Chapter 20

Mental Illness And Intellectual Disability: The Concepts, The Evidence And The Clinical Skills

David Dossetor

Introduction

This chapter describes the development of the scientific concepts of intellectual disability and mental illness including challenging behaviours. The empirical practice and limitations of adult psychiatry in intellectual disability is described and in particular the problem of recognising depression. There is a growing understanding of the multifactorial nature of mental illnesses and of challenging behaviours in the context of a holistic model.

Although family care can best provide for children with intellectual disability and parent training has the best evidence of efficacy, the biological drivers of disturbance have a major impact on quality of life and require a skilled multidisciplinary team and a range of services. The mental health problems of young people with severe intellectual disability particularly lead to an emphasis on a developmental perspective to the bio-*developmental*-psycho-social-cultural model of understanding. The chapter also looks at the need for different theoretical models, for example in Attention Deficit Hyperactive Disorder (ADHD) in intellectual disability. It may be more useful, because of greater clinical face validity, to conceptualise some mental health disorders such as Autism and ADHD as developmental disorders. The special needs and problems of young people with intellectual disability are driving the development of a range of subspecialty clinician skills in different disciplines.

This chapter emphasises the critical role psychiatry has made to enabling deinstitutionalisation and community care for many. All psychiatrists should have a holistic understanding of the needs of young people with intellectual disability and contribute a neuropsychiatric framework. The chapter is divided into two sections: Section I is on adult psychiatry of intellectual disability; Section II is on child and adolescent psychiatry of intellectual disability and looks at the mix of workforce skills required to provide for this population of special need.

Section I: Adult Psychiatry Of Intellectual Disability

Distinguishing Intellectual Disability And Mental Illness

Although intellectual disability and mental illness were mentioned in ancient times, it was in the 13th century that the English King Henry II showed a humane view and passed legislation to make these people wards of the king. *Prerogativia Regis* provided for care of their lands but distinguished ‘natural fools’ from ‘lunacy’ as ‘lunatics’ were expected to recover and resume such responsibilities (Harris, 2006). However accounts of such ‘community care’ suggested that, although some people were treated humanely by family and parish, others were chained or locked up and mistreated ‘for the devil in them’. Even today, due to significant poverty in Africa, in order to go to work a single mother may have to lock up her child with intellectual disability (Adnams, 2008).

Treatment Versus Rehabilitation

The modern notion of intellectual disability and mental illness arose subsequent to the development of asylums in the 18th and 19th centuries for the ‘insane’ and ‘feeble minded’. Admission to these institutions was on the judgement of a magistrate and was intended to protect vulnerable groups who couldn’t cope in society. The better institutions provided a ‘moral’ culture with fresh air and fresh water, and were frequently identified by their fine rural real estate and the landmark water tower. Harris (2006) noted that Seguin’s text of 1866 described how people too disabled to learn from classroom instruction still benefited from training, similar to the rehabilitation movement for those with mental illness. Seguin (as cited in Harris, 2006) also identified different levels of intellectual disability: idiocy, imbecility, and feeble mindedness (severe, moderate, and mild) but the intelligence test as an empirical measure of intellectual disability was not developed until 1905 by Alfred Binet and Theodore Simon (Harris 2006).

The industrial revolution led to the development of science in medicine and accordingly medical superintendents were appointed to manage and study their charges. For example, Langdon Down in 1866 identified several types of intellectual disability, including his eponymous Syndrome, well before genes had been discovered. With the recent epidemiology on the association of intellectual disability and social and economic adversity (Emerson, 2004), it can be speculated that the social and economic adversity of the industrial revolution also contributed to the proliferation of individuals with intellectual disability and mental illness in institutions.

Access To And Protection From Mental Health Institutions

The legal framework of the Mental Health Act (2007) remains an important part of the gate keeping process of the mental health system in New South Wales (NSW), Australia. It provides access to treatment for serious mental illness in the absence of insight and protects the individual from the abuse of psychiatrists and their institutions, particularly with the independent monitoring by the Mental Health Review Tribunal. Accordingly, access to psychiatric services is dependent on the notion of, a) an illness of the functioning of the brain that warrants psychiatric treatment; or b) disordered behaviour that needs an assessment for the presence of a psychiatric illness.

Psychiatry And Phenomenology

The term *psychiatry* means ‘healer of the soul or mind’ (Stevenson, 2007). It is taken as an assumption that subjectivity and conscious mindfulness is fundamental to the human condition. The models of mental illness come from studying people who were too disabled (and often bizarre) to participate in the community and who neglected themselves or put themselves at risk. Psychiatry is based on the examination of the individual’s subjectivity. Psychiatry was described by eminent philosopher psychiatrists, such as Bleuler and Kraeplin in the 19th century, whose works classified these deviant moods and thoughts into mental illnesses. This process is termed phenomenology and is the practice of describing the patterns of phenomena of the mind (Alexander & Selesnick, 1966). From these origins, the diagnostic classifications of the American Psychiatric Association’s (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and World Health Organization’s (WHO) *International Classification of Diseases* (ICD) developed. The classification processes of the DSM and ICD are still based on a committee of experts who debate and research the best way to classify these abnormalities of subjectivity, associated with social impairment and dysfunction.

Medical Advances And Deinstitutionalisation

The rise of medicine and the science of healing brought notable progress in treating mental illness. These medical advances led to significant deinstitutionalisation of people with a progressive increase in community care. The start of the decline of psychiatric institutionalisation arose with the development of penicillin (1940s) for treating *general paresis of the insane* (neurosyphilis) and chlorpromazine (1950), that was the first major tranquilliser for psychoses, especially schizophrenia. Lithium (first reported in 1949) as a treatment of manic depression has saved more lives of the mentally ill than any other medication.

Deinstitutionalisation led to rehabilitative approaches to treatment of people with mental illness with integration of services into mainstream hospitals and community support. Mental illness remains real and harmful. This has been illustrated by a recent report stating that the main cause of maternal death is not directly due to the process of childbirth but to suicide from postnatal depression (Cliffe, Black, Bryant, & Sullivan, 2008). Although better treatment and community integration of services is associated with more accepting views of mental illness, it is still treated with stigma and denied the concern shown to other illnesses. Yet people with mental illnesses have an increased risk of death by suicide, and suicide is second only to accidents as the main cause of death in youth.

In the last 10 years the introduction of selective serotonin reuptake inhibitor antidepressants (SSRIs) has been associated with a reduction in suicide rates in the western world. Indeed, temporary reversal of access to SSRIs in Japan, due to fears that they increased suicide attempts, led to an increase in deaths because of loss of availability. Both Lithium and SSRIs have been shown to prevent cell death of neurones particularly in the hippocampus (crucial for memory) in the presence of depression and bipolar disorder.

Epidemiology And The Economic Costs

It is the public health and epidemiological approach to health that has raised the political importance of psychiatry, highlighting the cost to the community of psychiatric morbidity and mortality. The World Bank and WHO now puts the economic cost of mental health, particularly depression, ahead of other diseases in developed and developing countries. The success of the contribution of psychiatry to humanity is due to what has been described as a combination of ‘evidence based medicine’ with ‘values based practice’ (Fulford, as cited in Fannon, 2008).

Psychiatry In Intellectual Disability: Part Of Mainstream Skills, Subspecialty Or Neither?

Mental illness or disorder is defined as ‘psychological or behavioural pattern or syndrome that occurs in an individual and causes distress or disability that is not expected as part of normal development or culture’ (DSM-IV, APA, 1994). For several decades it has generally been recognised that those with intellectual disability suffer from the full spectrum of mental disorders experienced by the general population but that these may present in different ways. Commonly used diagnostic criteria, such as that used in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV, APA, 1994), or in the tenth version of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10, WHO, 2007),can be difficult to apply in this group.

Methodical approaches to recognising mental illness in intellectual disability is a recent phenomenon. The *Diagnostic Manual - Intellectual Disability* (DM-ID, Fletcher, Loschen, Stavrakaki, & First, 2007) is a textbook of diagnosis of mental disorders in persons with an intellectual disability. It was developed by the National Association for the Dually Diagnosed (NADD) and the American Psychological Association (APA), and authored by an international (mainly American) expert group. The group reviewed the strength of the evidence supporting each diagnosis and the adaptations of diagnostic criteria required for persons with an intellectual disability. However the levels of Cochrane-based scientific evidence are generally poor, with evidence mainly based on cohort studies and expert opinion. The Royal College of Psychiatrists published a similar guide in 2001 titled *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation*. This guide provided a consensus of current practice for adults with moderate to profound intellectual disability leading to ICD-10 diagnostic categories. Sometimes it is not the criteria that need alteration but the method of eliciting the necessary information.

It has been noted that children and adults with intellectual disability are one of the most underserved populations in the USA. The situation in Australia is also poor (AMWAC, 1999) as these individuals fall through the cracks of both disability and mental health service systems. Although 40% of young people with intellectual disability have significant mental health problems, only 9% of these received services skilled in mental health and intellectual disability (Einfeld & Tonge, 1996b). A further 31% received help from disability or mental health services. This is not dissimilar to other child mental health disorders as found in the National Mental Health and Wellbeing Survey (Sawyer et al., 2001). This difficulty accessing services partly reflects the history of funding for individuals with intellectual disability. For example, in NSW Australia, funding moved from health to social services (Family and Community Services) in 1987 and subsequently to disability services in 1999 (now known as Ageing Disability and Home Care, Department of Human Services NSW). There is therefore no historical ownership or funding for mental health of this special need population. The lack of a recognised subspecialty of psychiatry in Australia means that there is a lack of advocacy for services for individuals with these mental health needs.

Special Problems Of Phenomenology And Reliability In Intellectual Disability

Diagnostic criteria and reliable interviews for the psychiatry of adults with intellectual disability have been developed in the last 10 years! This is yet to be established for children and adolescents. People with intellectual disability may have additional difficulties (e.g., cognitive, verbal) which in turn lead to difficulties in articulating abstract or global concepts such as depressed mood. Part of the problem is that subjective mental phenomena cannot be elicited reliably below an age of 7 years or an IQ of 45 (Brugha, 1988). Reliance on observable behaviours meant that it was not until the 1980s that psychiatry recognised depression in children, and down to the level of 7 years. Yet it is a strongly held assumption that criteria symptoms are identifiable and the recognition of psychiatric diagnoses is possible regardless of level of intellectual disability or age.

Failure to identify co-morbid psychiatric disorder in people with intellectual disability has been attributed to the problem of these people giving answers to please interviewers in assessments and, of course, the problems of diagnostic overshadowing, where the presenting problem is attributed to the intellectual disability. The majority of those who have intellectual disability have a disability in the mild range. There is a growing literature validating psychiatric disorders in this population. However, the greatest problems occur in reliably recognising and validating major psychiatric disorders in those with moderate or severe intellectual disability or with major developmental disorders such as autism.

Approaches To Classification: Phenomenology Or Factor Analysis?

The DM-ID (Fletcher et al., 2007) provides a multidimensional framework and is based on diagnostic criteria that are ‘generic’, that is, they can be applied to all individuals independent of age, ethnicity, culture, gender, or co-morbid medical or mental conditions. For many diagnostic categories, the expert committees determined that the diagnostic criteria ‘didn’t need’ modification and that they could also be applied to individuals with moderate, severe, and profound intellectual disability. For other diagnostic categories there were modifications of the criteria. Obsessive Compulsive Disorder (OCD) and Post-Traumatic Stress Disorder (PTSD) were not classified under anxiety disorders but given separate chapters because of their under diagnosis and importance to the intellectually disabled population. Further, behavioural diagnostic criteria were added for those with severe or profound intellectual disability.

The expert group used for the development of the DM-ID (Fletcher et al., 2007) acknowledged that a number of different approaches to diagnosis had been proposed over the last 20 years. Such approaches included the dimensional approach used by Sovner and Hurley (1986) or a factor analysis approach used by Einfeld and Tonge (1996b) with six factors. However, Aman’s review (1991b) of a range of factor analyses of symptom checklists, suggested seven factors for types of behaviour. Given the lack of consensus or an evidence base for many decisions, the expert group concluded that peer discussion and committee agreement was the best way forward in the diagnosis of psychiatric disorder in individuals with intellectual disability. They resolved that at least DSM methods was a means of giving people with an intellectual disability the same entitlement to mental health services as non disabled people. Clinical usefulness of the DM-ID was tested in 2006 with a field trial of clinical data on 900 individuals, using eighty clinicians from eleven countries. The evaluation concluded that the DM-ID was user friendly and enabled clinicians to be more specific about the diagnosis than using the DSM-IV text revision (DSM-IV-TR, APA, 2000).

Problems In Eliciting Symptoms In Intellectual Disability

The special problems and considerations in diagnosis in intellectual disability (DM-ID, Fletcher et al., 2007) are described below.

1. Baseline exaggeration or the increase in frequency and intensity of existing maladaptive behaviours during the course of a mental illness e.g., increase in self injurious behaviour at a time of stress.
2. Intellectual distortion or the effects of intellectual limitations e.g., saying ‘yes’ to ‘hearing voices’ from not understanding the question.
3. Psychosocial masking of symptoms that are recognised within a developmental framework e.g., an individual with moderate intellectual disability believing that he can drive a car might indicate grandiosity and therefore a symptom of mania.
4. Cognitive disintegration, disorganisation, or psychotic behaviour due to lack of cognitive reserve and stress or problems coping.
5. Existence of symptoms that are seen as appropriate for a child (e.g., talking to oneself out loud, fantasy play, pretend friends) but that would be abnormal in an adult of normal intellect.
6. The risk of families and professionals diagnosing serious psychiatric disorder where none exists, especially when individuals with intellectual disability present with behaviours and interaction skills of chronological younger children and these can be maintained throughout their life.

7. The inability of individuals to articulate their losses or stresses, or changes in physical health or problems of health treatment.
8. The misinterpretation of stress as a serious mental illness e.g., stress related to change (change of a teacher, staff member, classroom, accommodation arrangement, frequency of family visits) or to the anniversary of a loss, may be precipitants that carers do not identify.
9. Specific considerations in mental health assessments include,
    - Anxiety symptoms frequently go unnoticed by family/carers and need careful eliciting.
    - Vegetative symptoms are important and may be sourced from sleep charts, mood charts, dietary records, and changes in activity or cognitive capacity from school/work records, and in particular any decline in functional capacity.
    - Mood changes may be expressed typically or in terms that are implausible or delusional such as referring to important figures as dead or no longer caring.
    - Both mania and depression can present as irritability, sometimes with explosive anger.
    - Abnormal ebullience and elation may not be recognised as part of hypomania.
    - Delusions and hallucinations are frequently very difficult to distinguish from a range of normal developmental phenomena such as concrete thinking, pretend friends, stereotypic thinking, and imagination, particularly in the context of Autistic Spectrum Disorder (ASD). Evidence of a psychotic process is best indicated by a pervasive change in the trajectory of social engagement and independence skills (Dossetor, 2007; Hollis, 2008).
    - Substance abuse and suicidal or homicidal ideation need to be considered.

- Vigilance for physical or sexual abuse needs to be kept in mind as communication difficulties, greater dependency, and the large numbers of carers make people (especially girls) vulnerable to such exploitation.

Despite these cautionary observations, there is no guidance on dealing with these errors, for example when one rule or another might apply. In practice, trusted expertise is the only standard, that is, significant experience or mentoring as a psychiatrist with people with an intellectual disability.

What Psychiatric Disorders Are Found On Intellectual Disability?

Studies From USA

The New York State Institute for Basic Research in Developmental Disabilities did a study which found one, and frequently more, psychiatric disorder in 60% of the 4468 clients, three quarters of whom were in out of home residential settings (Tsiouris et al., 2008). The main DSM-IV psychiatric diagnoses that were found in this study can be see in Table 20.1 and are listed in order of frequency.

[Insert Table 20.1 here]

It is curious that such a large clinical cohort did not identify many other diagnoses identified in DM-ID, for example, adjustment disorders, post traumatic disorders, substance-related disorders, sexual and gender identity disorder, dementia, and mental disorders due to a general medical condition not otherwise classified. It also suggests that the following diagnoses are only applied to children or by child psychiatrists: learning disorders; motor skills disorders; elimination disorders; Pervasive

Developmental Disorders (PDD); ADHD and disruptive behaviour disorders; somatoform and factitious disorders; other disorders of infancy; childhood and adolescence (attachment disorders and stereotypic movement disorders including self injurious behaviour); and behavioural phenotypes of genetic disorders.

One of the areas of ambiguity is that, while adult psychiatric disorders can be applied to adolescents and sometimes children (except personality disorder by definition), it is less clear to what extent child psychiatric disorders can apply to adults. Also, there is a lack of understanding of the relationship between ADHD in childhood and impulse disorder in adults. It is known that PDD is a lifelong disorder, yet it is not identified as an adult psychiatric diagnosis. It is now understood that ASD is a dimension of impairment, not solely a categorical diagnosis, but not what the relationship is between stereotypic behaviour or thinking, and obsessional compulsive disorder.

Studies In UK/WHO

It is critical for clinicians to learn to adapt their interviewing techniques to be sensitive and understandable to someone with an intellectual disability. This necessitates specific experience and can be aided by training in purpose designed, reliable and validated semi structured interviews such as the PAS-ADD 10 (Costello, Moss, Prosser, & Hatton, 1997) that is the ICD 10 version of the *Psychiatric Assessment Schedule for Adults with a Developmental Disability* (PAS-ADD, Moss et al., 1993). This instrument relies on information from a key informant to identify and rate the psychiatric symptoms to diagnose ICD 10 diagnoses with the aid of algorithms.

The PAS-ADD checklist (Moss et al., 1998) is a screening questionnaire, from which those with symptoms above the threshold can be assessed with the Mini-PAS-ADD (Moss, 2000). The Mini PAS-ADD can diagnose anxiety disorders, mood disorders, obsessive compulsive disorder, psychotic disorder, dementia, unspecified mental disorder, and autistic disorder. Cooper, Smiley, Morrison, Williamson, and Allan (2007) provided an epidemiologically sound study of psychiatric disorder in Scotland of a sample of 1023 adults over the age of 16 years with mild, moderate or severe intellectual disability. They found the prevalence rates of psychiatric disorder as outlined in Table 20.2.

[Insert Table 20.2 here]

The rates of diagnosis of different disorders in the USA and UK are strikingly different, which is a measure of methodological differences such as sample selection and screening processes. However the extent of the differences also indicates a lack of uniformity of diagnostic thinking and processes. This is reminiscent of discrepancies in recognising ADHD in children and adolescents on different sides of the Atlantic in the 1980s, which reflected thresholds of recognition and attitudes to such a diagnosis.

The Smiley Scottish prospective study (Smiley et al., 2008) found a two year incidence of mental illness (i.e., new disorders) of 16.3%, and 12.6% excluding problem behaviours. Factors related to mental ill-health included: type of accommodation (out of family care), previous mental ill-health, not having impaired mobility, urinary incontinence, more severe intellectual disability, adult abuse, parental divorce in childhood, and preceding life events.

Approaches To Challenging Behaviours

The concept of *challenging behaviour* derives from a social construction influenced by behavioural psychology and is defined as ‘culturally abnormal behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to limit use of or result in the person being denied access to ordinary community facilities’ (Emerson, 2001, p. 3). It is a mainstream view that unwanted or challenging behaviours need to be examined, not just by a descriptive functional analysis (Einfeld & Emerson, 2008), but with a thorough behavioural assessment by an experienced professional using a detailed approach as characterised in applied behaviour analysis. Such a standard of intervention has been shown to lead to better outcomes (Grey & Hastings, 2005) although long term data are lacking. More recently it has been proposed that causes and intervention should also be considered from multidimensional approaches of understanding. Such approaches include exploration of sensory, motor, communication, relationships, context, and cultural issues, as opposed to seeing the function of challenging behaviours solely as the need for stimulation or tangible reinforcers, or avoidance of a task or an undesired event. Neurobiological models, such as the role of endorphins (endogenous opiates) in self injurious behaviour and measures of physical arousal also need to be considered. Challenging behaviour can serve many functions.

Cohen and colleagues (2009) conducted a survey of aggressive behaviours and associated factors in a clinical cohort of over 2000 adults with intellectual disability. They used the Modified Overt Aggression Scale (MOAS, Sorgi, Ratey, Knoedler, Markert, & Reichman, 1991) and found 4 types of aggression including,

1. Aggressive displays, such as shouting or breaking something (25% of the variance);
2. Verbal threats (16%);
3. Self-injurious behaviour (13%); and
4. A small group of less than 10% of serious aggression.

Aggressive displays were mostly associated with environmental disruptions such as task demands and social intrusions (e.g., teasing or touching others' property), more frequent in those with moderate to severe level of intellectual disability, and were more severe in people with autism (Cohen et al., 2009). Verbal threats were mostly associated with social intrusions, were more common in females, less common in autism and highest in 'borderline' intellectual disability level. Self-injury was associated with physical discomfort (e.g., from medical problems and environmental change), highest at the lowest intellectual disability levels, declined with age and was higher in people with autism. Severe aggression was relatively rare, declined with age and was marginally more common in males but with no significant antecedent triggers.

This study suggested that most aggressive behaviours toward others in this population are avoidant, defensive or territorial in nature. Consistent with other reports, self-injury was associated with more severe intellectual disability and may be linked to arousal/stress. There were associations with psychiatric disorder, particularly with impulse control, psychotic, bipolar and personality disorder in persons with mild to severe intellectual disability, and depressive and personality disorder in borderline intellectual disability. Self injury was associated with all psychiatric disorders. Aggressive displays and threats were associated with all psychiatric disorders except anxiety and obsessional compulsive disorder. Based on this cohort, most aggressive challenging behaviours have environmental and communicative implications. However self-injurious behaviour and severe aggression may have other more complex features.

Associated Medical Problems

The importance of other health problems must not be underestimated in individuals with intellectual disability. Tsiouris and colleagues (2008) found the following associated medical problems in 40-45% of their population with Psychiatric Disorder (in descending order of frequency): constipation, reflux and indigestion, problems of mobility/walking, dental problems, seizures, sleep problems, heart problems, ear problems, and kidney problems. However they also found a similar co-morbid incidence of medical problems in their aggression cohort (Tsiouris et al., 2008).

Clinical experience indicates that medical problems therefore play a significant role in both challenging behaviour and psychiatric disorder, although epidemiological evidence for this causing challenging behaviour is weak. People with an intellectual disability have higher rates of a range of general health problems with significant morbidity and reduced life expectancy. These problems require routine systematised general health checks, health promotion intervention, and the use of structured assessment such as the Comprehensive Health Assessment Program (CHAP, Lennox, Rey-Conde, & Cooling, 2006).

Cooper et al. (2006) did a randomised control trial of nurse health screening of fifty people with intellectual disability (average of 4 hours/patient with information being passed on to their general practitioner). More than twice as many health needs were identified for the intervention group compared to the control group. The intervention group had better health from a higher level of health need met of 3.56 per patient, compared to 2.26 in the controls. The main interventions were dental check ups, eye tests, healthy diets, exercise, and influenza and hepatitis immunisation. With these data, it is clear that good regular general medical care is central to every person with intellectual disability. However, there was no outcome information on psychiatric disturbance.

Aggression And Psychiatric Disorder

Tsiouris, Mann, Patti and Sturmey (2003) found that aggression was not an indicator of depression, but symptoms of depression (including irritability) were still valid in those with intellectual disability. Aggression and self-injury are the most common cause for a mental health appointment in those with an intellectual disability but not in those with normal intellect. Aggression can be occasionally associated with any diagnosis, but frequently, despite multiple informants and comprehensive assessment, the clinician is left working in clinical and diagnostic uncertainty. Nonetheless, in practice, psychotropic medications are frequently used for severe aggression whether this is associated with a psychiatric disorder on not.

Drugs For Aggression Versus Psychiatric Disorder?

A recent randomised control study of adults with aggression compared haloperidol, risperidone, and placebo (Tyrer et al., 2008). This study showed 58-79% improvement in aggression on the MOAS (Sorgi et al, 1991), but the placebo was as effective as either major tranquilliser. This study drastically oversimplified the question of whether drugs can help aggression in that it failed to consider whether the aggression was predatorial (for which there is agreement that psychotropics generally don’t work) or affectively driven aggression (which has significant research interest). Furthermore, there was no consideration of whether aggression occurred in the context of psychiatric disorders, such as ADHD/impulse disorder, autism, depression or psychosis, which may benefit from treatments, including psychotropic medication, that help the psychiatric disorder. Sedating medication can have a role in acute situations to help contain an individual safely, assuming it is with consent or possibly assent, or justifiable under common law or the NSW Mental Health Act (2007).

Tsiouris, Cohen, Patti, and Korosh (2003) reported a study of serious self injurious behaviour that had failed to respond to intensive behaviour management. In all twenty-six cases, identification and treatment of a psychiatric disorder contributed to significant improvement, although cessation of self injury was a minority occurrence. Only in a minority was the effective medication a major tranquilliser. This observation suggests that psychiatric disorder is more likely to be found in severe behaviour disorder, and severe psychiatric disorder is more likely to benefit from psychotropic intervention.

Accordingly, there are a range of different medications that may have a role in serious behaviour disorder. There is a growing literature on drug effectiveness that focuses on treating symptoms rather than disorders, partly because of the problems of diagnostic reliability and co-morbidity in intellectual disability. It can therefore be concluded that, in the context of severe challenging behaviour that fails to respond to thorough behaviour analysis and intervention, assessment by a psychiatrist is indicated and that psychotropic medication may well have a role.

Differing Rates Of Psychiatric Disorder According To Level Of Intellectual Disability

Cooper and Bailey (2001) have looked at the rates of psychiatric diagnosis according to level of intellectual disability in adults. Some disorders were more commonly found in persons with milder levels of intellectual disability, such as psychosis and anxiety disorders. Whereas, some disorders were more commonly found in persons with more severe levels of intellectual disability, such as pica, behaviour disorder, ADHD, and autism. However very few studies look at whether the reliability and validity of these diagnoses are different at different levels of intellectual disability.

Identifying Depression In Intellectual Disability: Experience And Skill, Or Education And Time?

The research on depression, as the most common and treatable disorder, illustrates the problems of identification and therefore access to treatment. While there is consensus that depression can be identified using DM-ID or ICD10, in practice there are real problems with the use of these standardised criteria and with reliable identification of the critical features for diagnosis. In Scotland, Cooper et al. (2007) found a point prevalence of affective disorders (unipolar depression and bipolar disorder) of 6.6% based on clinical diagnosis by a specialist intellectual disability mental health professional compared with 5.7% using DC-LD (Royal College of Psychiatrists, 2001), 4.8% using ICD10, and 3.6% with DSM-IV TR. The equivalent figures for unipolar depression was 4.1%, 3.5%, 2.8%, and 2.0% respectively. Smiley et al., (2008) also described problems with the presence of unusual features such as lability of mood, onset of challenging behaviours, reduction in speech, social withdrawal and increase in somatic complaints.

Hurley (2008), in a retrospective clinic population, found that most individuals with intellectual disability and depression could not meet the required number of criteria for DSM-IV or DM-ID criteria for depression. The main problem was that individuals with intellectual disability and depression do not complain of depressed thoughts. They still had depressed mood, sadness, crying and anhedonia, and withdrawal, which distinguished them from those with anxiety or bipolar disorder. Few reported suicidality. Bipolar individuals differed in having elevated mood, acute anger episodes, increase in verbalisation, pressure of speech, talk of sexual themes, increase in appetite, and poor concentration (Hurley, 2008). Anxious individuals had more fearfulness without other features of depression. Depressed individuals also had more aggression and impulsivity than anxious individuals or controls.

Torr, Iacono, Graham, and Galea (2008) in an Australian study, examined general practitioners (GPs) and long term paid carers’ capacities for identifying features of depression with the aid of a fifty-three item checklist for depression. The routine assessment of individuals with intellectual disability by a GP was compared with subsequent comprehensive psychiatric assessment. Carers identified many of the features that the GPs failed to identify, even with the carers present. Factor analysis identified that the consistent features of depression in individuals with intellectual disability were depressed mood (6 items), loss of interest (5 items) and loss of social interaction and communication (8 items). Carers were able to describe these but they were not reliably identified by GPs. Depressed thinking was not a reliable feature of depression, reflecting the limited communication skills of many participants. GPs tended to focus more on sleep, appetite, weight control, and general functioning. It was found that 30% of this clinical cohort had depression but 25% had a PDD which the study did not examine.

One case scenario study (Einfeld et al., 2007) and one clinical study (Lee, Moss, Friedlander, Donnelly, & Honer, 2003) suggested schizophrenia can be reliably diagnosed by psychiatrists or psychologists experienced in intellectual disability. However, the findings by Torr, Iacono, et al. (2008) illustrated that diagnostic recognition is not a manualised procedure but relies on familiarity in the field of intellectual disability as well as clinical expertise in psychiatry. In addition, diagnosis requires reliable information from a range of sources preferably aided with specific structured questionnaires. The gravest implication is that access to mental health service provision for people with an intellectual disability is severely disadvantaged by the lack of an appropriately trained workforce both in general practice, which is the main gateway to psychiatric services, and in psychiatry, where there is a need for psychiatrists with subspecialty skills in intellectual disability. The texts by Hassiotis, Barron, and Hall (2009) and Bernard and Turk (2009) are useful in providing the diagnostic features of the main psychiatric diagnoses and a practical framework for establishing a specialist service.

Section II: Child And Adolescent Psychiatry Of Intellectual Disability

The Development Of Community Based Child And Adolescent Psychiatry In Intellectual Disability

The original epidemiological studies of child psychiatric disorder of the ‘Isle of Wight Study’ and Camberwell (Rutter, Tizard, Yule, Graham, & Whitmore, 1976) showed rates that were three times higher in an inner city population at 18%. This led to a biopsycho-socio-cultural framework of risk factors and a model of multiple causal mechanisms of child psychiatric disorder. The initial emphasis of child psychiatry was on the importance of the psychosocial context with a focus on the influence of emotional deprivation on the developing child. However Rutter et al.’s study also demonstrated that an intellectual disability raised the risk of a co-morbid psychiatric disorder fourfold.

The realisation that attachment was important for children’s development led to a change in social policy in 1981 in the UK in relation to the institutionalisation of children with severe intellectual disability. Often children had been placed in hospitals or institutions from birth. Some of these environments were homely and personalised, and some were depriving and anonymous. The change in policy led to these children moving from hospitals to community-based children’s homes. What was evident was that good quality community-based care was about three times more expensive than hospitals.

Care in the community may provide opportunities for community access and belonging, but for some children with severe intellectual disability, the change in quality of life can be minimal as community homes can risk poor and inconsistent care with greater difficulty of supervision and accountability. Furthermore, the lack of service-based residential options for most children meant that the biggest change was for mothers who had to shoulder an inordinate burden of care (on average 7 hours a day, 7 days a week of care) at considerable personal cost. However, the normalisation of the care of children meant that they could be recognised as children first, with human needs for security and attachment. As part of the process of normalisation, it has taken time for mainstream services such as those for mental health to recognise their responsibility for the special needs of these children.

It has been contended that the medical and psychological study of delayed development has much to teach clinicians about the development of consciousness, the sense of mutual awareness (empathy and theory of mind), and the biological and social contributors to that process and its problems. This merges the biological with the psychosocial in the context of development as illustrated in Figure 20.1. This diagram illustrates the multiple factors that interact on child development and behaviour. The longitudinal aspect illustrates how earlier events influence later development and that interactions occur between the physical environment and physical development, and between the emotional environment and social development. Both biological and social environment have big effects on the child’s potential even before birth. The crossectional view (based on Brofenbrenner, 1979) illustrates how brain function influences intelligence, developmental skills, and relationships. The wider environment influences relationships which in turn influence interior circles including brain development. Recent genetic reseach illustrates the influence of the external environment on the internal environment (i.e., factors within the growing child). A common language of understanding behaviour has to take account of this full range of interactive factors.

[Insert figure 20.1 here]

Accordingly, this area of study is remarkable for its potential to reinvigorate child psychiatry (Dossetor, Santhanam, Rhodes, Holland, & Nunn, 2005) and provide a broader base from which to develop approaches to intervention. Many of the approaches come from the greater intensity of intervention required for young people with intellectual disability. The integration of the psychiatry of intellectual disability and child psychiatry also leads to a framework of developmental neuropsychiatry that takes into account developmental processes in all young people (see Figure 20.2).

[Insert Figure 20.2 here]

Evidence In Psychiatry In Intellectual Disability

There are few epidemiological studies of ICD or DSM child psychiatric diagnoses and minimal research on the reliability of these diagnoses specifically in children with intellectual disability, let alone the validity. One exception was the study of Dekker, Koot, van der Ende, & Verhulst (2002) of a random sample of 474 special school students aged 7-20 years old. Parents were interviewed using the Diagnostic Interview Schedule for Children (NIMH DISC IV, Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000) limiting the examination to common diagnoses. They found 38.6% of students met DSM-IV symptomatic diagnostic criteria and 21.7% also met criteria for significant impairment of everyday functioning. Of the sample, 21.7% had an anxiety disorder, 4.4% had a mood disorder, 25% had a disruptive behaviour disorder, and 37% had more than one disorder.

Further difficulties with child psychiatric diagnoses in children with intellectual disability occur when clinicians describe problems differently, for example, one clinician may describe as a behaviour problem what another clinician sees as a psychiatric problem. There are no objective measures to distinguish the impairment associated with an intellectual disability from impairment associated with a psychiatric disorder. Child mental health researchers include any disturbance of behaviour or emotions sufficient to cause significant impairment to the child or to those caring for them as a significant psychiatric disorder. For older children and adolescents, mental health services start to prioritise their business for practical and pragmatic reasons. The current Australian Federal and State Governments' logo of '*Mental health is everyone's business*' suggests that all services that deal with children have responsibilities to understand and manage mental health problems. For example, most aggression is a chronic problem that doesn't improve in psychiatric in-patient units. Most conditions are best treated in the community, and the quality of the care in the community is a shared responsibility between families, neighbourhoods, and all government departments.

The longitudinal study of young people with intellectual disability by Einfeld and Tonge (1996b) indicated that 40% had a severe mental health disorder using the Developmental Behaviour Checklist (DBC, Einfeld & Tonge, 1995). The DBC provides a symptom score as a severity measure of disturbance, but it does not readily translate into psychiatric disorders, although selected items can be used to screen for autism or depression. However whether a problem constitutes a mental illness in terms of a DSM or ICD diagnosis, or whether it is a behaviour disturbance is a subjective determination, that is affected by the professional discipline and employing agency that use different theoretical models, languages, and indeed priority selection criteria for service provision.

What Treatments Work In Children With Intellectual Disability?

Can the problem of diagnosis be clarified by considering the evidence of the benefits of treatment? A recent literature search of the empirical evidence of effectiveness of intervention in children with intellectual disability revealed two Cochrane systematic reviews. Diggle and McConanchie (2002) found that parent training had the best evidence of being helpful. The review on behavioural intervention by Hassiotis and Hall (2008) reported short term benefits of behavioural intervention but there was only limited evidence of longer term benefit.

Parent Training Approaches To Intervention

What can the parent training approach such as Stepping Stones Triple P (Sanders, Mazzucchelli, & Studman, 2003) for emotional and behavioural problems teach clinicians? First the program has a normalising philosophy and framework that is the same for children with intellectual disability as for those without. This framework includes the tenets of creating a safe, engaging environment; the environment should facilitate learning of skills and positive behaviour; use of assertive discipline to shape behaviour; parental emotional adaptation to the (disabled) child; having developmentally realistic expectations; being a part of the community and taking care of parents' wellbeing (Roberts, Mazzucchelli, Studman, & Sanders, 2006).

There is evidence that promoting skill growth, independence, and self determinism improves problem behaviour even in adults with intellectual disability (Nota, Ferrari, Soresi, & Wehmeyer, 2007). For parents to be emotionally and developmentally in tune is important for progress. Recognising the need to belong to a wider community is also important for both parents and children. However this parent training approach assumes a complex understanding of behaviour problems. These include,

1. Genetic factors e.g., sociability, reactivity and activity levels;
2. Family environment factors e.g., accidental rewards of undesirable behaviour, escalation traps, emotional messages, ineffective use of punishments, parents' beliefs and expectations, parents' relationships and emotions, stress; and
3. Influences outside of the home such as other relationships including peers, school, media and technology.

The reason for working on family environment factors is they are the most accessible and easiest for parents to influence. Improving family environment factors can also influence the extent of the influence of genetic factors, and makes it easier to sort out influences outside of the home. Furthermore, the rigor of this approach is likely to have a long term effect by improving emotional communication and attachments.

Multiplier Effects Of Risks And Disadvantage

The risk of child psychiatric disorder rises in relation to the number of social adversity risk factors, but the risk rises exponentially. The epidemiological studies of Triple P - Positive Parenting Program® also illustrate how psychiatric problems and adverse social context have a multiplier effect. A study by Zubrick et al. (2005) found that children in primary schools who received intervention demonstrated improvements of both emotions and behaviour which were sustained with associated improved parent child relationship. Those who did not receive intervention, not only did not get better but their behaviour deteriorated and the parents' views about them got worse, leading to an even more damaging parent-child relationship. Thus change and progress is due to complex interactive mechanisms.

Medication for ADHD shows significant improvement, but it seems likely that the long-term outcome is dependent on such secondary multiplier effects, in terms of whether home and other relationships become less developmentally deleterious and indeed developmentally enhancing. Such suggestions on multiplier effects are supported by the widespread research on the negative influence on all types of psychiatric disorder of high expressed emotion (which includes criticism and hostility or emotional over-involvement or depression) in the closest relative(s). Intervention also involves engendering hope and optimism which in turn improves interpersonal emotional communication.

The principles of promoting positive behaviour, limiting emotional over arousal, reducing risky behaviours, improving positive and realistic expectations, and strengthening developmentally enhancing relationships, would seem to be universal aims for all psychiatric disorders. These processes are beholden in psychology, and may also be a critical part of the process of admission to a mental health unit. The roles that are distinct for a doctor/psychiatrist are considering in greater detail the child's physical health and the possibility of intervening in the internal environment, especially through the use of medications.

ADHD And Disruptive Behaviour Disorders: An Example Of The Interaction Of The 'Internal' And The 'External' Environment

In child and adolescent psychiatry, clinicians are faced with the same mix of factors as described in the Stepping Stones Triple P (Sanders et al., 2003) parent training approach. For example, in disruptive behaviour disorders both aetiological and treatment studies show that it is predominantly family factors that drive disruptive behaviour disorders (Scott, 2008). The final common pathway of the main genesis factors are inept parental discipline and monitoring. Yet there are also temperamental vulnerability factors such as activity and reactivity levels that have genetic components. Indeed these genetic factors in the child induce greater reactivity in the parents and therefore less optimal parenting.

Furthermore, ADHD is commonly associated with disruptive behaviour disorders. It has been found that 60-90% of the variance of ADHD is genetic (Thapar & Rutter, 2008). This means that 60-90% of the impairment of ADHD is due to the biological factors of brain function. These factors are polygenetic, but a few of the genes have been identified. These genes then influence brain development, neurone migration, dendrite connection through proliferation and pruning, neurotrophic factors, neurotransmitters and their receptor processes and a whole range of other largely unknown molecular processes of the brain. There is no doubt that these biological factors are affected by the environment, for example, the number of hours of non-educational TV watched by toddlers was related to the risk of having attentional problems in 7 years olds (Zimmerman & Christakis, 2007). Also, ADHD is not a categorical disorder (i.e., when either you have it or you don’t), but it is a question of how much of it you have (Levy, Hay, McStephen, Wood, & Waldman, 1997). Stress, abuse, and emotional deprivation make features of ADHD worse and conversely, an improved social environment also ameliorates them. There is a large literature on the influence of these factors on the developing brain.

The Interaction Of Genes And Deprivation In Childhood: Pathways To Adult Psychopathy

It has been found that the combination of genetic vulnerability (e.g., with a reduced presence of the enzyme MAOA, an adrenaline gene) and the co-occurrence of childhood deprivation leads to life long violence to such a degree that accounts for a large proportion of violent adults in the community (Caspi & Moffit, 2006). However this is purely a research finding and hasn’t led to diagnosis or treatment. Nonetheless, scientists talk about the effect size in ADHD of the ‘external’ environment being 10-40%, and the other 60-90% of effects is due to what happens at the neuromolecular and neurobiological level or the ‘internal environment’ (Thapar & Rutter, 2008).

Clinicians may only have a very limited understanding of the processes of the internal environment but the interactive and multiplier effects between the internal environment and external environment are important and complex. Similar gene and early deprivation interactions have been found for anxiety, PTSD, substance abuse, and depression. Through reducing the reserves of serotonin in the brain, individuals with these disorders are less likely to respond to serotonin reuptake inhibitor antidepressants and are more likely to get side effects. However in ADHD science has discovered medications that do alter the internal environment and alter behaviour. It is exploring the neurobiological and pharmacological components that are specific to medicine/psychiatry.

ADHD In Intellectual Disability

ADHD in those with mild intellectual disability has a significant research literature indicating reliability and predictive validity, that is, it is recognisable and it has predictive meaning (Antshel, Phillips, Gordon, Barkley, & Faraone, 2006). However there are significant differences, such as a prevalence of 30%, equal sex ratio, possibly greater family factors, depression, and social impairment. Further, standard pharmacological treatment is not as effective and is more prone to side effects than for those with a normal range of intelligence.

ADHD in those with severe intellectual disability lacks the same level of research for reliability and validity, and is likely to be affected by more biological and developmental factors. For example, there is an association with other developmental disorders. Both Developmental Coordination Disorder and ADHD occur in 7% of the community, but co-occur in 50% (Martin, Piek, & Hay, 2006). In clinic populations of PDD, ADHD is found in 78% of cases (Lee & Ousley, 2006). In a control study of teenagers with intellectual disability with and without autism, the presence of ADHD was found in one in two of those with autism and intellectual disability versus one in seven with intellectual disability but without autism (Bradley & Isaacs, 2006). Such observations indicate that delays of different domains of development are genetically link, as development and its delay are polygenic processes.

Genetic studies have shown linkage between autism and intellectual disability suggesting some common pathways of development. There are reasons for considering autism as a delay of social development leading to a delay of social understanding, reciprocity, and theory of mind (Dossetor, 2004). ADHD in different (genetic) behavioural phenotypes is reported to be extraordinarily high including: Smith Magenis Syndrome 90%, Fragile X Syndrome 75%, Williams Syndrome 65%, Charge Syndrome 50%, Neurofibromatosis 50%, Velo Cardio Facial Syndrome 43%, Cornelia de Lange’s Syndrome 40%, Soto’s Syndrome 38%, Tuberose Sclerosis 35%, and Turners

Syndrome 24%. Binge drinking in pregnancy causes fetal alcohol syndrome with a range of consequent problems including ADHD in 49%, intellectual disability in 55%, learning disorders in 46%, oppositional defiant and conduct disorders in 41%, and anger control problems, mood disorders and sleep disorders in 50% (Bhatara, Loudenberg, & Ellis, 2006).

Given the frequency of ADHD in these genetic syndromes associated with intellectual disability, it may be helpful to identify co-morbid ADHD for the benefit of drug treatment. ADHD certainly adds to the problems of quality of life and degree of difficulty of care and parenting, but it may not be the same condition as identified in the population of children of average intellect. In the context of intellectual disability, the features of impulsivity, hyperactivity, and inattention may be more appropriately seen as elements of developmental challenge and progress affecting intellectual efficiency in the establishment of conscious processes. These are important to establish theory of mind and a sense of self/others which are key to consciousness. It may be more appropriate to describe it as a developmental delay of these attributes of efficient mentation. Indeed there are well recognised developmental sequences of attention, from modulation of arousal, to selective attention, to dual tasking with attention switching. These are associated with different neurotransmitters, that is, dopamine, acetylcholine, and noradrenalin respectively.

Accordingly there is a dichotomy of intervention approaches. One approach supports the developmental sequence of skill building as a unifying model for improving intellectual disability and disturbance of emotions and behaviour. The other is a deconstructive approach to specific psychiatric syndromes in the hope of identifying individual factors of causality. However a developmental model for ADHD creates expectations of gradual improvement with support as shown by parent training programs (AACAP, 2007). Indeed while most treatment studies have focused on drugs versus cognitive behaviour therapy, parent skills training has been shown to be effective in ADHD (Bor, Sanders, & Markie-Dadds, 2002).

Developmental Models: Valuable Guiding Principals

The universal principle of development was propounded by Heinz Werner, ‘wherever there is life there is development in a systematic sequence’ (as cited by Burack, 2008). Perhaps clinicians know so little about the development of the mind, of consciousness, of emotions and socialisation that developmental principles are the best guide. Piaget (1972) asserted that development involved the orderly and universal development of functioning that evolved in a consistent way. Therefore, despite the differences of every individual, the commonality of human development is the most striking feature, even for individuals whose development is distorted by genetic or biological differences.

Werner also described the orthogenetic principle that ‘development progresses from relative globality and lack of differentiation to increasing differentiation, articulation and hierarchic integration’ (as cited in Hodapp & Burack, 2006, p. 237). As both the individual and context differentiates, so the process of development becomes more complex. This leads on to a development-transactional approach which recognises that real development is complex and involves relations constantly changing or transacting with its environment. Perhaps it is not so strange that researchers of the major psychoses are raising notions that psychoses are developmental disorders, with vulnerabilities of early development leading to later crisis of adaptation, loss of wellbeing and quality of life, and a loss of integration of subjective consciousness.

With the progress of science, an entirely dualist approach to the mind is no longer acceptable. In some situations, clinicians' assistance to people's mental health is clearly enhanced by their understanding of and intervention in the internal environment. However where there is no evidence of the validity of a deconstructive approach to mental health, then developmental models have face validity and are intuitive for families and professionals alike. In many instances delay and deviance cannot be distinguished psychometrically. A developmental framework is a good guide to clinical practice because it is understandable intuitively and problems of intellectual disability need to be understandable to be accepted.

This is not to say that biology isn't important in children and young people with intellectual disability. Indeed the available research suggests that standard measures of family function account for only 4% of the variance of behaviour disturbance in young people with intellectual disability over time (Tonge & Einfeld, 2000; Einfeld et al., 2006) and that the best predictor of disturbance is past disturbance. For example, even the best of family functioning can be overwhelmed by the behavioural impact of a 12 year old with Smith Magenis Syndrome, with real risks of major harm to another member of the family, making family care no longer feasible. However the best bet for helping young people with intellectual disability is through understanding developmental need, particularly getting in early to help these families with atunement, skills, and mitigation of the inordinate burden of care. The more it is understood how biology is manifested through developmental processes, the more parents can develop the skills that match the needs of a child with a developmental disability and promote their development in the context of loving family relationships.

Developmental Approaches To Understanding Young People And Their Behaviour

In a stratified random selection of ninety-two 12-18 year olds with mainly severe intellectual disability, emotional and behavioural disturbance measured on the Handicaps Behaviour Skills Schedule (Wing & Gould, 1978) formed a single factor for analysis (Dossetor, 1991). Emotional and behaviour disturbance was not related to chronological age but to developmental age. Disturbance gradually increased from a developmental age of 1 year to 2.5 years, and then progressively declined. This concurs with developmental norms of children of normal intellect. That is, as children of normal intellect become older and more able, they show more exploratory and intrusive skills until their third year, when they develop a theory of mind. They start to realise that they have an imagination which relates to other peoples' thoughts and feelings. Accordingly their exploratory skills focus on their internal world and they become less problematic to others. Although other developmental factors such as adolescent hormones and life roles also influence behaviour, the author's clinical and research experience suggests that the developmental age is most formative.

In the same way as tantrums are a normal part of development in 80% of 2 year old children, it is a complex normative developmental behaviour that most children grow out of by 3-4 years, rather than being due to environmental or neuropsychiatric features. Family environmental factors are most related to severity and persistence of tantrums, but it is temperamental factors of the child (including significant genetic factors) that predispose. Thus toddlers face a stressful challenge in integrating the meaning of the world with a growing capacity for a perspective of self and other, an internal voice and sufficient concentration to reason. Indeed malice of forethought or antisocial premeditated behaviour can't really be attributed before the age of 5-6 years and the development of concrete operations. Depression requires similar developmental milestones for the capacity for guilt, as an internal/cognitive means of maintaining depressive mood and its biological concomitants. Such a framework suggests that before this developmental age, psychiatric presentations are generally reactive to their environment, in keeping with a model of challenging behaviour or adjustment disorders. The exception to this would be developmental disorders including autism and ADHD.

Dealing with moderate, severe and profound intellectual disability focuses on the developmental processes of the under fives. Making sense of behaviour in children with intellectual disability requires a detailed understanding of the multidimensional components of development. When development is delayed, it is likely that delay will be unequal across different developmental domains. If one domain is delayed then it is likely that another will be delayed. For example if language development is delayed there is greater risk of intellectual disability or problems of social reciprocity. If you have coordination disorder then you are more likely to have enuresis. If you have delayed development you are more likely to have ADHD. Autism is more likely in ID (confirmed by genetic linkage studies). The implication is that *developmental processes vary but also are genetically linked to each other.* The main domains of development are listed below.

Sensory/Visuospacial Skills

Sensory processing is a source of pleasure and stimulation for individuals, but it is the primary source of physiological conscious arousal before the establishment of theory of mind and an internal imaginary world. Modulation of arousal is facilitated by adult engagement, for example, in modifying the environment and providing predictability.

Once theory of mind has developed, thought, imagination and social engagement have predominant roles influencing the control of arousal.

Motor Development, Activity, And Coordination

Motor calmness is a prerequisite for concentration and awareness of time.

Independence Skills (e.g., for feeding, dressing, toileting)

The level of achievement in independence skills is the best clinical measure of general intelligence before the development of educational skills. It can also involve community access safety and skills.

Communication Skills

a) Receptive communication, tested functionally by response to commands, the complexity and grammar of commands and an understanding of concepts such as time.
b) Expressive communication again depends on its functionality.

Social Development

Social development is a measure of social reciprocity and empathic understanding and progresses from affective reciprocity to joint attention, turn taking, reciprocal interaction to participating in group dynamics. Emotional understanding is related to social development and is specifically delayed in ASD, which is found in 50% of those with intellectual disability (Wing & Gould, 1979). It is not surprising that the presence of ASD is associated with behaviour disturbance, as social engagement is central to the social nature of humans. The author’s rule of thumb is that in children with Autism, social developmental level is less than 2 years, and for Aspergers it is less than 4.5 years.

These five domains relate to assessment, skill building approaches and intervention of the allied health disciplines of occupational therapy, physiotherapy, speech pathology, and psychology. All these disciplines may be required to assess and help understand complex developmental profiles and the relationship to difficult behaviour.

A number of other child mental health clinicians working in intellectual disability have also suggested models of understanding development processes and the relationship to the development of emotions. Curran and Kyrkou (2008) developed the acronym SPICE for assessing the developmental dimensions of Social, Physical (including sensory, motor processing, other neurological impairments and seizures), Intellectual (including the executive function skills), Communication, and Emotional development. On the other hand, Greenspan and Wieder (2008) presented a model of social development that can be applied to autistic children or typically developing children. They identified specific focus areas that equated to developmental ages and included: parent oriented (0-1 years - affective reciprocity); adult oriented (1-2 years - joint attention); toddler independence (2-2.5 years - parallel play); peer skill development (2.5-.4 years - Theory of Mind); peer group association (4-8 years - second order Theory of Mind); pre-adolescent (9-13 years); and adolescence (13+ years - abstract cognitive capacity). Both Curran and Kyrkou’s (2008) and Greenspan and

Wieder’s (2008) models address similar dimensions, starting from different frameworks.

Clearly a developmental model is only one component of a child psychiatric assessment which also requires assessment of the medical, family environment, peer and community influences, and neuropsychiatric components. On the one hand, intensive clinical approaches, particularly in behavioural psychology, developed in intellectual disability have significantly influenced behaviour modification and skill building approaches of mainstream child psychiatry. Conversely, disability services can no longer be restricted to thinking in a behavioural framework and have to accept a holistic, multi-causal approach where multiple factors contribute to the complexity of behaviour, emotions, and development. The secondary challenge is to look at which factors can be modified or which theoretical models provide a basis on which to intervene as illustrated in Table 20.3.

[Insert Table 20.3 here]

Behavioural Phenotypes: Intellectual Disability’s Contribution To Understanding The Mind

The study of behavioural phenotypes has been described as a window into the biology of the brain. Behavioural phenotypes are where a behaviour or cluster of complex emotions and behaviours are associated with a genetic condition. This is a fascinating area of study particularly when a specific gene is associated with a symptom of psychiatric concern to a wider population. For example, the association of high rates of psychotic disorder in Velo Cardio Facial Syndrome (22q11 gene deletion) may improve the understanding of the biological correlates of schizophrenia. Other research is linking a gene with a certain medical or neuropsychological attribute to developing certain behaviours. For example, the self injury of Cornelia de Lange's Syndrome was found to be related to unexpressed pain from oesophageal reflux or dental pain and responded to Omeprazole for reflux (Oliver et al., 2003; Oliver, Arron, Sloneem, & Hall, 2008). In contrast, obsessive behaviour was related to ASD features in a range of behavioural phenotypes. Other research findings suggest that in Cornelia de Lange's Syndrome, anxiety was increased in social behaviour such as before speaking. Task-orientated attention switching was found to stress people with Fragile X and was associated with tantrums, whereas those with Prader Willi Syndrome were only stressed by a verbal challenge to switch or a switch of routine (Oliver, 2008). These genetic based differences help clinicians to understand some developmental and neuropsychological attributes that underlie maladaptive behaviour.

In some instances, the specificity of behavioural phenotypes in relation to understanding the internal environment leads to experimental biological treatments and opens the hope of new medical treatments. Some examples include,

- Fragile X Syndrome, where trials with a selective antagonist for a glutamate receptor subtype 5 drug, Fenobam, demonstrated a short lived improvement in intellectual performance. This was an attempt to intervene in the neurobiology of a lack of fragile X mental retardation protein (FMRP). Fenobam and Lithium can reverse a lack of methylation and a lack of FMRP that acts as a synaptic messenger, downgrading synaptic activity (Hagerman et al., 2008).
- Tuberose Sclerosis, where the associated intellectual disability is not purely related to the tubers in the brain, but also to the protein mTOR (Target of Rapamycin)

(Ehninger, de Vries, & Silva, 2009). Rapamycin, an anti transplant rejection drug, reduces tuber sizes and improves cognition and memory in animal models.

- Lesch-Nynhan Syndrome, that is caused by deficiency of the purine enzyme hypoxanthine-guanine phosphoribosyltransferase with over-production of uric acid, along with mental retardation, recurrent self-injurious behaviour and motor disability. The use of deep brain stimulation by electrode implantation, which was ethically approved to improve dystonia, also reduced severe mutilating self injurious behaviour incidentally (Harris, 2008). Proton magnetic resonance spectroscopy showed that this was associated with improvement of the basal ganglia dopamine deficits and an increase in dopa action in meso cortical and frontal areas and better emotional regulation.

Such examples of neurobiological science could lead to future important treatments. However, Dykens and Hodapp (2001) reminded clinicians that even though behavioural phenotypes can unlock some biological processes, these usually prove to be only one component of the behavioural phenotype, often challenging our deconstructive concepts of mental illness. Biologically driven behaviour is also still influenced by context and external environment (Dykens, 2000).

Conclusions

People with intellectual disability have raised levels of emotional and behavioural disturbance which significantly impair quality of life for the individual and their family/carers. A study by Emerson and Hatton (2007) found that children with intellectual disability accounted for 14% of all children in the UK with psychiatric problems compared to 3% prevalence of intellectual disability. Costello, Holt and colleagues (2007) indicated that a failure to intervene early in emotional and behavioural problems led to long term morbidity and cost to the community. Thus, issues of equity demand that people with intellectual disability and mental health problems have access to an appropriately skilled multidisciplinary clinical workforce.

Biological forces in intellectual disability drive problems of developmental delay and disturbance. Particularly in severe intellectual disability, developmental understanding has greater relevance to understanding behaviour. The best evidence for improving disturbance, or minimising its handicap, is by promoting stimulating, supportive, and protective relationships as provided by a family. These types of intimate relationships promote a progressive sequence in independence, communication, emotional and social skills, and the development of functional consciousness.

There is a growing empirical literature on different processes, theories and interventions. Consensus suggests that multidisciplinary assessment and intervention can improve outcomes, but knowing which interventions will work in a particular child or young person with intellectual disability depends on clinical expertise.

There is need for investment in specialist parent training as one of the early universal interventions. Multidisciplinary skills in intellectual disability are needed for assessment and skill promotion. Intensive behavioural management remains a key skill, but is no longer sufficient (Carr, O’Reilly, Walsh, & McEvoy, 2007). Both disability clinicians and mental health psychologists need to be trained in the modifications of cognitive behavioural therapy for people with an intellectual disability. In current practice, it has been found that family therapy knowledge and systems thinking skills are a critically needed (Rhodes, 2003; Seligman & Darling, 2007). There is a self evident need for a multidisciplinary approach to mental health in intellectual disability.

Lastly there is need for collaboration with psychiatrists. Mainstream psychiatrists are familiar with psychotropic medications and understand mainstream presentations. However they lack experience especially of the clinical differences in people with a severe intellectual disability, whose mental health problems are complex and have a major impact on their quality of life. Thus, there is an imperative need to develop and recognise a psychiatric workforce in intellectual disability.

In Australia there is no specialist mental health service for people with an intellectual disability. However a psychiatric workforce in intellectual disability is necessary to provide a clinical expertise in areas for which other professionals cannot substitute, even as an opinion of last resort. This review has illustrated some of the reasons for needing a psychiatric workforce with specialist experience and knowledge. Such a subspecialty would be an essential source of advocacy for services and for clinical research for this special population but would also enrich mainstream mental health and psychiatry.

Table 20.1

DSM-IV Psychiatric Diagnoses Found In The US By Tsiouris et al. (2008)

Psychiatric Diagnosis	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 Syndrome	2%
No psychiatric diagnosis	40%

Table 20.2

Psychiatric Diagnoses Found InTthe UK By Cooper et al. (2007)

Psychiatric Disorder	Types of ICD10 Psychiatric Disorder
Mental ill-health of any type 40.9%	Psychotic Disorder 4.4%
Problem Behaviour 22.5%	Affective Disorder 6.6%
Mental ill-health of any type excluding problem behaviours 28.3%	Autistic Spectrum Disorder 7.5%
	Anxiety Disorder 3.8%
Mental ill-health of any type excluding autistic spectrum disorder 37%	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%

Table 20.3

Some Common Theoretical Models And Their Common Context

Theoretical Models	***Context***
Society	▪ Welfare, rights, cultural attitudes and socio-economic influences
Community	▪ Environment, social structures and social capital
School	▪ Communication, other skill enhancements and peer relationships
Family	▪ Emotional environment and substitute care
Group	▪ Social skills and role learning models
Individual Relationship	▪ Attachments, intra psychic or somatoform emotional models
Cognitions and affect	▪ Problem solving, CBT, affect regulation and coping skills models
Neuropsychology	▪ Neuroanatomical function and integrity
Neuropsychiatric processes	▪ Neurochemical and psychopharmacological models
Neurobiological risk and resilience	▪ Genetic and neurodevelopmental and molecular biology

Figure 20.1

Bio-Developmental-Psycho-Social Cultural Model

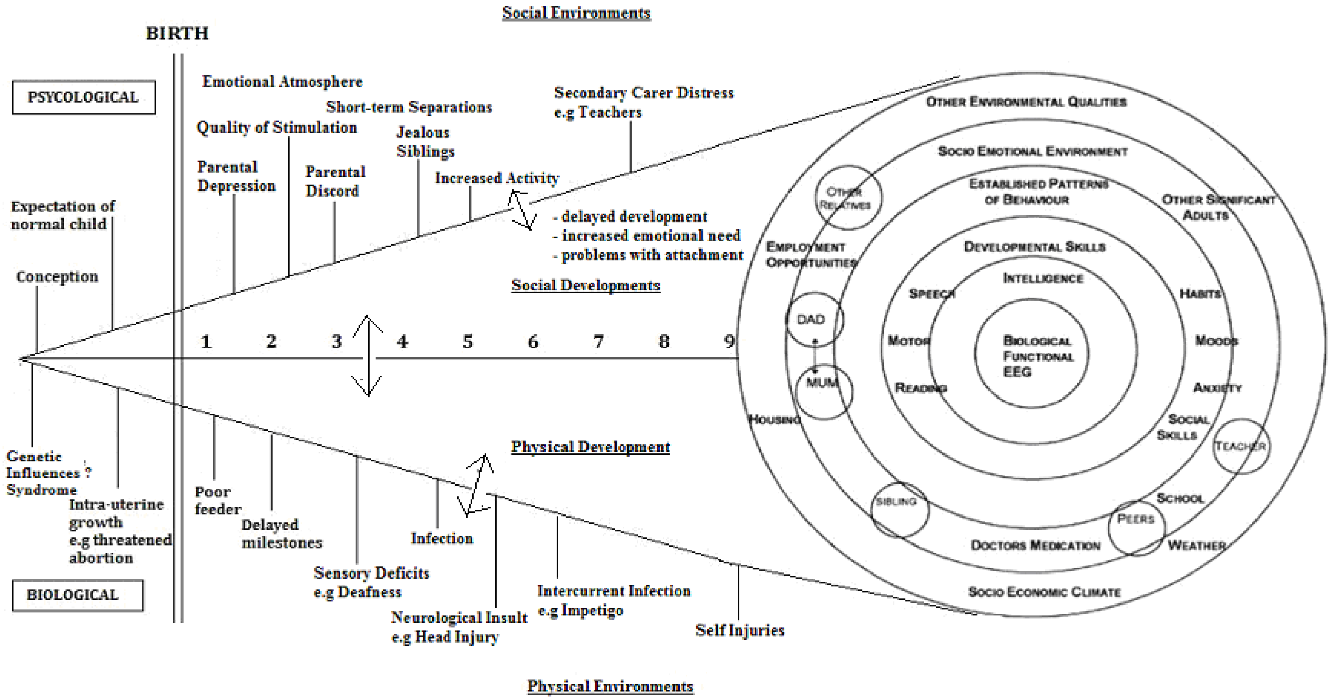
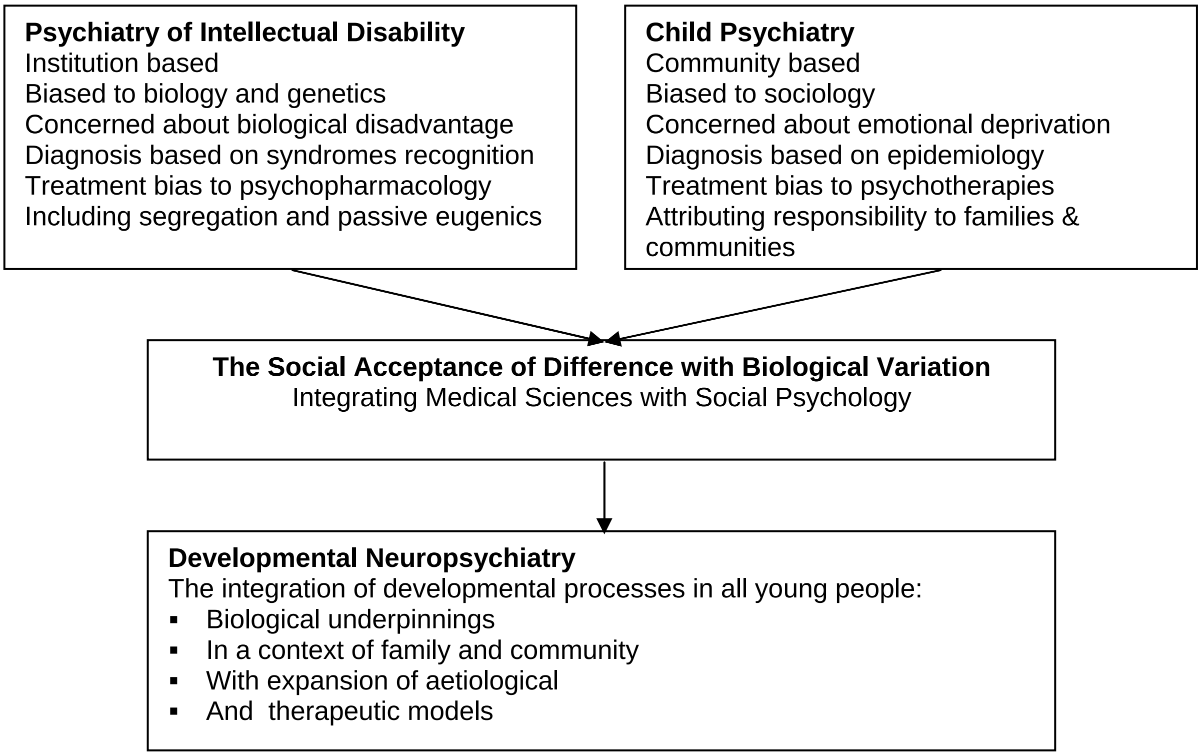


Figure 20.2

The Integration Of The Psychiatry Of Intellectual Disability And Child Psychiatry



Psychiatry of Intellectual Disability
Institution based
Biased to biology and genetics
Concerned about biological disadvantage
Diagnosis based on syndromes recognition
Treatment bias to psychopharmacology
Including segregation and passive eugenics

Child Psychiatry
Community based
Biased to sociology
Concerned about emotional deprivation
Diagnosis based on epidemiology
Treatment bias to psychotherapies
Attributing responsibility to families & communities

The Social Acceptance of Difference with Biological Variation
Integrating Medical Sciences with Social Psychology

Developmental Neuropsychiatry
The integration of developmental processes in all young people:

- Biological underpinnings
- In a context of family and community
- With expansion of aetiological
- And therapeutic models