



## a note from David Dossetor...



Associate Professor David Dossetor, Child Psychiatrist with a special interest in intellectual disability and autism, Area Director of Mental Health, Children's Hospital at Westmead.

### Identifying factors that impede training and service development for mental health of children and adolescents with intellectual disability. Experiences from the development of a curriculum for inter-disciplinary training.

**Dossetor, D.**, Child Psychiatrist, Area Director of Mental Health, The Children's Hospital at Westmead, A/Prof, University of Sydney. [Davidd@chw.edu.au](mailto:Davidd@chw.edu.au)  
**White, D.**, Senior Speech Path, Clinical Consultant, State-wide Behaviour Intervention Service (SBIS), Ageing Disability, and Home Care, Department of Human Services, NSW.  
**Whatson, L.**, Coordinator of the Children's Team, SBIS.

### Introduction

The mental health of children and adolescents with intellectual disability (ID) is a public concern. It is recognised that 30-50% of children and adolescents with ID have significant mental health problems. It is also found that the mental health of children and adolescents with ID constitutes 14% of mental health burden of all children (Emerson & Hatton 2007). 25% of CAMHS services capacity in UK is for ID and/or Autism. These mental health problems and the concomitant burden affect the quality of life of these young people and their families. They lead to 2-3 times greater financial burden for care, treatment & education as well as reduced income capacity. Over half of carers (59%) experienced a decline in physical health & two-thirds felt that their mental & emotional health was affected with depression, anxiety or stress (Cummins et al 2005). This is in the context of no designated mental health service for

mental health and ID in Australia. The question of what impedes the training and service development for mental health of children and adolescents with ID arose during the development of a curriculum for inter-disciplinary training when we became aware there has been no previous textbook covering this area of multidisciplinary expertise (Dossetor, White and Whatson, 2011)?

### Method

This paper is based from discourse with colleagues and trainees which identified some of the differences of mental health for children and adolescents with ID from mainstream mental health. This was in the context of developing the Training Curriculum Project, which is a 2 day inter-disciplinary curriculum. This project had 3 years funding from 3rd National Mental Health Plan and Ageing, Disability and Home Care, NSW Human Services (ADHC) for a project manager (DW) and was a partnership project between the Department of Psychological Medicine at the Children's Hospital at Westmead with Statewide Behaviour Intervention Service (SBIS) ADHC (LW). Observations came from: a literature review; clinical experience of what works in a tertiary multidisciplinary multi-agency clinic; areas of demand for training from SBIS; a stakeholders' survey of areas of intervention-focused learning; evaluations and 3 month outcomes on workshops; commissioning 28 chapters which were independently reviewed for the textbook. In 2009/10 we provided 4 2-day workshops to >500 clinicians and the evaluation and feedback from the curriculum was positive and clinicians reported at three months that it had made a difference to their clinical practices.

### The findings

The findings are presented under 8 headings below.

#### 1. Ambiguous terminology

There is a lack of an internationally accepted language: The term "Mental Retardation" is still used in America. The term "Learning Disability" is used in UK, whereas this term is used in America is for Specific learning problems. In Australia you are never sure what group of problems this term is being used for. The term "Dual diagnosis" refers to ID and mental health problems in USA and UK, but mental health and drug and alcohol problems in

Australia. There is widespread obfuscation of communication through agency/discipline specific jargon; we readily identified 125 abbreviations in common usage and no workshop attendee could accurately interpret all. One is forced to conclude that there is no evident common language.

#### 2. Dichotomous and Divisive Concepts

Challenging Behaviours is a concept of poor social adaptation that implies an environmentally caused or maintained problem and needs a linear behavioural approach to intervention. This is the primary model used by Disability Services. Psychiatric Disorder is an alternative concept that implies a disease model of poor social adaptation identified by syndromal clustering of features and requiring the expertise of mental health services. Yet both models acknowledge bio psychosocial factors. Some practitioners only work with one of these concepts although the research indicates that they frequently co-occur.

Professional discrimination persists against ID as illustrated by the comment: "if the patient can't talk then they can't have a mental disorder".

Most condition specific research is limited to Mild ID and there is little agreement on how mental disturbances are different in the earlier stages of mental development.

#### 3. Problems of diagnosis of mental health problems in adult with ID

A mental health problem is defined as "**a diagnosable illness that significantly interferes with an individual's cognitive, emotional, or social abilities.**" Experts assert that generally it has been recognised that those "with ID have the full spectrum of mental illness, but usual diagnostic criteria are difficult to apply".

Methodical approaches to diagnosis are a recent development. The textbook of diagnosis of mental disorders in persons with an ID (DM-ID) was published in 2007. This diagnostic and statistical manual of mental disorder for people with ID was developed by an international, predominantly American, expert group. Each chapter reviews of the strength of the evidence supporting each diagnosis and the adaptations of diagnostic criteria for persons with ID. However the levels of Cochrane based scientific evidence are generally poor, mainly based on cohort studies and expert opinion. Nonetheless this manual of diagnosis gives people with ID entitlement to MH services. Its clinical usefulness was evaluated in 2006 with a field

trial 900 patients, 80 clinicians from 11 countries. This reported that the DM-ID was user friendly and more specific than the DSM-IV-TR (text revision 2004). The main alternative is the DC-LD (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation) which was developed in UK (2001, Royal College of Psychiatrists). This provides a “consensus of current practice” for adults with moderate to profound ID leading to ICD10 diagnoses. Their approach is slightly different emphasising that “sometimes it is not the criteria that need alteration but a different method of eliciting the necessary information”.

Nonetheless both diagnostic manuals identify a number of special problems of eliciting phenomenology in ID.

1. Firstly it is not possible to elicit subjective mental phenomena reliably < 7 years or an IQ <45. It is little surprise that debate still surrounds the age at which depression or psychosis can be identified in children.
2. People with ID have difficulty articulating abstract or global concepts eg depressed mood, because of limited cognitive and verbal skills.
3. They are more likely to give answers to please the interviewer.
4. They may be subject to intellectual distortion for example saying “yes” to “hearing voices”, without understanding the implication of question.
5. “Diagnostic overshadowing” is the failure to identify co-morbid psychiatric disorder attributing disturbance to the underlying intellectual disability.
6. This has to be distinguished from baseline exaggeration or intensification of existing maladaptive behaviour. Examples include an increase in self injurious behaviour under a time of stress. A significant stressor can be an anniversary of a loss that carers may not identify, or a change of a teacher or other staff, or a classroom or accommodation or of family visits.
7. Conversely stress on coping with a lack of cognitive reserve leads to disintegration, disorganisation or psychotic behaviour implying that such a major stress response does not constitute a mental illness (although adjustment disorders are part of the diagnostic manual).
8. Delusions and hallucinations are frequently very difficult to distinguish from a range of normal developmental phenomena such as concrete thinking, pretend friends, and stereotypic thinking and imagination, especially in ASD.
9. Irritability including explosive anger may be the most common problem of

challenging behaviour but is also associated with depression and mania.

Indeed it is concluded that families and professionals alike are at risk of diagnosing serious psychiatric disorder where none exists. Conversely the literature also illustrates that non specialised doctors (GPs) fail to identify mental disorder eg depression in this population. Further there is no advice on how to tackle these special problems, apart from consulting “an expert”.

#### 4. Comparing diagnoses in America and UK

Tsiouris and colleagues (2008) probably did the largest study of 4468 clients, ¾ of whom were in out of home residential settings, and found psychiatric disorder in 60%. The main DSMIV psychiatric diagnoses in order of frequency:

- Impulse Disorder 21%
- Anxiety Disorder 19%
- Schizophrenia and other psychoses 18%
- Depression 14%
- Bipolar Disorder 12%
- Obsessional Compulsive Disorder 11%
- Personality Disorder 8%
- Sleeping Disorder 4%
- Eating Disorder 3%
- Tourettes 2%

Almost as interesting was the absence of many other diagnoses described as of high prevalence in DM-ID such as Adjustment Disorders; Post traumatic Stress Disorders; Substance-related disorders; Sexual & Gender Identity Disorder; Dementia; Mental Disorders due to a General Medical Condition Nos. None of the childhood disorders that are also recognised to continue into adulthood were identified such as Learning Disorders; Motor Skills Disorders; Elimination Disorders; Pervasive Developmental Disorders; ADHD and Disruptive behaviour disorders; Somatoform & factitious disorders; Other Disorders of infancy, children and adolescents eg Attachment Disorders and Stereotypic movement disorders incl. self injurious behaviour; Behavioural Phenotype of Genetic Disorders.

The Epidemiological study in Scotland by Cooper and colleagues (2007) was of 1023 adults over 16yrs with mild, mod or severe ID. The PAS-ADD checklist, a screening questionnaire, was used to screen the population and the psychiatric diagnosis was made on the PAS-ADD 10 (The psychiatric assessment schedule for adults with a developmental disability) which relies on a key informant to identify and rate symptoms and produces diagnoses using algorithms (Costello et al, 1997).

The types of ICD10 Psychiatric Disorder were:

- Psychotic Disorder 4.4%
- Affective Disorder 6.6%
- Autistic Spectrum Disorder 7.5%
- Anxiety Disorder 3.8%
- Organic Disorder 2.2%
- Pica 2%
- Hyperkinetic Disorder 1.7%
- Personality Disorder 1%
- Alcohol/substance abuse 1%
- Obsessional Compulsive Disorder 0.7%
- Sleep Disorder 0.6%
- Other mental ill-health 1.4%

Why is there such disparity of diagnoses identified and of their frequencies? The American study is of service users, where the UK study is more epidemiologically representative. It is evident that research diagnostic tools identify lower levels of disorder than specialist clinicians seeking to understand disturbance. However one is still left to conclude that there is a lack of uniformity of diagnostic concepts and of thresholds of diagnosis. It suggests a lack of diagnostic reliability at least across an international community of clinicians. Indeed behind these discrepancies lie different diagnostic and schools of psychiatric thought. This is reminiscent of the 1980s when ADHD was diagnosed at rates ten times that in UK, before international collaboration clarified the concept and the dimension of severity which is dealt with differently in the different diagnostic systems. Evidently the research process to establish an international consensus is yet to be investigated and funded.

#### 5. The Need for Special Diagnostic Skills

Part of the problem is the need for special diagnostic skills to make a psychiatric diagnosis in people with ID, as has been illustrated in research on identifying depression in ID.

For example Hurley (2008) found that in a retrospective review in a clinic population that most patients with ID and depression did not meet the required number of diagnostic criteria for DSM or DM-ID. Patients with ID and depression do not complain of depressed thoughts. They still had depressed mood, sadness, crying, anhedonia and withdrawal which distinguished from anxiety or bipolar disorder. Few reported suicidality.

Torr and colleagues (2008) in an Australian study compared GPs’ and long term paid carers’ capacity for identifying features of depression in patients with ID having a routine assessment. These findings were then compared with subsequent assessment with a comprehensive



specialist psychiatric assessment. The study used a 53 item checklist for depression and factor analysis identified the consistent features of depression: depressed mood (6 items), loss of interest (5 items), loss of social interaction and communication (8 items). Carers identified the features of depression but GPs failed, even with the carers present. Depressed thinking was not a reliable feature of depression reflecting limited communication skills. GPs focussed more on sleep, appetite, weight control and general functioning. In this cohort, expert opinion found that 30% had depression but 25% had a Pervasive Developmental Disorder.

GPs are normally viewed as the gate keepers to specialist services, including mental health. Such evidence indicates that access to mental health services for people with ID is disadvantaged by the lack of workforce training. Both GPs & general psychiatrist will fail to provide the same level of case identification as a psychiatrist with special experience in intellectual disability. There is a need for further education and support for the recognition of subspecialty psychiatry skills in ID.

#### 6. Differences in defining mental health problems in children and adolescents with ID

Child and adolescent mental health defines a psychiatric disorder as *any disturbance of behaviour or emotions sufficient to cause significant impairment to the child or those caring for them*. The longitudinal study of young people with ID indicates 40% have a severe mental health disorder (Einfeld & Tonge, 1996). The Developmental Behaviour Checklist (DBC) measures the range and severity of disturbance but doesn't translate to psychiatric disorders. Although it is observed that psychiatric disorders in ID create greater problems for their families, there is no study that has quantified the additional impairment of Psychological Disorder in ID versus that of ID alone. In children and adolescents with ID a clinician may ascribe disturbed behaviour to a Mental Illness, a Mental Disorder, a Developmental Disorder, a Challenging Behaviour or Behaviour Problem. However the use of these labels is substantially a subjective determination affected by profession, employing agency and different theoretical models.

Mental health services, including child and adolescent mental health services have progressively prioritised their business to **severe mental illness** and the provision of **emergency intervention services for acute mental disorder**. The concomitant community message that "mental health is everyone's business" suggests all child orientat-

ed services have to understand and manage mental health problems.

Aggression is the most common community based childhood problem but research finds that by the age of 10 years such behaviour is an entrenched and chronic problem that generally doesn't improve in psychiatric in-patient units. Accordingly most conditions are best treated in the community which requires shared responsibility between families, neighbourhoods and all government departments. Too often the Juvenile Justice system becomes the default service for a lack of community based mental health services.

#### 7. Mental health problems in children and adolescents with ID are different and need different approaches, e.g. ADHD and other developmental disorders.

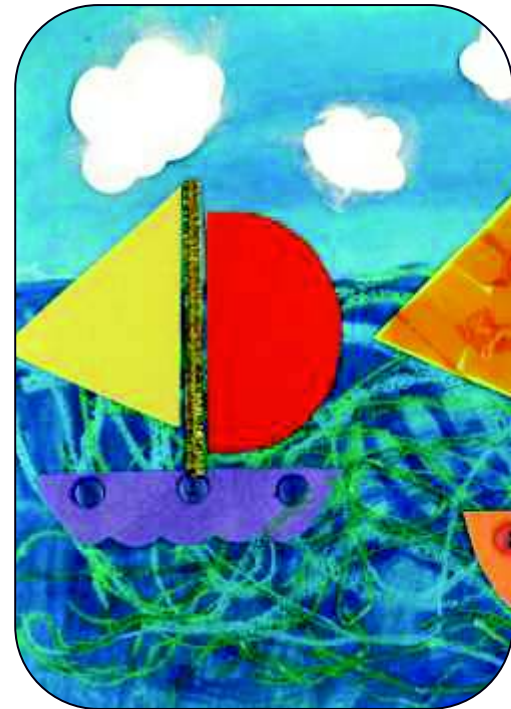
The way mental health problems in children and adolescents with ID present are different to those with average IQ. For example 30-50% of children with severe ID have ASD (compared 1% in the average population). The significance and meaning or validity of a diagnosis may be different for different levels of ID. Using ADHD as an example, Anstel and colleagues (2006) reviewed ADHD in Mild ID. Although they confirmed the diagnosis could be made reliably, there were differences in the predictive validity of this diagnosis. The differences included: the prevalence is 30%, with equal frequency in girls as boys, stronger factors of family functioning, and a stronger association with depression and social impairment. Further standard drug treatment is not as effective and patients are more prone to side effects.

In contrast for ADHD in severe ID there is a lack of research for reliability and validity, although it can be observed that these cases are more affected by general neurobiological factors as well as the polygenic processes considered important in ADHD of average IQ.

Further ADHD is associated with other developmental disorders. Examples include:

- ADHD and Developmental Coordination Disorder each occur in community studies at a rate of 7%, but co-occur in 50%.
- ADHD is found in 50% of teenagers with ID plus autism vs 15% with ID without autism (Bradley 2006)
- ADHD is found in 78% of PDD in clinic population (Lee & Ousley 2006)
- Genetic studies confirm linkage between ID and Autism indicating a commonality of development processes behind both.

ADHD is particularly high in behavioural phenotypes:



- Smith Magenis Syndrome 90%, Fragile X 75%, Williams Syndrome 65%, Charge Syndrome 50%, Neurofibromatosis 50%, Velo cardio facial syndrome 43%, Cornelia de Lange's Syndrome 40%, Soto's Syndrome 38%, Tuberosc Sclerosis 35% and Turners Syndrome 24%.
- In Fetal alcohol syndrome ADHD is found in 49%, ID in 55%, learning disorders 46%, ODD 41%, anger problems, mood disorders and sleep disorders in 50%.

Taking these observations into account suggests that ADHD in ID represents the specific problems of developing coherence & efficiency of consciousness, rather than a specific disease process. It may still be helpful to identify co-morbid ADHD particularly based on the evidence and experience of the reduction of impairment from drug treatment.

In conclusion Developmental Disorders have high risks of co-occurrence, which are highly genetic and may all relate to problems of developing neural complexity.

#### 8. Other problems in mental health for children and adolescents with ID

In the provision of mental health services for children and adolescent with ID there are a number of other problems. These include:

- Different models for understanding mental health are used by different disciplines and agencies.
- Some agencies are individual centred and lack of family centred approach.
- There is a lack of clinicians with evidence-based practice expertise, and experience in both mental health and ID.

- There is an increased association with complex medical problems.
- There is a lack of recognition of the range of the disciplines and agencies required to be optimally involved.
- There is a lack of inter agency collaboration with service cost shifting.
- There is a lack of service structure for more severe problems.
- There is a lack of attention to Prevention Promotion and Early Intervention
- There is limited empirical evidence on the contributions to be gained from occupational therapy, physiotherapy, speech therapy, psycho-pharmacotherapy, family therapy and systemic practice which are all considered part of comprehensive treatment. (The best evidence is for parent training and behaviour therapy.)

As a result, families experience a rotating front door of inexperienced community clinicians. Problems escalate without effective intervention. This provides some explanation to why parental murder/suicide ideation is such a frequent presentation in the families of children and adolescents with mental health problems and ID.

### Solutions for the mental health problems for children and adolescents with ID

Our educational research identified the need for a coherent curriculum for mental health for children and adolescents with ID. This included:

- A framework that is applicable for all professionals working with children and adolescents with ID
- In the context of the family life cycle for a child with ID
- With a focus on the quality of life for child with ID and family
- Within a developmental framework that
  - informs multidimensional assessment
  - provides a context for understanding behaviour
  - and an alternative approach for understanding developmental psychiatric disorders eg ADHD and ASD
- That assumes multi causal mechanisms to disturbance and disorder
- Puts an emphasis on multimodal skill building/positive psychology
- Requires multidisciplinary/multiagency collaboration

In practice a specialist mental health service for children and adolescents with ID needs a multidisciplinary/multi-agency team that works closely together. Although the team uses a multi causal framework as a common language for

mental health problems in ID, clinical expertise and consensus decides whether these causes may be additive, or whether one may be dominant in an individual case. There is a valuable tension between developmental models versus deconstructive (illness) models.

A Problem solving service system needs to be tiered so as to involve greater expertise with difficult to solve problems with rules of interagency collaboration. This could lead to a final common pathway of complex case conference, where clinical judgement and service management meet.

Specific Prevention, Promotion and Early Intervention approaches are needed for this population as generic mental health strategies are not applicable (CHW School-Link Needs Analysis, 2010).

Some of the components should include:

- Universally available **specialist** parent training
- Emotional literacy programs in schools
- Multidisciplinary approaches to building skills

### Conclusion

The scientific evidence in mental health problems in ID is still in an early stage of development. Mental health for children and adolescents with ID is different from adult psychiatry for ID and mainstream child and adolescent psychiatry. A curriculum framework is necessary to establish a coherent service with interdisciplinary and interagency collaboration. Specialised clinicians are positive on the impact that such services can have on the morbidity from co occurring psychiatric disorder in ID in partnership with families and child orientated agencies. Lastly developmental psychiatry for in children and adolescents with ID has much to contribute to mainstream psychiatry. After all, how can you be interested in "losing your mind" without studying the development of the mind.

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