations are analysed to identify the key clinical and/or systemic themes. The most prevalent issues in the most recent review are:

- Require additional clinical and casework expertise

- Need more comprehensive medical care

- Collaborative approaches with other agencies needed

On a number of occasions where the child or young person lives outside the family home, it was noted that maintaining connection between child and family was a critical factor in restoring relationships that had deteriorated prior to the child moving homes. The data reflects that the One Facs realignment (which has brought various parts of the Department under the same management structure within a District) has strengthened relationships and collaboration across ADHC and Community Services where children with **disability have been identified as "at risk", . Panel recommendations** regularly highlight the importance of connection across agencies.

Response to identified risk and emerging themes

In response to the issues identified through the CMRS and other key issues arising in the disability field CIG is undertaking a number of initiatives in the following areas:

- Building the capacity of the service system: eg. Core Standards for clinical disciplines; Practice Guides for clinical risk assessment, and service model assessment.
- Enhancement of working relationships across agencies eg. MOU between Mental Health and ADHC, expansion to NGO sector.
- Policy development and alternative models of care eg. Trauma Informed Practice Framework for supporting people with intellectual disability.

- Monitoring and quality assurance eg. Restricted Practice Authorisation monitoring system for NGO's.

Where to from here?

There has been a significant amount of change to ADHC as an agency since the original conceptualisation of the CMRS and its implementation strategies. The move to Districts, a FACS realignment as well as the implementation of the NDIS have altered the disability landscape considerably. CIG is currently developing a strategy to share the approach and resources with the NGO sector to help prepare for the NDIS transition. A discussion regarding the CMRS transition will be offered in the next edition of this journal.

Interview with Associate Professor Julian Trollor

Chair, Intellectual Disability Mental Health
Head, Department of Developmental Disability Neuropsychiatry
Professor, School of Psychiatry
UNSW Medicine

How did you become involved in intellectual disability psychiatry? And were there any key influences?

There were some key influences. A key opportunity came up in 2009 to pursue something I had always been passionate about. It was visionary that ADHC set aside funding for the new chair of intellectual disability mental health. When I saw that I was immediately interested in applying for that role because I could see that this was an area of quite substantial need and it provided a great sense of challenge to me. However, my interest goes back much further than taking on the role in 2009. I had some quite remarkable early mentors when I was training in psychiatry, in particular during my training in child and adolescent psychiatry I encoun-

tered a senior and highly respected psychiatrist Dr Helen Molony.

At that stage Helen was partly funded by disability services to work in intellectual disability mental health seeing a broad range of clients. I sat in on some of her assessments and learnt a lot about assessing people with intellectual disability, adapting approaches and about working in a collaborative framework in a multidisciplinary team and indeed across service sector boundaries. She provided inspiration, so much so that some of the patients I saw with her as her trainee, I still see today.

After finishing psychiatric training I went straight into neuropsychiatry and trained in that specialty area. A core part of my work was seeing people with intellectual disability and complex neuropsychiatric disorders for evaluation in a tertiary setting. Some of those evaluations were inpatients and some were outpatients. That was a really significant experience that again reinforced the need for a very systematic approach for often very complex mental health and physical health problems. This background made me jump at the opportunity to contribute in the new role as Chair of Intellectual Disability Mental Health. Particularly as it was geared towards capacity building.

You hold the first formal chair of Intellectual Disability Psychiatry in Australia. What do you see as the role of the chair? How important are the developments in intellectual disability psychiatry for the welfare of people with intellectual disability?

The mental health needs of people with an intellectual disability are very significant and overall the burden of mental health problems are about 3-4 times of the general population. That tells us that really in order to uphold the basic human rights of a person with an intellectual disability it is very important that we address health and in particular mental health needs. In order to support a person or a population group to achieve a high standard of mental health and wellbeing, developments in this area are quite critical. Prior to taking on the role I now have, I am very much aware that there have been many initiatives and significant work in this area by others. Very broadly, I see the role of the chair as one of the national leadership of services, workforce and research initiatives in intellectual disability and mental health. This is divided into three main sections; ca-

pacity building, research and consultancy. For readers interested in the key projects we have in those areas, please refer to our website www.3dn.unsw.edu.au.

What are the main projects and research being undertaken with your team?

They fit into those three main areas of building capacity, research and consultancy. If I could take you through those current and future plans; firstly, in current projects for building capacity we have a very strong focus on intellectual disability mental health education. We completed staff surveys of confidence and learning needs with mental health staff in NSW. We have developed intellectual disability e-learning modules which keeps us very busy. We have conducted a local and then national audit of medical and nursing schools looking at intellectual disability health content with a view to developing minimum suggested content and a toolkit for curriculum enhancement in medical or nursing schools in Australia.

We have fostered the development of the workforce in various ways firstly by developing then launching the new national guide for mental health professionals in 2014. Also, more in the background we have had a collaborative role in a number of initiatives that others have led including the formation of a special interest group in the Royal Australian and New Zealand College of Psychiatry and including the development of some training initiatives for specialist training in this area. I have mentored each intellectual disability mental health fellow, have supervised many of them, and have assisted them in putting together a training experience so they can begin to contribute back to both the public and private mental health services. We are developing competencies for the public mental health workforce in intellectual disability mental health and we have assisted by consultation the development of some enhancements within the health setting.

In terms of research, current or completed has really been quite interesting. A lot of the research is centred on our surveys but there have been other initiatives. I have been privileged to be invited to collaborate with Professor Eileen Baldry and Associate Professor Leanne Dowse, Professor Patrick Dodson and others in a focus on Indigenous offenders with cognitive disorders including intellectual disability. The team has completed an ARC linkage grant and also conducted interviews with families and people with intellectual disability to understand their experience with the correctional system and the factors that have shaped those.

We have conducted a study that is still underway, of people with intellectual disability over the age of 40, trying to refine the approach to assessment and screening for cognitive decline for people with intellectual disability and to better understand the mental health needs as people age. This research also has a qualitative component where we interview professionals and carers who provide support for people with intellectual disability as they age to better understand gaps in service provision and how to address them.

I have also been involved in a lot of research in cognitive disorders in the general population including early onset

"In order to uphold the basic human rights of a person with an intellectual disability it is very important that we address health and in particular mental health needs..."

dementia. Also a study of both elderly twins and older people in the community in collaboration with the centre for healthy brain aging and the Dementia collaborative research centres. My main focus in these studies has been the cardiovascular metabolic inflammatory contributions to brain aging and also the relationship between health factors and brain imaging markers; particularly looking at longitudinal changes that we can see that occur in the brain that are linked to certain aspects of health.

We also have a research program that looks at Fragile X related disorders. Of particular interest to me are carriers of pre-mutation of the Fragile X gene. In collaboration with colleagues in Melbourne we have looked at males and females who are carriers of the pre-mutation to begin to understand the neuropsychiatric effects of this gene.

There is more research planned for the future.

I hope that our data-linkage work will be a real contributor to the sector in the future. We have managed to link for the first time in NSW the administrative datasets for disability, health, mental health and mortality so that we can see the health service characteristics of people with intellectual disability, the ambulatory mental health needs, the inpatient mental health needs, the emergency department presentations of people with intellectual disability and the reasons for their presentation, length of stay and the services that have been provided to those individual. We will also look at death rates and cause of death. This will certainly be a large part of our new research program in a NHMRC partnerships for the Better Health project grant that will run for the next four years.

In terms of consultancy we have been very active in legislative and policy reviews and made lots of submissions to both NSW and the Australian Government. We have reports to the National and NSW Mental Health Commission; making sure the needs for people with intellectual disability are considered within various documents. I have enjoyed having personal and written representation to Government.

I very much value my clinical work but regret I don't have the time for as much clinical work as previously. I currently run a tertiary clinic to support psychiatrists in their role as they assist people with intellectual disability and mental health. The clinic is available for referral of adults where the psychiatrist might wish for a second opinion or has a specific question about the diagnosis or the management of the person they are supporting.

The most exciting part of our capacity building work is the expansion of our IDMH eLearning with specialised modules and there are five new ones coming including the development of a carer module. Later we will develop a complete suite of modules for disability service workers.

The broadening of our work with data linkage and interrogation of access; barriers and enablers to access to services and our more strategic focus of developing a policy framework will ensure people with intellectual disability are better included in health services development.

Since the establishment of the Chair of Intellectual Disability Psychiatry, have we made any significant steps in this area of health?

Significant progress is really hard to quantify. What I have seen is a sector and a people who are working together in a really cohesive way to make a difference. It is a big task with lots of different components. I think there has been incremental progress. What we have seen at both a state and a national level is a recognition that this is a group with high mental health needs and inclusion of this group in policy and frameworks. This is beginning to happen partly because people are vigilant and are really motivated to respond to the consultation process for policies and frameworks.

Really pleasing is the development of the national guide which was released in 2014 This was created by a group of

"We have managed to link for the first time in NSW the administrative datasets for disability, health, mental health and mortality ..."

us, and provides a framework for mental health providers across all relevant jurisdictions whether it be primary care, private practice, public mental health space or specialist providers; there is something there for everyone.
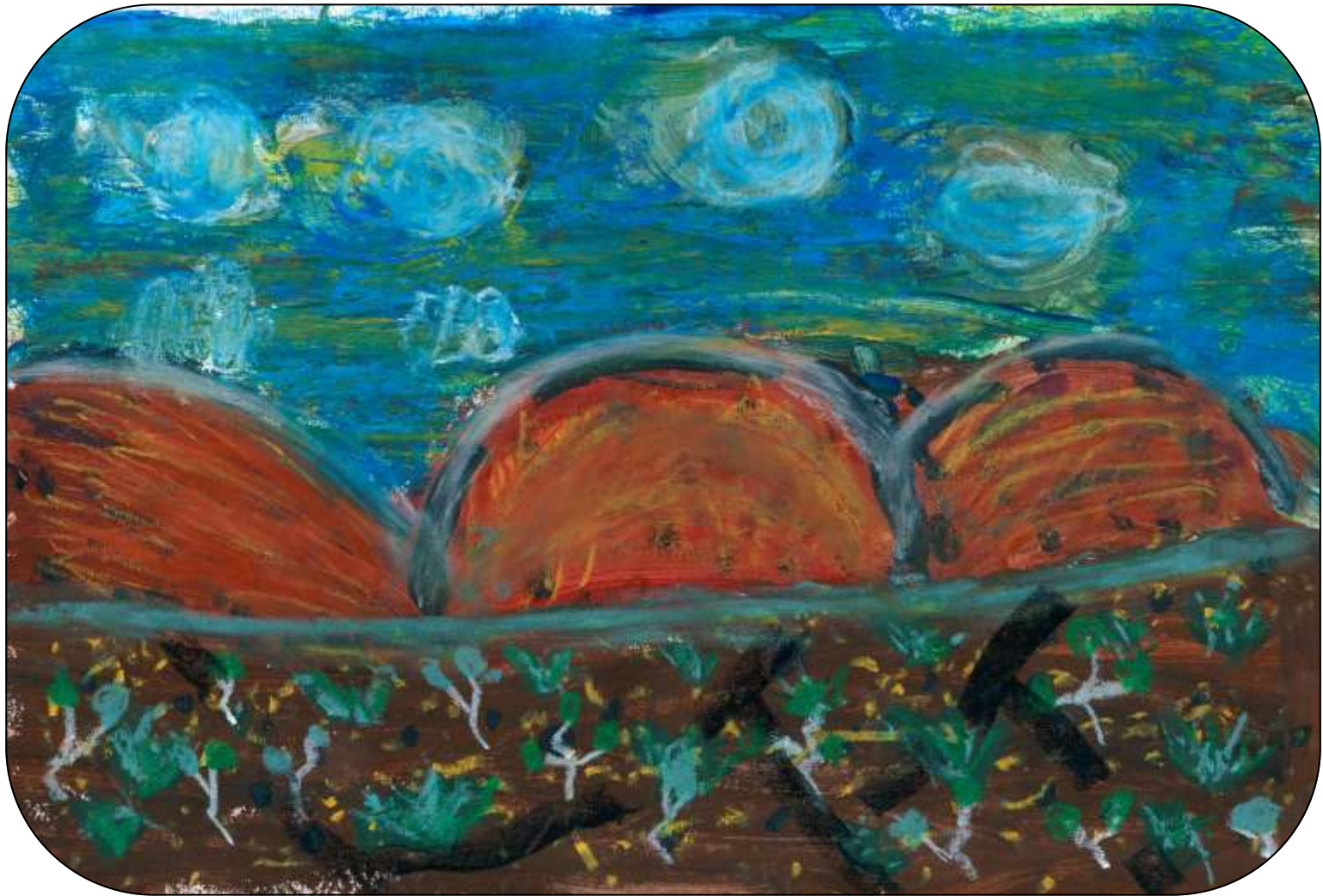
We will capitalise in the next five years on the foundation that we have laid so far. As others do as well, as their work plans and research efforts mature we will see an acceleration of action in this space. For the moment though we have to be satisfied with incremental progress.

How much do you think the NDIS will change things for People with Intellectual/Developmental disability? Do you have concerns about the effects on the mental health needs of people with an intellectual disability?

The NDIS represents a significant change of service and funding model. It is something that has received great fanfare and acclaim as it has been introduced. There are really positive signs so far as the trial sites have done what they set out to do. There has been a high degree of satisfaction from people with intellectual disability other groups. It is not without teething problems but by and large it has been a positive introduction.

As the trial is rolled out and expanded and as the systems are rolled out as per the national plan I think there will be a remarkably transformed disability service sector. I will say that some aspects of the new system worry me; the issue around people with complex needs, for whom I think service provision is more complex. As service provision is shaped by market forces and there is obviously a dollar bottom line, I am concerned that people with complex needs who need extra levels of support may miss out. At the moment in NSW, some of those individuals are catered for by very highly skilled teams funded or heavily supported by the NSW Government (Aging, Disability and Home Care). My worry is that if we move to a less regulated market economy, the expertise and sharp focus on people with complex needs may be lost. I think there will be a lag before such capacity is developed in the private sector, and there will need to be a specific strategy that is developed to supports its development and growth. I think people with intellectual disability and mental health fit within that more complex group and in particular some of those individuals have very high needs. We need to support the development of those capacities in the non-government sector and look for opportunities for NGO's to be taking the lead in service provision in those areas.

Do you have a vision of the future for Mental Health for peo-

ple with intellectual and developmental disabilities?
I think the primary vision is for the highest standard of health provision for people intellectual and developmental disabilities. The way we get there is by having a better understanding of the mental health needs, in children, adults and in older adults with intellectual and developmental disabilities. We need to have a very proactive approach to health care delivery and a proactive approach to prevention of mental health and health problems in this group. We need to see enhanced capacity developed in the mainstream so that mainstream health and mental health workforce feel equipped to provide a service. This needs to be backed up with specialist capacity so that mainstream mental health services are supported by specialists with high levels of expertise who can provide backup and consultation for those with more complex needs.

It is important that mental health workers in particular feel that people with mental health and intellectual disability are part of their core business. At the moment there is some distance from that but there is some increasing awareness of this group.

Some fun Questions:

What is your favourite book?
This is a difficult question for me as I don't sit long enough to read. I really prefer to be active. The inspirational book I would like to share is The Bible, that provides me with a backbone and underpinning that helps me understand life and its purpose.

Some leisure reading I enjoy is an outdoor magazine called WILD. It allows me to remember some of the more extreme outdoor experiences I have had whether it be bushwalking, cross country skiing or canyoning.

A web-link you would like to share:
An interesting website is theconversation.com which is beginning to have a few articles on disability and intellectual disability. That would be another interesting one to look at.

What do you always take on holidays?
A sense of adventure.

Is there anything else you would like to add?
One of the joys and privileges in the last few years of work has been the tremendous support, encouragement and collaborative approach adopted by colleagues. I mean colleagues very broadly: academic colleagues, clinical colleagues, colleagues from the consumer and carers sector, colleagues from health administration and policy. It is wonderful to be part of that shared journey, and to strive together to improve the capacity of the health sector in this area. I think that the people that are working in this area are generally very passionate, knowledgeable and very open. That has been wonderful to witness, and I have certainly benefitted greatly from that willingness to share and collaborate.

The beautiful artworks in this journal are taken from the participants of the **Operation Art project** at the Children's Hospital at Westmead. You can find out more at https://www.artsunit.nsw.edu.au/visual-arts/operation-art-2014

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