



Chapter 2

Conceptualising Dual Diagnosis

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1. Introduction

Conceptualising Dual Diagnosis



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This Chapter explores the perspectives of adults with a dual diagnosis and the issues that face their carers, both paid and unpaid who support and assist them. Historically, adults with significant developmental delays in cognitive and adaptive development have been diagnosed with intellectual disability alone and little consideration was given to mental health aspects of their needs (Fuller & Sabatino, 1998).

Characteristics of mental health and related needs, definitions and concepts used throughout the Report are clarified and considered in this Chapter. Reasons why adults with a dual diagnosis have unmet needs within Australia and other western democracies are also briefly explained. A glossary of terms is included within the Appendices. This glossary was used throughout the Project to guide language when communicating with Project participants.

2. Historical Overview

People with an intellectual disability have been marginalised and excluded from mainstream society since history began to be recorded. This vulnerable group of people share a long and sad history of discrimination, isolation, segregation, mistreatment and abuse. Contemporary Governments have legislated in a genuine attempt to ameliorate their negative life circumstances. Policy and program changes have followed that aimed to improve the lives of people with disabilities through changes to social, political, and economic structures.

Adults with an intellectual disability have a range of unique needs that require special consideration and support. Although mental health is critical to any conceptualisation of health or well-being or quality of life, the energy of Governments remains focussed upon challenges associated with the achievement of community acceptance, valued social roles and a reasonable quality of life. Despite increasing emphasis being placed upon the importance of quality of life, Governments have traditionally failed to recognise the breadth of needs faced by people with disabilities. In particular, the mental health needs of adults with an intellectual disability have not received due attention.

The strengthening of mental health services that are inclusive of adults with an intellectual disability has only recently begun to emerge as an internationally relevant issue. Most western nations, including a number within Eastern Europe, are making increasing progress towards the care and support of adults with a dual diagnosis in community-based settings. The mental health needs of adults with an intellectual disability have been brought into sharper focus as the impact of deinstitutionalisation and community care has been evaluated.

Motivations for change appear to have been philosophically sound ie driven by the desire to give people with disabilities the opportunity to live as normal a life as possible (Nirje, 1969). Regardless, questions have been raised about the repercussions of community care policy and other changes associated with deinstitutionalisation (Lindsey, 1998). Concerns fundamentally

relate to the vulnerability of people relocating to the community and the apparent failure of medicine to meet the needs of this group. It is a sad indictment upon contemporary human, health and disability services that the inverse care law remains operational - those most in need, marginalised people, appear least likely to receive the services that they require (Hart, 1971).

Community care policy was considered by many to be the political and ideological panacea that would reverse the wrongdoings associated with institutionalisation. Proponents appear to have assumed that the mental health needs of adults with an intellectual disability would be met by the existing mainstream mental health services. It was expected that financial and other resources that

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had been used to maintain institutions would be re-routed and used to promote independent living in the community for adults with an intellectual disability. The reality is quite different.

The UK experience suggests that in general, generic mental health services have been unwilling to take on the psychiatric care of people with an intellectual disability (Bouras et al, 2000). There are numerous inter-related reasons. Staff working within community-based services have different professional backgrounds, therefore skills and training may not address the needs of adults with a dual diagnosis (Holt et al, 2000). Resource pressures have resulted in inconsistencies between services delivered, eg locational disparities between metropolitan and rural areas. Tensions between service providers and eligibility criteria have resulted in restricted access of adults with an intellectual disability.

Community based service providers often hold divergent perspectives about which agency has primary responsibility for the provision of support services needed for people with an intellectual disability to live within the community. In some situations a culture of blame has emerged where health, mental health and disability service providers view themselves as victims of cost shunting. Service provision to adults with an intellectual disability within the UK has been severely compromised by eligibility confusion, unclear service provision and disagreements about who should be responsible for providing care (Bouras et al, 2000). Anecdotal experience suggests a similar situation in Australia.

Western nations are obviously in different stages of implementation and development in regard to responses to the mental health needs of adults with an intellectual disability. Disparate views about the appropriate ways to respond are also identifiable. However, there is little room for debate that the services required by adults with an intellectual disability are often complex. The population is diverse and individual mental health needs vary between individuals. Logically, services that respond should be multi-faceted and diverse to ensure they are sensitive to the individual needs of each adult with an intellectual disability. Adults with a dual diagnosis can be quite a demanding group for community-based services. Generic mental health and primary health care service providers need to have access to adequate training opportunities and possess appropriate skills that reflect an evidence-based approach to care and support.

Although Australia has been aware of international developments in service delivery (for example, numerous Department of Health, UK Reports over the last decade), mental health services for adults with an intellectual disability within Australia have remained under-developed. It is important to note that across Australia only a handful of Psychiatrists work solely with adults with an intellectual disability. Only one Psychiatrist within Queensland specialises in the area on a part time basis and there are no government-funded positions for full time Psychiatrists in this state.

Contributory reasons why the mental health needs of adults with an intellectual disability have been neglected include (Molony, 1993):

- no formal sub-specialty, eg “psychiatry of intellectual disability” within psychiatry and no special interest group within RANZCP;
- limited undergraduate and postgraduate medical education and training;
- lack of experienced mental health professionals, including clinical experiences for psychiatric trainees;
- controversy regarding psychopharmacological interventions for challenging behaviour in this group;

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- de-medicalisation of community based services and the transfer of responsibility from health to welfare services;
- ideological debate, eg conflict between normalisation/social role valorisation and the medical model; and
- the dearth of resources.

3. Terminology

Psychiatry, part of the medical profession, is concerned with the diagnosis, assessment and management of a spectrum of mental health problems and disorders. Although Psychiatrists are significant contributors, professionals and staff employed by health, mental health and disability services also play an essential role in the recognition, treatment and management of mental health problems experienced by adults with an intellectual disability. Similarly, carers and family members play key roles.

Terminology used by Psychiatrists and other mental health professionals can be confusing, particularly when clinicians tend to use the terms or concepts interchangeably. The language or discourse of mental health professionals is also not well understood by service providers and other professionals working outside of psychiatry, eg those working in disability services. Carers and family members may also be alienated by lack of familiarity or understanding of mental health terminology.

Important differences can be identified between common mental health terms (see National Mental Health Strategy, 2000), eg:

- **mental health problems:** these problems are often episodic in nature or transitory, and tend to be managed with personal supports rather than professional or clinical services;
- **mental illness:** may be a "one-off" experience but the problems experienced require clinical or professional services;
- **mental disorders:** major problems that can be recurrent & severely debilitating, often require (lifelong) ongoing clinical or professional services; and
- **psychiatric disability:** a chronic condition that is consequent to mental disorder or mental illness.

Barriers emerging from the different professional discourses used within government and non-government service sectors are discussed later in the Report. The Project Team was aware of the potential of terminology to be confusing therefore (as previously mentioned) a glossary of terms

was used throughout the duration of the Dual Diagnosis Project. This glossary can be found in the Appendices but key, select terms and concepts are briefly described below.

3.1 Mental Health

Mental health should always be inclusive of the skills and abilities that people need so that they can achieve and sustain a reasonable quality of life through successful interactions with other people within society. Synonymous with emotional and social health and well-being, mental health allows individuals to cope with ordinary and unusual demands, and the hassles or stresses of everyday life.

Mental health is probably best conceptualised as being located along a continuum. At one end is mental health and at the other end, mental disorder. The National Mental Health Strategy (2000) defined mental disorder as “a diagnosable illness that significantly interferes with an individual’s cognitive, emotional or social abilities.” This approach suggests that mental health & mental disorder blur or merge into each other at some point along the continuum, ie they are not discrete or separate categories.

Mental health is somewhat elusive in so far that it cannot be simplistically reduced to the absence of mental illness or mental disorders. The Australian Health Ministers defined the concept in 1991 as the “capacity of individuals to interact with one another in ways that promote subjective well-being, optimal development and use of mental abilities (cognitive, affective and relational) and achievement of individual and collective goals, consistent with justice.”

There have been significant improvements in the health and well-being of most Australians over the last decade. However, these gains have not been reflected in the mental health of the broader population and it is estimated that 20 % or 1: 5 people in Australia will be affected by a mental health problem at some stage in their lives (Wen,1997). Different patterns of mental health relate to diverse demographic and social factors, gaps in socio-economic conditions, changing social structures and economic restructuring.

3.2 Mental Disorders

Mental disorders may be classified as disorders of perception, thinking, emotion, body image, memory, consciousness and eating disorders (Gelder et al, 1996). Estimates suggest that 20% or 1:5 of the Australian population will be affected by mental health problems and mental disorders, at some stage in their life (Mulvany, 1998). In the general population, definitions of mental disorder are problematic for Psychiatrists and mental health professionals because diagnostic criteria tend to rely upon environmentally contexted social definitions.

Psychiatrists and mental health professionals tend to categorise mental disorders into psychotic and/or neurotic types of disorders. Standardised criteria are used to assist with the diagnosis of mental disorders including schizophrenia and other psychoses, depression, anxiety and dementia. The DSM-IV-TR, the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition with Text Review) is commonly used by Australian Psychiatrists. Detailed descriptions of mental disorders can be found within the DSM-IV-TR. This version was released in 2000 and includes new research information that had been developed since first publication in 1994. The DSM-IV-TR is published by the American Psychiatric Association (APA). A revision is not planned until after 2006.

3.3 Disability

Approximately 18% of the general population in western society has a disability. Despite the presence of disability, this group comprises a diversity of people with differing skills and social circumstances (Wen, 1997). Disability, according to the dominant medical discourse includes the following “types” or categories:

- perceptual (eg visual, hearing, cognitive);
- illness related (eg multiple sclerosis, HIV/AIDS);
- physical (eg cerebral palsy);
- developmental (intellectual disability);
- psychiatric (eg schizophrenia);
- mobility (eg quadriplegia);
- environmental (eg asthma, allergies) (Rauscher & McClintock, 1997).

The World Health Organisation (WHO) definition of disability underpins the approach of most western Governments. “Disability is a difficulty in seeing, speaking hearing, writing, walking, conceptualising or any other function within the range considered normal for a human being”. The medical discourse typically links disability with disease or as a theory of personal tragedy where people with disabilities are portrayed as unfortunate objects of pity. By comparison the social discourse of disability considers that many difficulties experienced by people with disabilities are social barriers created by society. Problems are therefore not associated with organic disease but the collective lack of acceptance and provision by society. The two discourses of disability have led to different conceptualisation of how Government understands disability and constructs policy and programs to meet needs arising (Rauscher & McClintock, 1997).

3.4 Intellectual Disability

Intellectual disability is formally conceptualised in most definitions with regard to deficits in adaptive behaviours, cognitive ability and the appearance of these problems during the developmental period (Sturmey, 1999). People with an intellectual disability may have abnormalities of brain development and function, and associated difficulties in communication and other skills needed to develop socially. The severity of the disability determines how many people need life-long ongoing support and assistance with basic living or functional activities.

Adults with an intellectual disability form a very diverse group, inclusive of those with low support needs or mild disability through to those people who have high and often complex support needs, eg severe disability. This population is growing in numbers and will continue to make significant demands upon human, health and disability services across Australia.

Australian Bureau of Statistics (ABS) disability surveys provide the best source of prevalence data. In 1993, the ABS Survey of Disability, Ageing and Carers reported that approximately 1.86% of the general population had an intellectual disability. The 328,000 people identified had an intellectual disability either as a primary disabling condition or as an associated condition. 174,000 of this group (0.99% of the total population) need ongoing support (Wen, 1997). Over the past fifty years prevalence rates have differed according to the definitions of intellectual disability used in research studies (Borthwick-Duffy & Eyman, 1990). Influences on prevalence rates include improvements in medical/health care, technology, and shifts in society’s attitudes towards disability.

Adults with an intellectual disability experience significant levels of health morbidity when compared to the general population ie increased health & medical problems (Lennox et al, 2000). Physical health care problems can be hidden or “occult” and interventions can be characterised by misdiagnosis, under-diagnosis and inappropriate management. There is a high incidence of sensory impairment, injury, obesity, heart disease, dental problems, epilepsy and psychiatric morbidity in this population (Howells, 1986; Martin et al, 1997). Many general practitioners and health professionals are confused about what constitutes an intellectual disability and how the disability impacts upon the person’s health and well-being (Marshall et al, 1996).

3.5 Dual Diagnosis

Dual diagnosis is a conceptualization of comorbidity in adults with an intellectual disability. Comorbidity refers to the presence of at least two distinct and separate disabilities or pathologies in the same individual (Fuller & Sabatino, 1998). First utilised in the USA during the 1970s, dual diagnosis was used to describe mental health problems in adults with an intellectual disability. The term, dual diagnosis, specifically refers to co-existing intellectual disability and mental disorder.

The term is also popular within the United Kingdom although “learning disability” is preferred to the term, intellectual disability. Some academics and professionals around Australia appear ambivalent about the term dual diagnosis. For example, some Victorian professionals appear to prefer the term dual disability. Concerns appear to relate to beliefs by some that use of the term dual diagnosis fits poorly with social role valorization, eg philosophically inappropriate connection with the medical model.

Because adults with an intellectual disability are vulnerable to mental health problems and it is important that carers, service providers, professionals and Psychiatrists recognise that it is possible to have both an intellectual disability and a mental disorder. There are a number of key reasons why adults with an intellectual disability are more likely to experience an episode of mental illness during their lifetime, eg:

- a number of syndromes of genetic origin that result in intellectual disability are associated with mental disorders; and
- brain trauma or insults can result in mental health problems.

Adults with an intellectual disability are also much more likely to experience stressful and adverse life events that result in trauma and increased vulnerability to mental health problems. Factors that trigger or enhance the development of mental health problems cluster in the lives of adults with an intellectual disability, eg genetic, biochemical, early experiences, psychosocial stressors and cognitive/behavioural problems (Moss et al, 1997). In combination, these factors can make assessment and diagnosis complex. The clinician must tease out whether presenting signs or symptoms are biologically driven, an environmental response, or a mental health problem or mental disorder. Case recognition must also consider the possibility and ramifications of multiple causation.

3.5.1 Prevalence

There is general agreement within the literature regarding a higher lifetime prevalence of mental disorders in adults with an intellectual disability when compared to the general population. However, there are differing opinions regarding the prevalence rate (Turner & Moss, 1996). Estimates of the prevalence of dual diagnosis will vary according to the age and location of the populations studied, definitions of intellectual disability and mental disorders, diagnostic criteria; exclusion or inclusion of challenging behaviour; and the instruments used (Borthwick-Duffy, 1994).

Research suggests that at minimum, 10% of people with an intellectual disability have a dual diagnosis (Reiss, 1990) although one study suggested 87% (Philips & Williams, 1975). Prevalence rates in other studies varied from 14.3% through to 67.3% (Campbell & Malone, 1991). Another review of twelve epidemiological studies showed that prevalence rates ranged from 14% to 80% (Borthwick-Duffy, 1994).

Results from an ongoing Australian study of young people aged 4-18 years has shown the prevalence of clinically significant emotional and behavioural problems is approximately 40% (Einfeld & Tonge, 1996). The classic prevalence study of psychopathology in children living on the Isle of Wight in the UK (Rutter et al, 1970) found similar rates. These prevalence rates suggest that psychopathology in adults with an intellectual disability is a more serious community problem than schizophrenia, eg that has a lifetime prevalence of approximately 1% (Einfeld & Tonge, 1996).

Adults with an intellectual disability have increased exposure to risk and psychosocial vulnerability factors that increase susceptibility to mental health problems (Moss et al, 1997). Consequently it has been suggested that the presence of intellectual disability can be considered to be a risk factor for the development of mental disorders, providing there is acknowledgement that not all people with intellectual disability develop mental health problems (Holland, 1999).

3.5.2 Assessment and Diagnosis

Accurate assessment, diagnosis and analysis of the presenting mental disorders are fundamental prerequisites for the treatment and management of dual diagnosis (Emerson, 1996). Psychiatrists and general practitioners are not trained to identify and analyse how psychopathology is masked or distorted by the presence of an intellectual disability. Effective treatment and support will be contingent upon appropriate diagnosis and assessment that addresses both the physical and mental health needs of adults with an intellectual disability (Fuller & Sabatino, 1998).

There can be major difficulties in establishing a diagnosis of a mental disorder in people with an intellectual disability, particularly when the capacity to participate in the clinical assessment is compromised. Many adults with an intellectual disability can describe complicated, internal feelings but those with more severe disabilities will have difficulty describing such phenomena (Deb et al, 2001). When an individual is unable to verbalise or describe psychiatric symptoms, there is increased reliance upon the observations of carers and substitute decision makers. Diagnosis and assessment must therefore adopt a practical approach. The clinician must draw upon different sources of information including carer reports, direct observations of behaviour and careful consideration of history.

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Despite such barriers there is broad consensus within the literature that the entire range of mental disorders can be diagnosed within this population (Arnold, 1993). Signs and symptoms of mental health problems are fundamentally similar to the general population. However, clinicians and professionals should adopt a thorough approach to assessment, try to understand individual psychopathology, and carefully choose a formal diagnostic label (Szymanski & Crocker, 1989).

The DSM-IV-TR is conventionally used by Australian Psychiatrists and mental health professionals to assist with the diagnosis of a mental disorder. Because the diagnosis of many mental disorders cannot be solely based upon aetiology, strict adherence to rigid classification tools such as the DSM-IV-TR can prove unhelpful. (Szymanski et al, 1998). There are limitations regarding the use of this and similar diagnostic criteria (eg the ICD-10) for people with an intellectual disability (Sturmey, 1995).

Signs and symptoms that are suggestive of mental health problems in people with an intellectual disability may not correlate well with the diagnostic criteria within the DSM-IV-TR or the International Statistical Classification of Diseases and Health Related Problems (ICD-10). Like the DSM-IV-TR, the ICD-10 is a manual of classification (developed by the World Health Organisation). Other factors compromise the value of classification criteria include:

- intellectual distortion, concrete thinking and impaired communication skills regarding the person's own experiences;
- psychosocial masking, impoverished social skills and life experiences that can lead to unsophisticated presentation and therefore a "missed" diagnosis or perhaps a "misdiagnosis";
- cognitive disintegration, stress-induced disruption of information processing presenting as bizarre behaviour and psychotic symptoms;
- baseline exaggeration, pre-existing cognitive deficits and maladaptive behaviours that distort symptoms and signs, making interpretation difficult;
- overshadowing, where the existence of the intellectual disability masks psychopathology;
- developmentally appropriate phenomena including talking to oneself, solitary fantasy play and imaginary friends can be mistaken for psychopathology (Sturmey, 1999).

In addition to cognitive skill deficits, a range of factors increases the risk of a mental disorder developing in people with an intellectual disability. Biological, psychological and social risk factors may be involved. Markers for mental health problems may include neurological damage, genetic abnormalities, birth trauma, adverse drug reactions, austere living environments, physical or emotional abuse, reliance upon others for care and decision-making, parental rejection, stigmatisation, low self-esteem, limited coping skills and social networks (Moss & Lee, 2000). It can be a difficult task to tease out whether behaviours of concern are in response to an organic, psychiatric, environmental causation or a combination (Szymanski et al, 1998).

A number of specific tools have been developed in recent times to assist with psychiatric evaluation of people with an intellectual disability. Two semi-structured clinical interviews include the Psychiatric Assessment Schedule for Adults with Developmental Disability (Moss et al, 1993) (PAS-ADD) and the World Health Organisation (WHO) Schedules for Clinical Assessment in Neuropsychiatry (SCAN). These instruments are not widely known, or used extensively within Australia.

The mental health assessment of an adult with an intellectual disability can prove to be a daunting task for many clinicians. Diagnosis can be more dependent upon the skills of the clinician undertaking the assessment, rather than the behavioural profile of the person with the intellectual disability (Sovner, 1990). A practical and yet methodical approach to diagnosis and treatment is therefore warranted. Symptoms, aetiology, current and past problems have to be considered upon an individual basis, and ideally within a multidisciplinary team setting. Identification and understanding of psychopathology in adults with an intellectual disability can often reveal atypical expressions of the common mental disorders. Some researchers have even suggested there are specific disorders that are not currently classified (Tuinier & Verhoeven, 1994).

3.6 Challenging Behaviour

Challenging behaviour refers to 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 that behaviour that is likely to seriously limit or delay access to or use of ordinary community facilities (Emerson, et al, 1987). The behaviours inferred typically involve aggression to others, self-injury, destruction of the environment or other life threatening behaviours that necessitate intervention and assistance. The term has evolved and is no longer used in the "spirit" originally conceptualised by Emerson in the 1980s, eg a small number of people who at times exhibit behaviour that is so challenging that services have extreme difficulty meeting their needs.

Challenging behaviour has developed to the point where it is now an umbrella term, a "catchall" phrase that can include such a range of behaviours that the usefulness of the term is compromised. Challenging behaviour is best understood as a social construct as opposed to a clinical diagnosis. However whilst it first emerged within the intellectual disability literature, it is increasingly found within psychiatry. The term is defined in relation to socially "normal" behaviour and the appropriateness of the behaviour in a social context. It is defined in terms of its effects on others as well as the person exhibiting it. The cause of the behaviour is not crucial to the definition and the events triggering the behaviour may be internal, external or unknown. Similarly any underlying predisposition to challenging behaviour may be found in the individual, the setting or both. The term challenging behaviour neither necessitates nor excludes a formal psychiatric diagnosis.

Importantly, many mental disorders may present or masquerade as challenging behaviour. Between 30% and 50% of people with learning disabilities may show a variety of behaviours, particularly challenging behaviour, that are precipitated by problems such as communication disabilities and physical and mental illness (Emerson, 1995). Regardless, the existence of a challenging behaviour should never be construed as automatically meaning that the person has a dual diagnosis. The existence of a mental illness is only one possible explanation for challenging behaviour (Emerson et al, 1999).

In response to complex presentations and the possibility of multiple causation, assessment and diagnosis should adopt a sophisticated biopsychosocial approach, eg consider all the variables that may be influencing the presenting behaviour (Moss & Lee, 2000). Ultimately the clinician must attempt to untangle potential psychiatric and behavioural causation.

3.7 Treatment and Management

Treatment ideally involves an individualised plan of intervention and support that considers the need for psychotropics and non-medication therapies. People with a dual diagnosis will require a coordinated array of services that may need to be drawn from mental health, primary health and disability agencies. In Australia an eclectic approach has developed in response to the apparent failure of traditional disability services to manage challenging behaviours and mental health problems. A consistent, evidence-based approach is required.

Despite ideological debate regarding the value of psychiatry or medicine, it is clear that having the correct philosophy, values and actions does not automatically resolve all emotional and behavioural problems in adults with an intellectual disability (Clements, 1992). There is increasing re-interest in the contributions that psychoanalysis, cognitive-behavioural therapy and other “talk therapies” can make when the mental health patient has an intellectual disability.

Although modifications of routine intervention practices may be necessary, multidisciplinary interventions should be considered. A range of therapies and interventions including physical therapy, occupational therapy, speech pathology, adaptive physical education, art therapy, music therapy, animal therapy and vocational therapy, have demonstrated beneficial results in adults with a dual diagnosis (Gouvier et al, 1986).

3.7.1 Psychopharmacology

The high prevalence of psychotropic medication use in adults with an intellectual disability is a controversial and persistent research theme (May et al, 1995). Decades ago research suggested that adults with an intellectual disability were being inappropriately medicated. In particular, these concerns related to the use of medications to sedate rather than treat a mental disorder (Wolfensberger, 1972). Current research continues to document the high frequency with which psychotropic medication is prescribed to adults with an intellectual disability (Kroese et al, 2001). Psychotropics remain among the most common treatments received by people with an intellectual disability (Rinck, 1998).

Despite wide acknowledgement of the benefits of psychotropic medication when treating particular mental disorders in the wider population, there is minimal scientific research that has adequately explored the safety of psychotropic medication in people with an intellectual disability (Moss et al, 1997). Clinical indicators are not well understood and little is known about long-term effects of psychotropics upon learning and cognition (Rinck, 1998). Similarly, sound methodological research has yet to be conducted that provides evidence of the efficacy of these medications on people with an intellectual disability (Duggan & Brylewski, 1999).

Patterns of medication use are not easily determined and research emphasises the need to investigate the complexities associated with understanding the effects of psychotropic medication on people with an intellectual disability (Harper & Wadsworth, 1993). Contemporary concerns regarding the prescription of psychotropics include:

- failure to review medication regularly and appropriately;
- rates of prescription being considered unacceptably high;
- long term medication use where the rationale is no longer known or understood;
- lack of monitoring and measurement of drug levels;
- use for carer convenience or purposes other than what it was prescribed for;

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- use to achieve sedation in people with behaviour problems, eg treating the behaviour outcome and not the cause;
- little evidence of a clear empirical basis for medication prescription – no indication of evidence-based reasoning;
- serious side effects without follow up; and
- failure to consider least restrictive or intrusive alternatives including non-pharmacological solutions, eg behavioural intervention, counseling or therapy (Sturmey, 1995).

The literature suggests that the prevalence of psychotropic medication use in adults with an intellectual disability living in institutions and community-based living arrangements, ranges between 10-50% (Aman et al, 1987). Prevalence rates in community settings ranged from 19-29% for psychotropics, 18-23% for anticonvulsants and 35-45% for psychotropic and/or anticonvulsant medications (Singh et al, 1997). Another review of more than 44 research studies suggests that the prevalence for psychotropic medications ranged from 45-67% for adults with an intellectual disability living in institutions and the prevalence in community settings ranged between 25-40% (Aman et al, 1997).

Similar figures have been reported in Scandinavia, the United Kingdom, Canada, New Zealand and Australia (Sachdev, 1991). In the UK, one study reported a 40% rate of prescribing for those people living in hospital, 19% for people in group homes or hostels and 10% for those living with in the family home (Kroese et al, 2001). Other studies have found similar rates and suggested that such rates appeared to be excessively high (Branford, 1994).

Analysis of the research reinforces the need for careful diagnosis and judicious medication use. Valid and reliable psychiatric diagnosis should be obtained through a clinical interview but this approach is often problematic when the patient has an intellectual disability (Kroese et al, 1997). Difficulty lies within the process of distinguishing between intellectual disability, which is generally considered not to be drug-responsive and comorbid drug responsive mental disorders (Arnold, 1993).

A careful review of US prevalence research during the period from 1986 to 1995 found substantial numbers of people with dual diagnosis were prescribed psychotropic medication inappropriate to their diagnosis (Singh et al, 1997). Research reinforces concerns that the diagnosis of a major mental disorder, eg psychoses or affective disorders, is often not the rationale for a decision to prescribe or choose a particular psychotropic medication when the person has an intellectual disability (Sachdev, 1991). Logically, appropriate treatment should follow diagnostic formulation. Diagnosis should mark the beginning of a process of ongoing information collation and review that guides ongoing clinical intervention and decision-making. Ongoing diagnostic review and evaluation should integrate new information, revise the validity of existing information and respond to the effects of psychotropic medication (Sturmey, 1994).

A number of prevailing misconceptions context the debate surrounding psychopharmacology and people with an intellectual disability. Negative perceptions surround psychiatry and psychopharmacology impede people from seeking help and prevent psychiatrists from contributing to the intellectual disability field. (Szymanski, 1994). Consumers and carers are often ambivalent shifting between blatant distrust, through to unrealistic expectation of quick cures or “fix-it” approaches. The involvement of psychiatrists in the care of people with an intellectual disability has

waxed and waned but historically their role has been commonly portrayed as one of “warehousing and sedation” (Hauser, 1997). This misperception continues to erroneously reinforce the myth that all psychiatry provides psychotropic drugs that manage challenging behaviour. Treatment should be comprehensive, eclectic, utilise rational psychopharmacology and should operate within a multi disciplinary team setting (Szymanski, 1994).

3.8 Dual Diagnosis and Service System Implications

Insight into dual diagnosis and understanding of the interrelationship of intellectual disability and mental disorder has major implications for the provision of disability and mental health support services. Despite psychopathological vulnerability, mental health services in Australia and the UK have failed to provide adequate support to this population (Webb, 1996). The USA experience is similar. Research suggests that the majority of people with an intellectual disability who have a diagnosable mental disorder do not receive treatment for this condition, and in most cases, are unknown to mental health services (Moss et al, 1993).

There is a high prevalence of unmet mental health needs within the community, specifically undiagnosed or misdiagnosed mental disorders in people with intellectual disability (Roy et al, 1997). Referrals to mental health services will depend upon a wide range of variable factors including availability of mental health services, awareness of general practitioners in regard to dual diagnosis, skills and knowledge, and attitudes of carers and families (Roy et al, 1997). The behavioural presentation may not be considered to be typical or indicative of a mental disorder but considered as typical of an “intellectual disability”. Behaviour of people with an intellectual disability has historically attributed to their “disability” and this form of diagnostic overshadowing adds to the complexity of assessment, diagnosis and treatment. (Ryan & Sunada, 1997).

The diagnosis or failure to diagnose a mental disorder can result in inadequate case management, increased hospitalisation, inappropriate medication regimes and an associated diminished quality of life (Sturmey, 1995). Psychotropic medication is usually prescribed by general practitioners with little experience in intellectual disability and dual diagnosis (Webb, 1996). Literature suggests the need for research, which pays attention to the role of general practitioners in relation to the mental health needs of this population (Moss et al, 1997). Where the mental disorder becomes chronic, the burden of care falls upon families and relatives. Recent reviews of training programs suggested knowledge and skills of physicians, nurses and medical students improved after education (Moss et al, 1997). The need for specialised expertise when responding to the complex mental health needs of this population is also explored within the literature (see Bouras & Holt, 2001).

The provision of dedicated services to people with a dual diagnosis is a relatively recent phenomenon originating in the second half of the 20th century. Prior to the early 1990s, it is difficult to identify UK or USA based literature that discusses the susceptibility of people with an intellectual disability to psychiatric morbidity, and there was virtual silence regarding treatment (Jacobsen, 1999). At this time interest associated with the psychiatry of intellectual disability began to emerge in the UK and parts of the USA but discussion tended to focus upon decisions regarding admission to hospital facilities or institutions.

Internationally, there have been major changes in service systems accessed by people with an intellectual disability in recent years. For example, within the UK government legislation is now encouraging disability and mental health services to work collaboratively when meeting the needs of adults with an intellectual disability in attempt to redress service fragmentation. The positive progress within the UK is also exemplified by the approach of the (UK) Royal College of Psychiatry.

The RCP maintains a learning disability specialty where Psychiatrists train in the “Psychiatry of Learning Disability”. The curriculum in learning disability has been a specialty within the College since 1971. Although the pace of change differs between and within countries (driven by normalisation and deinstitutionalisation), researchers and clinicians working with adults with a dual diagnosis do point out that gaps remain in service delivery (Holt et al, 2000).

In Australia, the emergence of community based care policies during the late 1970s marks the beginning of psychiatry’s “schism” with people with an intellectual disability. At this time responsibility for people with an intellectual disability moved from mental health services to disability services. The rationale for the move related to growing awareness that people with disabilities were not necessarily “sick” and other models of service delivery, aside from the medical model, had relevance to this group of people. Psychiatry did not fit well within the social construct of disability. There is general agreement within Australia that community care policies have provided positive outcomes for adults with an intellectual disability. However, the consequent neglect of the physical and mental health of this population may well be an unexpected and adverse side effect of community care. Within the Australian setting and unlike the UK, a “specialist” profession or professional group has not emerged to advocate for and meet the complex health and mental health needs of this group.

3.9 Barriers to Service Provision

Policy changes underpinning service delivery have had a major impact upon the health care status of people with an intellectual disability living in both Australia and other western societies. An increasing number of adults with an intellectual disability now live in community settings with varying levels of support and assistance provided by disability agencies, families or paid carers. Within Queensland, demands upon human and disability services are wide ranging. The Queensland Government Strategic Framework for Disability 2000-2005 provides the basis for planning, policy, and service development across all Queensland government departments, to meet the needs of people with a disability and their families. Within this framework is the vision for the Queensland government, “ a society that values people with a disability, upholds their rights and supports their equitable participation in everyday life”. The strategy included seven directions to sustain future services development including:

- strengthening individuals, families and communities;
- improving access to services;
- developing and reforming services;
- improving quality of services;
- increasing service provision;
- working collaboratively; and
- increasing safeguards and advocacy.

There is increasing pressure upon government and non-government sectors in Australia to respond to the unmet needs of people with an intellectual disability, their carers and family members. Demands upon current services include the needs of adults with an intellectual disability who have challenging behaviour; ageing carers and individuals with an intellectual disability; and the need for a range of flexible community based support arrangements. Other disability populations also compete for existing government services that are often thin on the ground (Bigby

& Ozanne, 2001). Intellectual disability in the 21st century is characterised by major gaps between policy and practice and high levels of unmet need (Bigby & Ozanne, 2001).

4. Concluding Comments

Adults with an intellectual disability experience complex health care problems and many have co-existing conditions. Within the 2% of the general population who have an intellectual disability, 1993 ABS data showed that 44% reported physical impairment, 25% reported communication problems and **22% reported associated mental health problems** (Wen, 1997). General health and well-being, including mental health, pivots upon access to primary health care providers. It is often the general practitioners who manage the "gateway" to a range of health and mental health services. Care provided by general practitioners is problematic in so far that many have minimal knowledge of the health care problems of this group of people. Carers of adults with an intellectual disability, whether family, friends or staff, are often ill equipped to identify and communicate signs or symptoms of psychiatric morbidity to the relevant health professionals (Bigby & Ozanne, 2001).

Mental health care provided to this population can be compromised by a range of barriers. Many professionals, including general practitioners and Psychiatrists, do not possess the skills and expertise, which enables them to undertake psychiatric evaluations of people with an intellectual disability. Whilst some medical practitioners, including trainee Psychiatrists might be "interested", they are hindered and limited by minimal or non-existent training, knowledge and resources. The 1993 Burdekin Report summed up the situation as "...there is an urgent need for academic research, increased clinical expertise and substantial increased resources in the much neglected area of dual disability".

The mental health needs of people with an intellectual disability have been documented in the literature for more than two decades. Some academics and clinicians argue for specialised mental health services for this population because their complex needs are unable to be met satisfactorily within mainstream disability services or generic mental health services (Holt & Bouras, 1997). Despite research supporting the need for dedicated specialised services, "enabling" policy and programs have not developed within the Australia setting. Many obstacles have hindered the development of appropriate mental health services for people with an intellectual disability.

Historically there was little distinction made between psychiatric and intellectual disability. Differentiation only occurred in the mid 19th century with the advent of psychotherapy and then psychopharmacology, eg adults with cognitive dysfunction ie intellectual disability, were treated "differently" from those with mental health problems from this point forward. Secondly, difficulty has been experienced differentiating between the primary handicap and the secondary handicaps (Bouras & Syzmanski, 1997). Other obstacles include:

- lack of awareness and sensitivity to the nature of the problem;
- government failure to quantify the size of the problem;
- assumptions that behaviour problems were a product of institutions;
- linked assumptions that community living would eradicate behaviour problems, eg "fix" the problem; and
- fundamental belief that generic, community based services would cope with the needs of people with an intellectual disability.

The individual needs of people with disabilities are increasingly visible within contemporary Australian society. Institutions continue to close and different community accommodation options are emerging in suburbs of every type and location. Deinstitutionalisation and community care underpins both mental health and disability policy implemented across Australia. However success is predicated on a number of assumptions:

- community would and could “accept” people with disabilities;
- generic services would provide appropriate services;
- staff would be trained and employed to support people with disabilities relocating in the community; and
- services infrastructure would be developed/funded to sustain people in community settings.

In the UK, the development of specialist dual diagnosis services has responded to government recognition that the mental health needs of this population must be planned and implemented in parallel with hospital closures and community care policies. A number of models of service for dual diagnosis have been developed and trailed in the UK although few have been objectively evaluated using sound methodology. Research tends to be descriptive in nature with few evidence-based outcomes (Jacobsen, 1999). However, research suggests that services for people with a dual diagnosis need to be community based with:

- high professional standards;
- least restrictive environments;
- appropriate treatments and interventions;
- expert staff;
- specialist training opportunities;
- individually tailored services; and
- standardised diagnostic and assessment methods.

People with a dual diagnosis don’t fit well within the traditional operating practices of generic mental health services. The mental health needs of adults with an intellectual disability are frequently multi-dimensional with require the involvement of many service systems. The realities and complexities of providing services to this population have had differing impacts within different western nations.

The literature suggests that comprehensive mental health services for adults with a dual diagnosis are needed to effectively meet the individual needs of this population (Holt et al, 2000). Should such a service model be developed, maintenance of links and relationships with generic mental health services would remain important. Despite a number of different approaches by western governments when providing dual diagnosis services, an “ideal” or a preferred model is yet to be identified or evaluated.

Australian policies and programs aimed at meeting the needs of adults with an intellectual disability have tended to be educational and philosophical in nature with a strong focus upon movement from the institution to community based care. There has been little or scant attention placed upon mental health needs of this population. Adults with an intellectual disability share with the general population, the same fundamental human right of access to appropriate and responsive mental

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health care. WHO defines the important elements of effective response to mental health and neurological problems as:

- psychological and social intervention – independent living skills, social skills training, vocational training, social support networks, family intervention; and
- pharmacotherapy used in conjunction with above.

Treatment efficacy is substantially reduced, WHO suggests, if not delivered within the context of a comprehensive and coordinated delivery service. The “ideal” service model to meet the mental health needs of adults with an intellectual disability needs to include WHO principles. Services should be:

- community based and locally accessible;
- multi professional including input from Psychiatrists, psychology, nursing, social work and other therapists;
- integrated with generic mental health services and generic disability services;
- integrated with primary health care services;
- linked with academic and university faculties with research capacity (Jacobsen, 1999).

A range of specialist options needs to be developed to support the mental health needs of adults with a an intellectual disability, inclusive of those with a dual diagnosis and those with suspected dual diagnosis. Unfortunately within Australia, service delivery to adults with a dual diagnosis has been stagnant and where it has developed, isolated and *ad hoc*. There are lessons to be learnt from the international experience. The global perspective is also discussed later in this Report in the concluding Chapter (Chapter 6).