a note from David Dossetor...

Clarifying concepts of disturbance, disorder and mental illness in children and adolescents with intellectual disability.

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How do you tell whether a child is going through a normal challenge of life, has a behavioural disturbance, a mental disorder or a mental illness? The dictionary describes "disturbance" as "a *temporary* change in average environmental conditions that cause a pronounced change in the ecosystem" whereas "disorder" is "a *physical or psychical malfunction*". This definition suggests disturbance is a temporary affair and at the other end of the spectrum disorder assumes a biological malfunction of the brain. It is less straight forward to apply this definition of disturbance in mental health functioning to a minority population whose functioning is in many ways different to those in mainstream due to their intellectual disability.

The recent experience of editing a book on "mental health of children and adolescents with intellectual disability" (Dossetor, White & Whatson, in Press) has highlighted how complex and confusing concepts of mental disturbance and disorder are. There are differences in the nature of disturbance in different populations and a diversity of interpretation according to who is doing the defining, what profession and what sort of interventions they represent and what is the strategic purpose of their agency. Accordingly the way the patterns of disturbance, mental disorder and illness in people with an intellectual disability, or children and adolescents with intellectual disability is different and complex compared with the mainstream population. I shall try to give some insight into some of the ways a child psychiatrist with a special interest in intellectual disability thinks about these issues.

Confusing Language

Adding to problems of understanding these problems, the language is often ambiguous and a source of confusion and even conflict. For example "Learning Disability" means different things on different sides of the Atlantic. In UK it is the term used for Intellectual Disability; in the USA it is the term for Specific Learning Disorders which may or may not be in the presence of Intellectual Disability. I am unclear where Australia stands in relation to these trenchant positions. Dual diagnosis means intellectual disability and mental health problem in USA and UK, and mental health and drug and alcohol problems in Australia.

In interagency work the terminology used often implies an obligation rather than a concept. For many people Mental Disorder means that mental health services or psychiatrists have to "sort" the problem out. Challenging Behaviour suggests that disability services or psychologists have to "sort" the problem out. Yet most dictionary definitions equate "emotional disturbance" with "mental disorder".

Other dichotomous ways of thinking include: "if the patient can't talk then they can't have a mental disorder". A more scientific way of saying this is that subjective mental phenomena cannot be reliably be elicited below the age of 7 years or an IQ of 45, and therefore diagnoses that depend on subjective mental phenomena cannot be reliably identified. But there is little agreement on how mental disturbances are different in the earlier stages of mental or intellectual development.

How broad or narrow is mental ill health?

Some clinicians limit mental disorder to a few defined mental illnesses such as depression, bipolar disorder, schizophrenia and certain anxiety disorders, as defined by criteria in the International Classification of Diseases (ICD10) or Diagnostic and Statistical Manual (DSMIV) (Moss, 2000). But in children and adolescents with intellectual disability ADHD and Autism are the most common conditions. Possibly most controversial is whether or when is Disruptive Behaviour Disorder a concern to mental health services? They are generally not considered a core focus of child and adolescent mental health services due to the lack of effective treatments and the lack of resources.

We mustn't forget that 'Intellectual Disability' is classified as a disorder of delayed or arrested development, but both human rights models and mental health services define this brain disorder out of scope for health or mental health services. Conversely diagnostic overshadowing has prevented people from looking for mental disorder and attributing all disturbance to the intellectual disability. Yet longitudinal epidemiological research suggests that mental disturbance, that is disturbance of emotions or behaviour in addition to the level of intellectual disability, occurs in a third to a half of people with intellectual disability (Tonge & Einfeld, 2000). However the best predictor is that they were disturbed before, i.e. that disturbance of any sort when it occurs is a pretty persistent co-occurrence of intellectual disability. Disturbed behaviour is therefore a significant part of the challenge of dealing with children and adolescents with intellectual disability adding to problems for the individual, the family and all community child orientated services.

To my knowledge no study has looked at defining how much functional impairment in this population is due to the intellectual disability and how much is due to an additional mental disorder. Conversely some specialist mental health advocates assert that people with an intellectual disability have the same mental disorders as those of any other population group and therefore have the same rights of access to services. But those with intellectual disability have marked increases in mental disorder. Doesn't this mean they actually need much greater access to mental health services, or does this raise questions about the types and validity of mental disorders in those with intellectual disability?

Do mental disorders differ in those with intellectual disability?

There is paltry consideration to differences to presentation according to level of intellectual disability, and there has been little attention to epidemiological findings of disturbance in children and adolescents compared to the studies in adults with intellectual disability. Empirical mental health diagnostic studies in adults indicate completely different diagnostic practices in intellectual disability on different sides of the Atlantic (Dossetor, White & Whatson, in press). Not only are there different diagnostic models but limited research in reliability and validity on these diagnoses in this population. Most of this research is in adult populations. The most common mental health diagnoses of childhood with intellectual disability of ADHD and Autism are hardly considered in adults even though they are often described as disorders that persist into adult life.

There are debates over what 'adult' mental disorders can occur in children of average intellect and to what extent they have a different group of disorders such as Attachment Disorders (which implies an environmental corollary). So to what extent do these specific diagnoses of childhood also apply to children with intellectual disability, or even to adults with intellectual disability because of the ways their mental development is

more 'child-like'. There is a limited research base showing that children with intellectual disability do have attachments but in both populations the linkage to subsequent mental disorder is not clearly established.

Historically psychiatric diagnoses were derived from doctors bringing scientific methods into the Victorian asylums where magistrates had admitted people so disturbed that they could not fend for themselves. Studying these people led to the establishment of most of the mental health diagnoses by a mixture of diagnostic fashion, research and a consensus committee process of the World Health Organisation or American Psychiatric Association to achieve a common language and a consistent approach incorporated as described in the diagnostic manuals of ICD10 or DSMIV (version V currently out for consultation). Defining these diagnostic criteria enabled the diagnosis and treatment of the same conditions earlier in our community without the need for admission. Nowadays admission to mental health services is generally for a brief period of medical assessment and treatment and subsequent care, support and rehabilitation is best managed in a community setting.

If one examines the general population of children and adolescents for mental disorder by using a general definition of mental disorder such as "disturbance of emotions or behaviour sufficient to cause persisting distress and causing handicap in other areas of function, out of keeping with cultural expectation" then this includes a broader range of disturbance than that by the defined diagnoses above. For example a reliable and predictive psychometric scale such as the Developmental Behaviour Checklist finds that approximately 40% of children, adolescents and adults with intellectual disability have significant emotional or behavioural disturbance but this does not readily convert to psychiatric disorder, opening the debate of what is behaviour disorder versus mental disorder.

The duration of disturbed behaviour is another factor influencing the term used. All children have periods of disturbed behaviour such as tantrums, or anxiety. Mental illness is indicated by a severity and persistence of change from a previous stable state. For example a change in affect such as undue sadness that lasts for at least 2 weeks. It often also includes vegetative or biological changes such as in appetite and weight or cognitive capacity. However what determines positive recognition of a mental disorder or illness is the co-occurrence of certain features to fulfil features of a syndrome or recognisable constellation of symptoms. For example depressive disorder is diagnosed by the presence of other associated features of the syndrome, such as loss of affect, guilt, anhedonia, irritability, diurnal variation of low mood, altered appetite, loss of energy, early morning waking, reduced memory and concentration etc. The diagnosis of a mental illness implies that the disorder has a momentum of its own to persist and is not purely a reaction to circumstances. The diagnosis of a syndrome, such as depression, also predicts what the approach to treatment should be. Standard evidence based treatment is therefore cognitive behaviour therapy and or antidepressants.

Conversely assessment and intervention approaches to challenging behaviour is linear in nature: that is to say it is not so much a case of identifying and counting symptoms, but starting with a single key symptom and looking for environmental factors that predicts that behaviour. As such it is often seen to provide a communicative function.

On these grounds, child psychiatric disorders are in between adult mental disorders and challenging behaviour: their descriptions are syndromal but assume multifactorial causalogy. This includes a wide range of factors: biological/genetic, temperament/personality, psychological, social, family, community (Dykens, 2000). It has been shown that those with cognitive impairment have greater rates of adverse social risk factors and even higher rates of adverse life events (Emerson, 2004). Both child mental disorders and challenging behaviours are now viewed from a bio developmental psycho social cultural framework and brought together with a formulation.

Mental Disorder and Developmental Considerations

In emergency health services many people are brought for assessment under the mental health act whose behaviour reflects a short lived severe behaviour, rather than a persistent syndrome. These people are referred to having 'a mental disorder' that may be stress/circumstance related, or part of a longer standing maladaptive style of functioning or personality, rather than 'a mental illness'. There is limited evidence based treatments for these mainstream presentations of people with mental disorder, but mental health clinicians may be involved in short term crisis management, and may have some involvement in helping others to minimise future crises. The similarity of these presentations of mental disorder, such as recurrent self harm or short lived bizarre behaviour, and Challenging Behaviour in people with an intellectual disability, is that they may both have chronically maladaptive patterns of coping, but they also are at a higher risk of having a psychiatric disorder.

There are however differences in such mental disorder presentations in children and adolescents. In paediatric emergency services for the under 14, presentations for aggression is at least as frequent as those for self harm, but by 16 years police will tend to deal with aggression, and self harm remains the assessment responsibility of medical services. These differences are partly because younger children have limited insight and understanding and adults and families have the major responsibility for their welfare and the way they grow up. Whereas by the age of 16, the assumption is that you have full capacity for insight and autonomous responsibility for such maladaptive behaviour. The social norm is that with adulthood, aggression is seen as bad or criminal.

The question arises therefore to what extent should limited skills of sensory integration, arousal modulation, attention, communication, social reciprocity and insight affect the way people with an intellectual disability are treated. It has to be said that the law works on the assumption that people with an intellectual disability have the same capacities and responsibilities as the mainstream population according to their age. This is not only a biological falsehood, but it clearly also influences mental health diagnostic and treatment practices. There is an increase in the rate of diagnosis of schizophrenia and other psychoses and also problems of the reliability of these diagnoses. Indeed it is my view that young people with autism in intellectual disability are at significant risk of being diagnosed as having a psychotic illness in mainstream mental health services, if their supportive environment fails to modify the stresses of their world and they become persistently mentally disordered.

The identification of depression in children is more difficult than adults, and more difficult in adults with intellectual disability. The diagnosis of associated psychiatric disorder in the context of severe behaviour disturbance in intellectual disability is difficult. Such diagnoses are often not best assessed by emergency services. There are therefore major gaps in mainstream adult and child mental health services for optimally helping these complex cases.

Environmental Deficits

The World Health Organisation has defined the distinction made between impairment, disability and handicap in those with intellectual disability: the biological deficit, the skills deficit and the loss of social access and valorisation. This has led to the suggestion that the handicap is dependent on the environmental match to enable social assess despite a skill deficit. A simple example is wheel chair access to community amenities reduces the handicap of someone who cannot walk. How much further can this environmental matching be expected for mental disorders for example for a young person with ADHD, who may need increased space and opportunity to let off steam and increased routine structure. Further to what extent can a specially enriched environment improve development in those with intellectual disability or autism?

The contention of the clinical working group that researched the Dossetor, White and Whatson book is that having a developmental perspective is a primary key to understanding disturbed behaviour in children and adolescents. The severity and type of behaviour disturbance is most related to developmental age or stage, and only secondarily related to chronological age. This is recognised in law in terms of both children and those with intellectual disability having limited capacity for understanding right from wrong, let alone being able to take responsibility for their

behaviour. It is of interest that the most common diagnosis in adolescent mental health units is of an adjustment disorder of emotions and/or behaviour which may be acute or chronic. This diagnostic bias implies that clinicians see environmental pressure or deficits as causal in the mental disturbance even of teenagers. Yet this thinking is seldom applied to people with and intellectual disability, who frequently have major environmental needs (even if they cannot be met). In a similar vein of causal thinking, the empirical evidence suggests skilled parenting has the best effect in improving childhood behaviour in children and adolescents with intellectual disability.

The most obvious differences in mental health diagnoses in children and adolescents with intellectual disability is the increase of the co-occurrence of Autistic spectrum disorder (ASD) (approximately 50%) and ADHD (approximately 30%), or the occurrence of ADHD in the presence of ASD (80%). The presence of either of these problems in children and adolescents with intellectual disability is a frequent cause of behaviour disturbance. Yet both the treatment of ADHD and Autism in this context is more difficult. In Australia, general paediatrics have taken the health lead in treating ADHD. The funded designated lead intervention service for Autism is an NGO, ASPECT, although developmental paediatrics has a significant role in early assessment. It is my contention that in those with intelectual disability that a developmental model of mind development is probably more helpful for understanding ADHD and ASD than a medical model. This then focuses on building and reinforcing mental skills over a persistent period of time rather than solely relying on medical treatment.

It is the co-occurrence of developmental disorders and genetic linkages that suggest underlying commonality of developmental processes. The developmental nature of disorders in children and adolescents with intellectual disability leads to the need for a wider treatment team than is traditionally used in mental health: not just psychiatrists, psychologists and social workers/family therapists but speech therapists, occupational therapists, physiotherapists and special educators. The more complex the problem, the greater the need for this diversity of assessment and therapy skills. This wider range of professional skills also generates a wider range of causal explanations or hypotheses for disturbed behaviour which is key to understanding and improving persistent and complex disturbance.

The range of professional skills and services

So what skills are needed to assess and treat what sort of problem? The first emphasis is supporting the skill base of families who need to have additional and special skills for the special emotional/behavioural needs of children and

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adolescents with intellectual disability, with help for community integration and the burden of care. The next level of help for such behavioural/developmental/challenging behaviour needs is specialist advice of a disability skilled psychologist. This may lead onto to further need to assess what other allied health services and special education are needed. In parallel to this is the need to consider physical health, especially in the ways it can contribute to disturbance. Developmental mental disorders of ADHD and ASD are best assessed by paediatric specialists and they have significant skills in the psychotropic medications that may be needed. Mental Health has a role specifically in the discrete mental illnesses outlined above and assists in the crisis management of mental disorder. However complex problems of unclear challenging behaviour/mental or developmental disorder/mental illness need cross agency collaboration of professionals and skills to offer the best outcomes. This includes mental health specialists who have a special interest in intellectual disability. In the NSW context it is clear we have clinicians with good quality skills with sustained learning, but we lack a service structure for collaboration and specialist mental health services for children and adolescent or adults with intellectual disability. Often the private sector is the most available substitute but this is not sufficient.

Behavioural phenotypes and individual difference

The study of behavioural phenotypes highlights a growing complexity and sophistication to our understanding of emotional and behavioural disturbance, and illustrates that different mechanisms can apply to different symptoms in the same patient. For example in those with Prader Willi Syndrome the incessant food seeking may relate to intrauterine starvation affecting hypothalamic function, the obsessive features are related to developmental stage and the ADHD type behaviour relate to problems of executive function, such as deficits in attention switching capacity. In Williams syndrome different types of anxiety are thought to have different mechanisms: fear of noise such as thunder is associated with hyperacusis, fear of heights is associated with clumsiness and poor coordination, and general anxiety disorder is associated with family genetic risk and parental reinforcement. Family stress has been shown to be predicted by aggression and attentional problems in the child with intellectual disability and protected by a child's social, empathic and kind spirited qualities.

Conclusions

These sorts of findings indicate that the diagnostic concepts and individual diagnoses are only partial guides to understanding any presenting disturbance. Ultimately up-to date informed clinicians are needed to bring to bear an understanding of potential external environmental factors and also internal and biological factors. This can have a bearing on how best to use our therapeutic skills to best advantage whether this is for a challenging behaviour, a developmental or mental disorder, or a mental illness.

Ultimately it is an open question as the extent that the mental disturbance of children and adolescents with intellectual disability can be resolved. However there is a diverse cadre of clinicians who believe in bringing the best state of scientific and professional understanding to these problems, with a belief that is it possible that, despite mental health problems, children and adolescents with intellectual disability and their families can achieve "a good enough" quality of life. Nonetheless there is good grounds to suggest that treatment and care has improved over the last 20 years, whereby children with intellectual disability are not sidelined to long term hospitalisation and institutionalisation.

This essay also suggests that the use of terms to describe mental disturbance, disorder and illness is changing and developing over time. There remain major gaps in our understanding, but clinical and scientific approaches are shaping the language, terminology and skills. As Sir Archibald Garrod (1857-1936) physician at Great Ormond Street and St Bartholomew's Hospital said: "Practicing medicine without textbooks is like sailing the oceans without charts".

See page 10 for the list of references.

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