D·D·U
DEVELOPMENTAL
DISABILITY UNIT

DUAL DIAGNOSIS
PROJECT

Chapter 1

Project Overview & Synopsis

Queensland
Government
Queensland Health

THE UNIVERSITY
OF QUEENSLAND

Chapter 1 Project Overview and Synopsis

1. Background

Many adults with an intellectual disability experience greater health needs when compared to the general population (Turner & Moss, 1996). This group of vulnerable people are more likely to experience mental illness and are more prone to physical comorbidity including chronic health problems, epilepsy, and physical and sensory disabilities.

The Second National Mental Health Plan identifies and prioritises the mental health care needs of this group. Ideally, service development should operationalised in the community at the local level. Adults with an intellectual disability and concurrent mental illness, their family members and carers, need to have access to a range of individualised and appropriate services. Anecdotal experience and the literature suggests this is not the reality for adults with an intellectual disability who have mental health problems. Contact with other dual diagnosis stakeholders (academics and researchers, medical practitioners, professionals, direct care workers, family members and consumers with disabilities) suggests that, where they do exist, services to meet the mental health needs of this group have developed in a poorly planned and *ad hoc* fashion.

Typically under-resourced and “thin on the ground”, services provided to adults with a dual diagnosis tend to operate in isolation, run on a “shoestring” and are unable to meet demand. Glance through most mental health publications or reports from around Australia and immediately noticeable is the fact that adults with a dual diagnosis are not mentioned. The needs of this population are virtually invisible. For example, despite a mention in the National Mental Health Strategy and before that, the Burdekin Royal Commission, this group of people remains outside of national mental health service development and hidden from the broader public policy agenda. At the state level, a similar picture emerges. The Executive Summary of Queensland’s Ten Year Mental Health Strategy (1996) prioritises a number of groups of people identified at the national level, who require specific strategies to ensure equitable access to mental health services. However, this summary fails to include people with a dual diagnosis as one of the targeted groups although the body of the 1996 Mental Health Strategy addresses some needs of adults with a dual diagnosis through reforms of extended inpatient services.

For some years the Developmental Disability Unit (DDU) has been increasingly concerned about the unmet mental health needs of adults with an intellectual disability. Repeatedly contacted for advice or clinical assistance by a wide range of individuals including consultant medical practitioners through to carers, the DDU was limited by its resources in efforts to contribute to dual diagnosis service development. The Developmental Disability Unit strongly believes in the importance of enhancing generic health, mental health and disability services to meet the needs of adults with a dual diagnosis or those who have a suspected dual diagnosis, eg show signs or symptoms that could suggest a mental health problem. However, the DDU also believes that specialist professionals with skills and knowledge grounded in an evidence- based approach to care, are urgently required in Queensland.

Accordingly between 1998 and 1999 the DDU lobbied Queensland Health to obtain funding to undertake dual diagnosis research related Project work. In late 2000 non-recurrent funding was gratefully obtained from Queensland Health, Mental Health Services for $ 62,000 to enhance understanding of the problems experienced by adults with a dual diagnosis and those people who provide support and assistance. During the same period, West Moreton Health District made a half time PO 4 position available for six months to complete a second dual diagnosis Project.

The most rational use of both Projects resulted in both briefs being rolled into the one Project, the Dual Diagnosis Project. The DDU is very grateful to the Queensland Health, Mental Health Services and the West Moreton Health District, Wolston Park Hospital for their financial/resource support to undertake the Dual Diagnosis Project. The funding of the Dual Diagnosis Project has enabled these two major stakeholders to better understand the nature, size and elements of the "dual diagnosis problem" in Queensland.

The DDU hopes that the Report of this Project will encourage these two partners and other potential partners to continue to support efforts to enhance and improve the physical and mental health of adults with an intellectual disability. After all, the Report clearly highlights there is much to be done to improve service delivery to adults with a dual diagnosis before this group can even begin to enjoy what members of society expect – a reasonable quality of life.

1.1 Project Rationale

The Developmental Disability Unit, working in collaboration with mental health, primary health care and disability professionals, has been aware of the growing number of adults with mental health problems whose needs challenge and confuse generic health and mental health services. Dual diagnosis is an area that has been sparsely investigated and is under-researched in Australia. Within Queensland, the Dual Diagnosis Project team is unaware of any prevalence studies ever being undertaken. The Project Team also believes that the education and training needs analysis that was undertaken is the first of it's kind in Queensland.

Motivation to secure funding for the Dual Diagnosis Project related to awareness that there are two groups of adults with an intellectual disability who require mental health services. The first group is either in receipt of services or demanding a service response. The needs of this group may challenge services because they don't "fit" well within organizational guidelines. For example, inpatient assessment may be problematic because of challenging behaviours. Members of the second group also have an intellectual disability but may be hidden or invisible to mental health services. This group typically does not have a formal diagnosis of mental illness. Some may have "suspected" mental health problems but carers may be unable to obtain assistance. Others may have been assessed as having no mental health problems but carers suspect they have a dual diagnosis.

The mental health care of adults with an intellectual disability, whether diagnosed or suspected, is of concern. Carers lack the skills, knowledge and confidence to obtain a mental health assessment that either rules mental illness out or provides a diagnosis and management plan. Other problems relate to mental health assessment, inappropriate diagnosis and misdiagnosis. For example, the diagnostic overshadowing appears to prevalent across Queensland. This phenomena occurs when mental health and disability professionals clinically attribute psychopathology to the existence of the intellectual disability, rather than searching for alternate explanations.

From the inception of the Dual Diagnosis Project, outcomes were expected to provide both qualitative and quantitative data that will enhance improved understanding of the needs of adults with a dual diagnosis and other stakeholders. Outcomes were anticipated to benefit:

- long term and short term strategic planning;
- service development and enhancement;
- prioritisation of funding; and
- Review of the Second National Mental Health Plan.

It is the belief of the Dual Diagnosis Project Team, that this Report demonstrates that the Project Team has fulfilled these expectations.

2. Funding Sources

The Developmental Disability Unit established the Dual Diagnosis Project by combining and incorporating funding from two sources:

- Queensland Health, Mental Health Services, and
- West Moreton Health District.

The Project addressed two related tasks:

- Training and Education Needs Analysis (Mental Health Services, Queensland Health); and

- Review into Mental Health Services for People with an Intellectual Disability (West Moreton Health District).

3. Project Goals

The Dual Diagnosis Project, following consultation with the funding bodies, aimed to systematically and objectively collect information that involved local community members in the process of identifying:

- adults with an intellectual disability who either had a dual diagnosis or are likely to have a dual diagnosis (suspected);

- education and training needs of stakeholders, eg those who work with, support or care for adults with a dual diagnosis or suspected dual diagnosis;

- roles and responsibilities of staff employed by agencies or organisations that provide services to adults with a dual diagnosis or suspected dual diagnosis; and

- services required by adults with a dual diagnosis and their carers (unmet need).

3.1 Objectives

The Dual Diagnosis Project aimed to provide:

- a Queensland profile of dual diagnosis, including demographics and estimated prevalence and distribution of adults with a dual diagnosis;

- identification and description of the major providers of mental health and disability services or support to adults with an intellectual disability across Queensland;

- analysis of the extent and nature of common clinical and service problems experienced when clients/consumers are adults with a dual diagnosis or have a suspected dual diagnosis;

- exploration of dual diagnosis service options and innovative solutions inclusive of the state, national and international perspectives;

- opportunities for the various organizations and agencies to network and enter into ongoing dialogue regarding dual diagnosis, including discussion of needs and problem solving activities;

- detailed discussion and prioritisation of critical education and training needs of service providers and major stakeholders that incorporated views of consumers, family members and significant others;

- recommended solutions and strategies that addressed how the dual diagnosis education and training needs of organisations, services and major stakeholders are best met within the Queensland context;

- a detailed end of Project Report exploring the "problem" of dual diagnosis within the Queensland setting that included recommendations for further action; and

- coordination of a Dual Diagnosis Symposium at the completion of the Project where outcomes, findings and feedback could be provided to interested stakeholders.

4. Methodology Synopsis

A practical approach to methodology was constructed. Major activities undertaken to meet the goals of the Project included:

- literature review;
- environmental scan;
- needs assessment where data collection involved key informant interviews; stakeholder focus groups; surveys of agencies, service providers, carers and consumers; and stakeholder dialogue, ie consultations and forums;
- data analysis using SPSS and content analysis;
- final Report incorporating discussion of findings and recommendations for further action;
- end of Project Dual Diagnosis Forum that provided overview of outcomes and findings.

4.1 Data Collection

Specifically, data collection drew upon multiple sources in an effort to draw together a cohesive and reflective picture. The approach included:

- a review of relevant literature;
- an overview of Australian and international dual diagnosis initiatives and educational outreach;
- surveys of service providers and professionals operating at the "coalface" or "cutting edge";
- consultations with persons in key positions, and/or with specific knowledge; key informant interviews completed primarily in South East Queensland; and
- focus groups (with survey distribution) in:

  - Wide Bay Burnett Health District, and
  - Logan/Beaudesert Health District, and
  - Cairns Health District.

4.2 Participants

The Dual Diagnosis Project identified five target groups from five different sectors:

- Psychiatrists and Psychiatric Registrars across Queensland;
- Managers of services providing either disability services, mental health services or other community based "human" services surveyed through telephone contact;
- Professional staff, including allied health professionals invited to complete survey and attend focus groups;
- Direct care workers involved in supporting clients/consumers in activities of daily living invited to complete survey and attend focus groups;
- Consumers and family members invited to complete survey and attend focus groups. Contact made through agencies providing support.

The rationale for the inclusion of these groups included:

- the Project Team wanted to adopt a "coalface" focus, eg psychiatrists, professionals, managers, carers or consumers;
- the Project Team were interested in views and opinions of those placed "where the action is" as opposed to middle management or more senior organisational representation, eg increased possibility of issues or concerns being diluted or blurred; and
- the Project Team desired a multiprofessional and transdiciplinary approach that did not focus or differentiate between particular professions in recognition that all stakeholders providing "services" had an important contribution to make.

4.3 Sectors

The Dual Diagnosis Project identified five major sectors for consultation:

Disability Sector
- government and non-government staff
- direct care workers and professional staff (allied health professionals, teachers, managers)

Mental Health Sector
- government and non-government staff
- nurses and professional staff (allied health professionals, psychiatrists, team leaders)

Primary Health Care Sector
- community health: General Practitioners, allied health professionals, nurses

Community Stakeholders:
- families: parent groups
- consumers: adults with an intellectual disability

Organisations/Services:
- disability specific organisations,
- health agencies,
- advocacy groups, legal services etc.

5. Project Team Membership

The Dual Diagnosis Project team became fully operational in February 2001 and completed major tasks by September 2001. Active data collection took place from May to August 2001.

Principal Investigator: Dr Nick Lennox, Director, Developmental Disability Unit, The University of Queensland

Assistant Investigator: Mr Morrie O'Connor, Director, Community Living Program, Nundah, Brisbane

Part time Project team:

- Niki Edwards (Project Coordinator)
- Miriam Taylor (Assistant Project Coordinator*)
- Jude McPhee (Project Officer)
- Dell Hele (Resource Officer)

*Madonna Tucker was the Assistant Project Coordinator until April 2000 and has provided ongoing consultation to the Project Team post this date.

The Project team comprised of part time staff with health, education and disability backgrounds. This approach was adopted in genuine effort to adopt a diverse approach to understanding and researching dual diagnosis.

Mr Morrie O'Connor, Director of the Community Living Program (CLP) provided collaborative support and advice to the Chief Investigator and the Dual Diagnosis Project team. CLP is a community-based organisation that supports young people with an intellectual disability. This group had been successful in securing a grant to conduct a needs assessment of education and training needs of service providers supporting young adults with a dual diagnosis. Following consultation between the Project Team and CLP it was decided to work cooperatively together to ensure research and Project activities were complimentary rather than repetitive. The CLP Dual Diagnosis Report was due to be released in early 2002.

5.1 Reference Group

The Project team was also supported by a Reference group. Terms of Reference were developed to guide the operations of the group. Fundamentally the group provided a forum where the Project team could discuss issues arising and seek advice. Membership of the reference group included:

- Dr Frances Dark, Consultant Psychiatrist, West End Integrated Mental Health Services.
- Dr Terry Stedman, Director, Clinical Services, Wolston Park Hospital, West Moreton Health District.
- Ms Pam Lane, Director Nursing, Wolston Park Hospital, West Moreton Health District.
- Mr Luke Hatzipetrou, Senior Psychologist, Wolston Park Hospital, West Moreton Health District.
- Ms Anne McMillan, Director, Mental Health Services, Queensland Health.
- Ms Lyn McPherson, Mental Health Services, Queensland Health.
- Ms Kay McInnes, Mental Health Services, Queensland Health.
- Mr Peter Gregory, Manager, Brisbane North Lifestyles Support, Unicare.
- Ms Grazia Catalano, Regional Manager, DSQ, Ipswich.
- Ms Marie Issackson, Manager, Clayfield House.
- Mr Greg Wagner, SUFY, Brisbane.
- Ms Majella Jordan, DSQ, Brisbane.
- Ms Michelle Denton, Manager, Community Forensic Mental Health Services.
- Ms Robyn Albury, Deputy Adult Guardian.

The Project Team would like to thank Reference Group members who participated in face to face discussions and also acknowledge the contribution of other members who communicated with the Team on many occasions and provided valuable feedback to material provided.

5.2 Participation Comments

Enormous efforts were spent attempting to engage the range of stakeholders in the Project. Very early in the data collection phase, the Project team became aware that it was essential to locate the “right” person to speak to, within organizations or agencies contacted. Despite repeated contacts using telephone, email or written information, the team was of the opinion that often contact was not made with “the one who opens doors”.

Obviously some of the difficulties encountered during the life of the Project partially reflects problems associated with Queensland demography, eg dispersed population and services. However, the experience also highlights how difficult it must be for consumers or their carers to identify or access services they require, eg barriers associated with lack of knowledge, getting past the gatekeepers because of language or communication problems, organisational mission statements lacking “fit” with actual services provided, time constraints, and the reality that key decision makers are not necessarily the people that answer the telephone or open the mail.

Other barriers to participation included:

- sectors and participants targeted are notoriously difficult to reach;
- “dual diagnosis” can be invisible or may be attributed a low priority for some stakeholders because the area or the characteristics and needs of the consumer group is not well understood; and
- discourses differ between the sectors, eg terminology and concepts vary and are poorly understood when communication between sectors take place.

Regardless, the Project Team would like to make clear that numbers of participants should not be construed to reflect lack of interest by stakeholders in the dual diagnosis area, but may be linked to the nature of providing services to adults with an intellectual disability. Services and their employees, regardless of their sector of origin, are stretched, constrained by lack of resources and constantly face overwhelming demand and unmet needs.

The Project Team would like to thank all participants and commend service providers and carers who continue to struggle to meet the complex needs of adults with a dual diagnosis, sometimes in the face of almost overwhelming odds.

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Chapter 2

Conceptualising Dual Diagnosis

Queensland Government
Queensland Health

The University of Queensland

1. Introduction

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 adapative 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 in 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 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;

- 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.

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 (Syzmanski & 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. (Syzmanski 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 (Syzmanski 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;

- 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. (Syzmanski,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 (Syzmanski, 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

& Ozannne, 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 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).

Chapter 3

Queensland Profile of Dual Diagnosis

Chapter 3 Queensland Profile of Dual Diagnosis

1. Introduction

The mental health of adults with an intellectual disability is poorly understood within Queensland, and across Australia. Although mental health services have been well studied, the literature has failed to provide information on adults with a dual diagnosis. This group of people tend to be invisible in major studies. For example, the National Survey of Mental Health and Well-Being (Andrews et al, 1999) notes that the mental health of a number of groups of Australians could not be well assessed. This survey goes on to identify Aboriginal and Torres Strait Islander people, people from non-English speaking backgrounds and the elderly as having special needs. Although an additional comment suggests there are smaller groups whose mental health could not be addressed, this report completely fails to identify adults with an intellectual disability who have mental health problems.

This Chapter provides a profile and descriptive analysis of service delivery across Queensland to adults with an intellectual disability who also have a concurrent dual diagnosis. Training and education needs are identified, as well as other challenges being experienced whilst provides services. Within this profile, descriptive estimates are made about the number of adults with an intellectual disability within Queensland. The Chapter also provides information about the training and education needs of dual diagnosis stakeholders. This profile can inform and contribute to a better understanding of dual diagnosis stakeholders living in Queensland. However, further well-resourced research is required to produce objective and reliable estimates of the prevalence of mental disorders in adults with an intellectual disability.

1.1 Process

Information provided in this Chapter, when condensed and considered together, provides a “snapshot” of dual diagnosis within Queensland. Data collection and analysis specifically aimed to provide a Queensland profile of adults with an intellectual disability and concurrent mental disorder (dual diagnosis) by producing:

- a current service delivery profile of services accessed by adults with a dual diagnosis; and
- the estimated number of adults with a dual diagnosis (both suspected and diagnosed) receiving services from those agencies or organisations contacted.

The Queensland profile draws upon three sources:

(a) *The Dual Diagnosis Forum*

This Forum was facilitated by Sir Llew Edwards on behalf of the Dual Diagnosis Project Team. The meeting brought together key managerial staff from the government and non-government mental health and disability sectors in the greater Brisbane area. Information from this Forum provides:

- insight into the issues and challenges surrounding adults with a dual diagnosis that are faced by middle and senior management;
- possible strategies and solutions to address the needs of adults with a dual diagnosis in the Queensland setting.

(b) *Queensland-wide Agency Screening Surveys*

Using a purpose-created telephone survey, the Project Team aimed to identify organisations that provided services to adults with an intellectual disability across Queensland. The survey also collected data that would result in a better understanding of the issues and challenges surrounding service delivery to adults with an intellectual disability.

Through initial telephone contact with agencies that provided services to adults with an intellectual disability, contact was then facilitated with those agencies that had consumers with a dual diagnosis. Analysis of the survey therefore enabled mapping of the:

- location of services being provided to adults with an intellectual disability who also had a concurrent dual diagnosis;
- location of consumers with a dual diagnosis or suspected dual diagnosis; and
- estimated number of consumers with a dual diagnosis or suspected dual diagnosis.

(c) *Consultations and Opinion Surveys of Dual Diagnosis*

This final stage collected information from a range of dual diagnosis stakeholders in the Logan Health District, Fraser Health District and the Cairns Health District. Information collection aimed to identify, on a local basis:

- current dual diagnosis knowledge & skills; and
- dual diagnosis education and training needs.

2. The Dual Diagnosis Forum

The Dual Diagnosis Project consultation process commenced with the hosting of the Dual Diagnosis Forum. Attendance was by invitation. The list of Forum participants has been included in the Appendices. The Forum was held over half a day in the Mayne Medical School Building, The University of Queensland at Herston in March 2001. The Project Team welcomed the involvement of Sir Llew Edwards who agreed to facilitate the Forum's agenda.

Sir Llew Edwards, former politician, respected Queensland businessman, current Chairman of the Prince Charles Hospital Board and Vice Chancellor of The University of Queensland, had historical links and a great interest in adults with an intellectual disability. He had managed numerous patients with an intellectual disability when he was a busy general practitioner in Ipswich during the era when the institution at "Sandy Gallop" - Challinor Centre, was fully operational. Sir Llew Edwards was also formerly the Queensland Government Health Minister who had overseen the development and implementation of the 1972 White Paper that had heralded the move of the then

Intellectual Handicap Services from Psychiatric Services to the then Department of Family Services. Sir Llew Edwards had supported the inclusion of normalisation, the developmental model and the least restrictive alternative into government policy and had watched with interest the building of the "villas" in Ipswich that were the forerunner of government supported community living in Queensland.

2.1 Findings

Forum participants were assisted by members of the Project Team to tease out key issues relevant to adults with a dual diagnosis living in Queensland. These issues have been themed and are briefly described below:

2.1.1 Service Difficulties

Participants voiced major concerns about the capacity of their organisations and agencies to effectively respond to the needs of adults with an intellectual disability. Strained relationships between the service systems added to the struggle. Although many suggested that the consumers would be better served through collaborative efforts, the sectors had difficulty in communicating and interacting. It was suggested that:

- *The system is failing this population: current services did not cater to the needs of adults with a dual diagnosis, eg the needs of this population were poorly acknowledged and where acknowledged, poorly met.*
- *No dual diagnosis services to refer to: participants were unaware of specialist dual diagnosis services and felt there was the need for access to experts with experience in meeting the mental health needs of adults with an intellectual disability.*
- *The current model is "one model fits all" and this model of service delivery doesn't fit everyone, particularly those with a dual diagnosis, eg:*
    - *i. coordination of services for individuals is lacking;*
    - *ii. flexibility of funds is needed;*
    - *iii. current community models which are successful are under-resourced; and*
    - *iv. services provided by Disability Services Queensland (DSQ) and individualised funding approaches are uncommon/unknown to mental health staff.*
- *Lack of resources constrained appropriate service responses, eg staff and funding: a frequent concern for all sectors.*
- *The only response possible is a crisis response: little evidence of a genuine regard to preventative or proactive strategies that would maintain or encourage mental health in adults with an intellectual disability. Further, responses only occurred when situations became major problems rather than early and appropriate intervention when problems or concerns began to develop.*
- *Early intervention (in teen years) is not happening: transition of children and adolescents with an intellectual disability through to adult services was of concern because of minimal services and resources but also lack of skills and commitment.*
- *Absolute cultural chasm between Mental Health (MH) and Disability Services Queensland (DSQ), eg:*

    - *i. MH and DSQ place different priorities on values and lifestyle support issues;*
    - *ii. choices are made for clients by staff;*
    - *iii. MH can't refuse to provide services whereas DSQ can;*

   iv. *collaboration between both service systems does not happen and yet should happen on a regular basis;*
   v. *there is a waste of resources due to failure of DSQ and MH to collaborate.*
- *Historical baggage – "it is a war between MH and DSQ": there was much concern about apparent professional and clinical alienation but genuine interest in remedying these problems.*
- *Legal and criminal justice system issues exist– victim and offender issues: a neglected area that again appears plagued by resource constraints and crisis responses as opposed to preventative or supportive early interventions.*

2.2.2 Attitudes

Attitudes are more complex than simple fear of people with an intellectual disability or fears of those who have a mental illness. However, insightful comments from participants suggested that service providers never got past the person's intellectual disability. They argued that negative attitudes and stereotypes were the major barriers. If service providers were "stuck" on the intellectual disability, it was only logical that mental health problems were not considered or understood.

- *Staff and others who are involved see intellectual disability first (diagnostic overshadowing) and are not prepared to consider an alternative explanation to the problems - that is a barrier.*
- *There is general failure to acknowledge that dual diagnosis exists, eg what is dual diagnosis?*

2.2.3 Training and Education

The lack of resources appears to have a severe impact upon staff training initiatives. Participants suggested that training and education (of any type) was accorded a low priority within agencies and organisations. Training and education in dual diagnosis was virtually unknown:

- *Staff aren't trained in specific issues that impact mental health and well-being, eg behaviour management training failed to address dual diagnosis.*
- *Participants were unsure if staff have the necessary expertise and skills to work with the mental health problems of adults with an intellectual disability, eg same skill based for anyone with a mental health problem and therefore they just need more confidence to acknowledge their skills.*
- *Staff from MH and DSQ don't talk the same language therefore education and training had to address the need for a shared professional language and framework of understanding when working with adults with a dual diagnosis: both disability and mental health professionals were needed when working with adults with a dual diagnosis.*
- *Service providers need to be taught how to collaborate; interaction and mutual collaboration between the sectors didn't occur naturally therefore situations/contexts had to be initiated and supported to encourage it to occur.*
- *Academic research and an evidence-based approach to care and services is lacking: service providers actively sought expert advice and information but did not know where to go to obtain such quickly.*

- *Academic input to policy and service direction is missing: the needs of adults with a dual diagnosis only came to light when a crisis was occurring, the invisibility of the population was of concern.*
- *Few experts out there to refer to: professionals needed to know where to go when there were problems: training and education was considered the appropriate medium.*

2.2.4 Consumer/Client Perspectives

The diverse characteristics of the population means that needs vary considerably from individual to individual. For example, some clients exhibit extreme challenging behaviours and yet others do not. The differing presentations and associated needs is very confusing to some professionals and consequently means there is no standard response when working with an adult who has an intellectual disability.

- *This population is isolated in terms of services and support and knowledge of where to go for help, eg often all avenues appear to be deserted: the consumers appeared to fall into the "too hard basket" because there was no easy answer or response to problems being experienced..*
- *Complex needs are being ignored and people therefore fall through gaps: the typical response when no one knew what to do was to refuse entry into the service or refer onto another service.*
- *Families are cut out of the decision making process: families and carers were often exhausted by the need for constant and vigilant advocacy to obtain basic needed services.*
- *Crisis response again: families and carers felt that only when the problems rose to an almost unmanageable state was there some chance that there would be a service response.*

2.3 Strategies and Solutions

Once the key issues had been articulated, Forum participants were asked to identify and prioritise strategies and solutions that could improve the current situation. Responses have been compiled into summary figures, organised by priority level that appear below. For example, the recommended strategy accorded the number one priority by the participant is recorded in the Table 1: Priority 1. Table 2: Priority 2 identifies the strategy that the participant recommended as their second strategy etc.

The second column of the Figure relates to how many of the participants stated that that particular strategy was their number one priority. For example, four participants stated that the strategy of organising a Ministerial reference group was their number one priority.

All participants identified three priorities, with only a small number of participants choosing to identify more than three. It should also be noted that the strategies below have not been categorised or themed but transcribed as participants wrote them. Thus, some strategies may seem similar but with subtle degrees of difference. The Project Team felt there was value in capturing the essence of each participant's ideas and to feedback the raw data as it was received. There is remarkable cohesion regarding the problems encountered and recommended strategies to address these.

Table 1

Forum Participants <u>1st Priority Solutions & Strategies</u> to Improve Services & Support Required by Adults with a Dual Diagnosis

Strategy Identified	No. of People
Ministerial reference group of all stakeholders needs to be organised to develop recommendations and strategies	**4**
Training for staff is needed across sectors and at all levels, including collaboration training	**4**
Top down commitment is needed to increase collaboration between departments	**3**
Integrated and flexible funding is needed (joint collaboration from Health, DSQ & Department of Families)	**1**
Development of a pilot project to facilitate change	**1**
Change in attitude at the political level	**1**

Table 2

Forum Participants <u>2nd Priority Solutions & Strategies</u> to Improve Services & Support Required by Adults with a Dual Diagnosis

Strategy Identified	No. of People
Pilot project to develop and identify best practice and ways to resource in human and dollar terms to meet individual needs	**2**
Training and education required in the area of dual diagnosis	**2**
Projects of collaboration between departments needed	**2**
Pooled funding for demonstration projects	**1**
Collaboration across Government and non-Government agencies at a community level	**1**
Flexible funding needed – including for community services	**1**
Commitment from highest level of Government needed for change	**1**
Increase research funds	**1**
Attitude: change in attitudes needed	**1**
High profile person who can be the interface with public and government is needed	**1**
Education & recruitment of people who are willing to implement a change in attitude at the political level.	**1**

Table 3

Forum Participants <u>3rd Priority Solutions & Strategies</u> to Improve Services & Support Required by Adults with a Dual Diagnosis

Strategy Identified	**No. of People**
Demonstration projects needed: including collaboration on local, as well as at a departmental level	**4**
Education and training strategies needed, including collaboration training	**3**
Best practices and more integration of DSQ and MH	**2**
Information and support for families is required	**1**
Information centre is needed that is accessible to parents, carers, community etc	**1**
More research into challenging behaviours - cause and management	**1**
Forming relationships with all stakeholders through the formation of a reference group is needed	**1**

Table 4

Forum Participants <u>4th Priority Solutions & Strategies</u> to Improve Services & Support Required by Adults with a Dual Diagnosis

Strategy Identified	**No. of People**
There is a need for more Information and support for families	**1**
Forming relationships with all stakeholders through a reference group is needed	**1**
A high profile person is required to facilitate co-ordination between departments	**1**
Target key management structures within organisations, eg direction of mental health meetings	**1**

Table 5

Forum Participants <u>5th Priority Solutions & Strategies</u> to Improve Services & Support Required by Adults with a Dual Diagnosis

Strategy Identified	**No. of People**
Research base increased to ensure accurate up-to-date information	**1**
Education in dual diagnosis needed	**1**

Table 6

Forum Participants <u>6th Priority Solutions & Strategies</u> to Improve Services & Support Required by Adults with a Dual Diagnosis

Strategy Identified	**No. of People**
Training /education strategy targeting needs groups, eg General Practitioners, Psychiatrists/Registrars, support workers.	**1**
Increased funding	**1**

3. Agency Screening Surveys across Queensland

Comments from respondents in the agency screening surveys provide a good introduction and aptly summarises the view of the majority towards contact regarding adults with a dual diagnosis. Generally service providers and agencies were enthusiastic about the research and clear that there were limited services and resources for these consumers.

"Thanks for the research. It is long overdue."

"Research in this area is vastly needed. As is quality service."

3.1 Objectives

The screening surveys had multiple purposes. The object of contact with the agencies/organisations providing services to adults with an intellectual disability was to compile a state-wide snapshot of:

- current service delivery to adults with a dual diagnosis;
- estimated prevalence of dual diagnosis (diagnosed & suspected)
- potential service delivery to adults with a dual diagnosis (unmet need); and
- training and educational needs of service providers and other dual diagnosis stakeholders.

3.2 Process

The Dual Diagnosis Project Team identified four sectors operating across Queensland within which service providers to adults with an intellectual disability were located. The list of potential participants to contact was generated on a sector-by-sector basis. There was minimal overlap between sectors.

- ***Disability Sector***: Those contacted included government and non-government staff at a State and Commonwealth level; direct care workers; and professional staff (allied health professionals, teachers, managers) at a local level.
- ***Mental Health Sector***: Those contacted included government and non-government staff at a State and Commonwealth level; and clinicians and professional staff (nurses, allied health professionals, psychiatrists, team leaders) at a local level
- ***Primary Health Care Sector***: Those contacted included clinicians from Community Health, eg general practitioners, allied health professionals and nurses.
- ***Community Sector***: Those contacted included families and parents groups, consumers with an intellectual disability and organisations from the disability, health and human services sectors.

The Project Team was limited by resource and timeframe constraints therefore needed to design a convenient, practical and economically "do-able" approach to access the key dual diagnosis stakeholders. It was ascertained that telephone contact would be the most efficient and timely mechanism to gather information to develop the state-wide snapshot. The telephone survey tool was designed by the Project Team and is included within the Appendices.

3.3 Recruitment

The Project Team used a modified snowball technique to recruit participants. “Snowball sampling” was considered appropriate because the desired population is difficult to identify and hard to locate. Also known as chain sampling, the snowball technique involves the identification of potential participants or subjects, from sources that “know people who know people”. Fundamentally, the technique involves contacts that then lead to further contacts and so on.

The technique was adopted for the following specific reasons:

- inaccessibility of consumers with a dual diagnosis, eg lack of awareness and visibility of those adults with a “dual diagnosis”;
- extreme difficulties associated with identifying and locating service providers, professionals, clinicians, carers who provide services to consumers with a dual diagnosis across Queensland, eg demography of Queensland and logistical issues;
- associated prohibitive costs in the above situation; and
- time constraints of the Project.

3.3.1 Queensland Wide Contact List

A contact list of agencies and organisations that potentially provided services to adults with an intellectual disability was collated by the Project Team. The criteria for contact and therefore inclusion on the list was: if there was “potential” that an organisation or agency would or could provide services, of any type, to adults with an intellectual disability. Using the snowball technique, agencies successfully contacted were also asked to nominate other organisations or services in their local area or region, that the Project Team should make contact with.

The Project Team anticipated that non-identifying information regarding consumers with a dual diagnosis or suspected dual diagnosis could be provided through these telephone contacts. The contact list of agencies/organisations was developed following review of:

- Disability Services Queensland DIAL database; and
- Developmental Disability Unit contacts.

The Disability Information and Awareness Line (DIAL) is a free, statewide information, resource and referral service maintained and operated by Disability Services Queensland. DIAL operates during business hours from Monday to Friday. The database can be accessed at the DIAL office at Level 3, 75 William Street, Brisbane or can be searched online at http://www.disability.qld.gov.au/dial.cfm. Information available through DIAL addresses all types of disabilities and includes:

- information about services for people with a disability;
- information about different disabilities;
- journals and newsletters;
- government publications;
- student fact sheets;
- information kits; and
- information about trends, philosophies, and legislation.

Anyone wanting to know about supports and services for people with a disability in Queensland can call DIAL. The information officers that maintain DIAL are trained to provide up to date information. The database includes all services (Government and community based) including:

- accommodation;
- employment;
- transport;
- respite care;
- recreation;
- independent living;
- education;
- advocacy;
- community access;
- family support; and
- lifestyle support.

The Dual Diagnosis Project Team also included a number of agencies on the initial contact list that had been suggested by the Reference Group. It is important to note that a number of additional agencies/organisations were contacted following suggestions or referrals from agencies contacted. These referrals had not appeared on the original contact list.

The initial contact list identified 576 agencies/organisations that met the contact criteria, eg had the potential to provide services to adults with an intellectual disability. Because of the time constraints associated with the Project, decisions were made that telephone contact with all these agencies/organisations was unrealistic. Accordingly, following careful deliberations, there were

181 agencies/organisations culled from the initial contact list. ***The contact list that was used by the Project Team therefore comprised 395 agencies from across Queensland.***

3.4 Survey Tool

The telephone survey tool used was a questionnaire that was purpose developed by the Project Team. The tool was used in the three stages in the survey:

- ***Stage One***: initial contact;
- ***Stage Two***: questions regarding services to adults with an intellectual disability; and
- ***Stage Three***: linking contact with consumers with a dual diagnosis.

Agencies and organisations identified for initial telephone contact (n=395) were to be given information regarding the Dual Diagnosis Project and invited to participate. Participation was clearly voluntary. Potential participants were to be advised that the Project had three stages and they were to be informed that the agency/organisation could choose to be involved in only the initial phase of the Project or choose to be involved in all of the phases outlined below, or as many as they would like. The choice was entirely up to the individual agency/organisation. Finally, the organisation/agency was prompted to advise of other relevant contacts that would benefit the Project.

3.4.1 Stage One: Initial Contact

At initial telephone contact, the agency/organisation was verbally provided with brief information regarding the Dual Diagnosis Project. When requested, the information package was either faxed or mailed to the respective agency. The agency/organisation was asked whether services were provided to adults with an intellectual disability. If the answer was no, this was recorded and there was ***no further contact***. If the answer was yes, then the agency/organisation was invited to continue to Second Stage Contact. The Information Package is included in the Appendices.

3.4.2 Second Stage Contact

After identifying and making contact with the appropriate individual (within the agency/organisation) who could respond to the survey questions, the respondent was prompted to provide:

- basic agency information;
- an estimate of the number of adults with a dual diagnosis that services or assistance was provided to; and
- views and opinions regarding the educational and training needs required to provide services and support to consumers with a dual diagnosis.

Wherever possible, surveys were completed over the telephone. When completion over the telephone was not possible or when requested, the survey tool was forwarded to the appropriate person nominated for completion. The nominated person was asked to return the completed questionnaire to the Project Team.

3.4.3 Third Stage Contact

The third stage of the Project involved the agency/organisation being asked to nominate participants for a focus group about dual diagnosis educational and training needs. The Project Team was keen for nominations from each of the following groups: Manager/Team Leader; Carer; Professional (eg: psychologist, speech therapist etc), Consumer and family member of a person with dual diagnosis.

While focus groups were completed in the Logan Health District and Fraser Health District, it became evident to the Project Team that participant numbers would be small. Many potential participants were unable to participate therefore a purpose designed opinion survey was posted to them through the agencies/organisations originally contacted. Opinion surveys were also distributed within the Cairns Health District where there was considerable interest in dual diagnosis. Information packages containing details of the Project, sample questions and consent forms were also posted through the agencies.

Once the contact details and consent form had been returned to the Dual Diagnosis Project Team, potential participants were contacted regarding the focus groups. Alternatively, for those who were unable to attend but were interested in the Project, a survey was mailed to them.

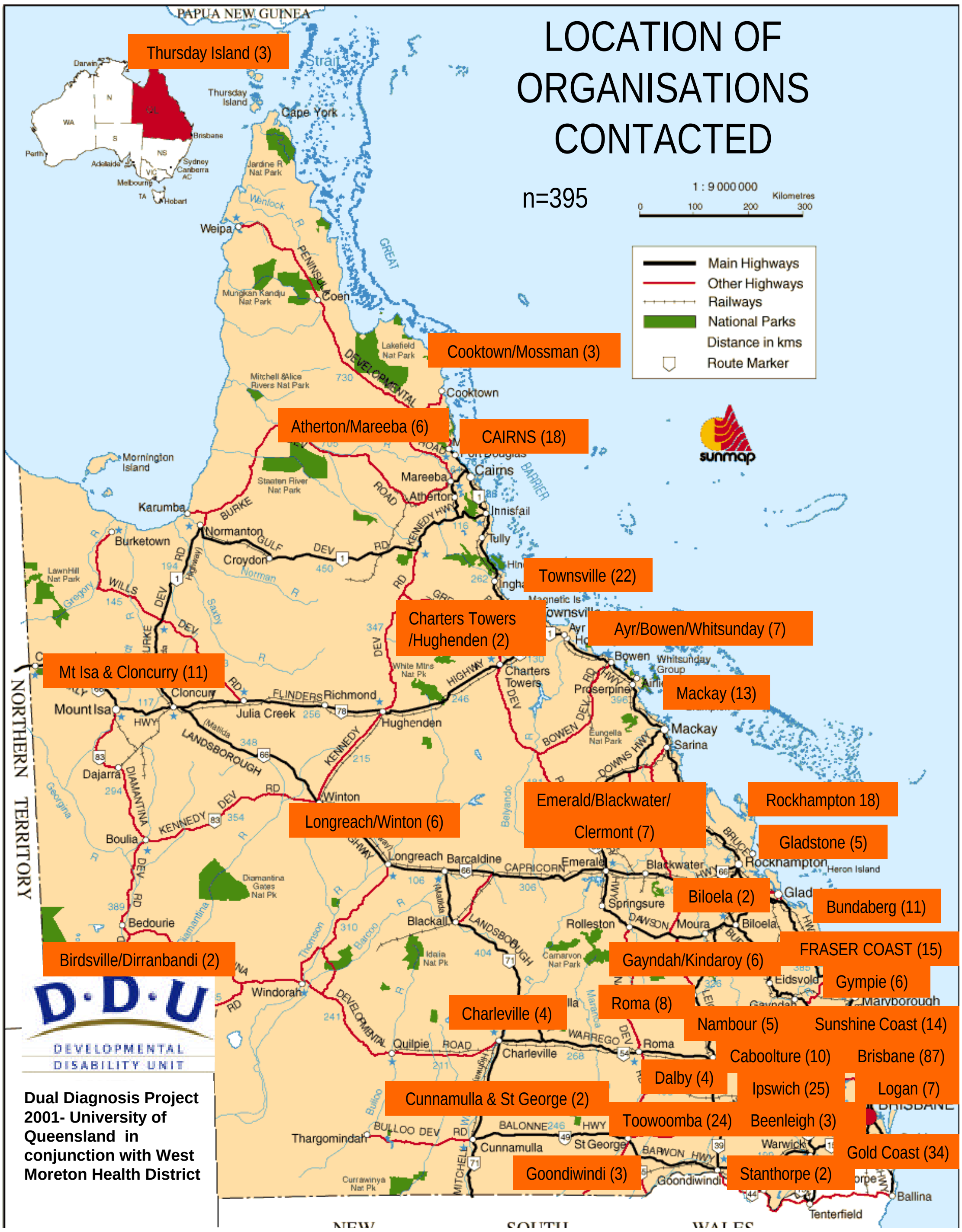
3.5 Stage One Findings

3.5.1 Stage One Initial Contact

The contact list used by the Project Team identified 395 agencies/organisations that met the Project Team criteria for the telephone survey. These agencies/organisations were deemed appropriate for contact by the Project Team on the basis of their likelihood that they had contact with or provided services to adults with an intellectual disability. This list of organisations (n=395) includes the agencies/organisations (n=99) that the Project Team became aware of through the telephone survey process, eg through the modified snowball technique adopted by the Project Team.

MAP 1 shows the location of the 395 agencies/organisations that were ***contacted*** by the Dual Diagnosis Project Team to ascertain interest in participating in the survey. These agencies/organisations were telephoned by the Project Team during the four month timeframe available. Approximately 60% (n=239) of agencies/organisations identified as potential participants (n=395), did not progress to Stage Two Contact when surveys were completed.

MAP 1 Agenices/Organisations Contacted by the Dual Diagnosis Project Team



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3.5.2 Non-respondents

There were 239 agencies or organisations (60%) of those identified on the contact list (n=395) did not participate in the survey. Within this group of non-respondents (n=239), 39% of non-respondents (n=94) did not participate for the following reasons:

- not interested or not appropriate (n=41);
- not able to make telephone contact (n=35);
- referred to other agencies (n=10);
- not able to participate due to time constraints (n=4);
- staff issues, eg unavailability of key contact person nominated (n=3); and
- service no longer exists (n=1).

The remaining 43% of non-respondents (n=145) of the agencies/organisations had provided consent to participate in the Project. However, these 145 agencies/organisations failed to return the questionnaire to the Project Team.

3.6 Stage Two Contact

156 agencies/organisations (40%) of those identified on the contact list (n=395) progressed to Stage Two and completed the full questionnaire. MAP 2 demonstrates the location of Stage Two respondents (n=156). To protect confidentiality of respondents, the location of respondents is presented regionally. Figures per regional location indicate how many questionnaires were completed within this location.

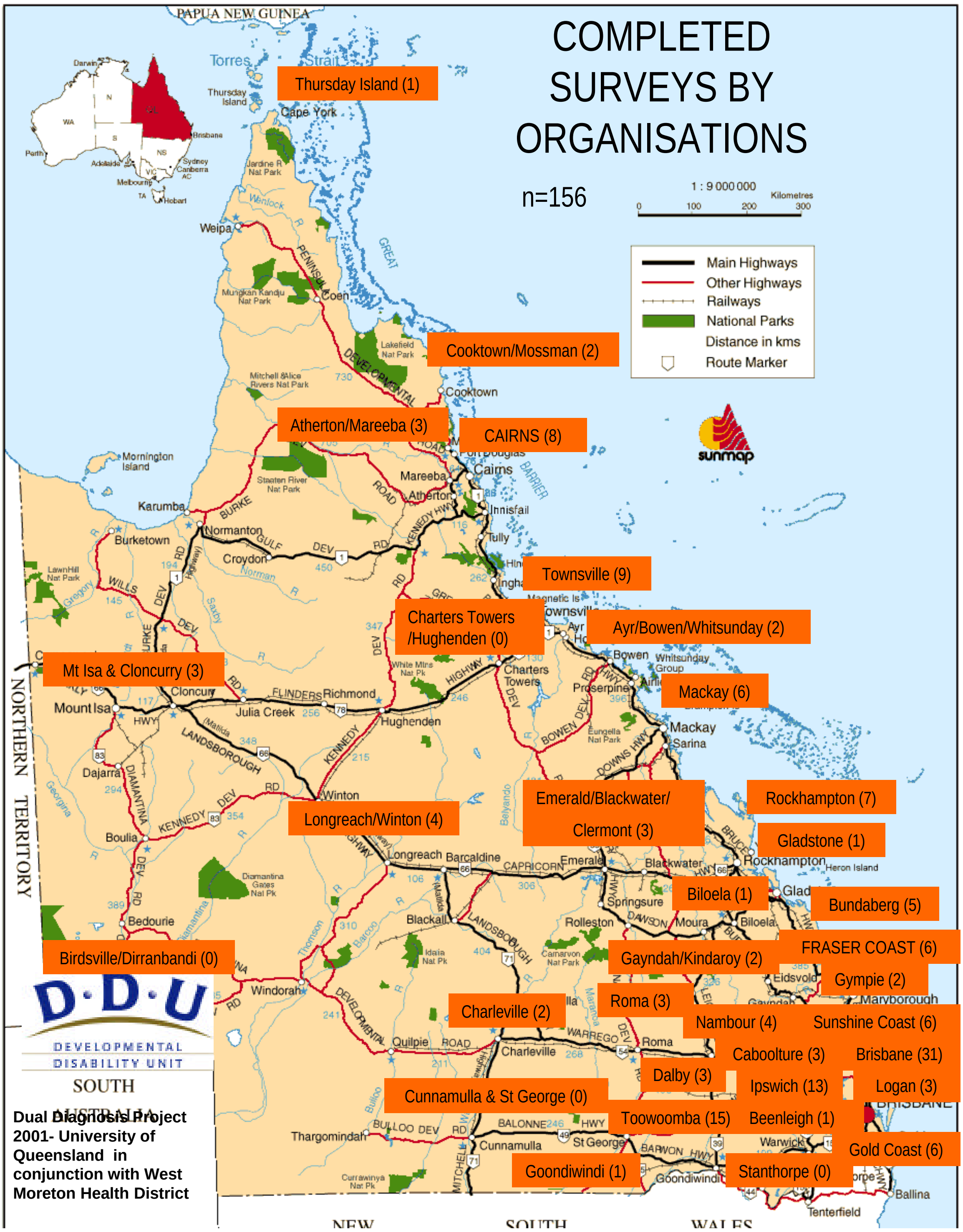
The Project Team was disappointed with this result in light of the telephone contact, information packages sent out and time spent explaining the Project rationale to potential survey participants. At the completion of the data collection stage, this Report has already stated that there were 145 agencies that provided services to adults with an intellectual disability, who consented to participate, but did not return a completed questionnaire. The failure of this group to participate, increases the likelihood that the identified and suspected numbers of adults with a dual diagnosis reflect underestimations.

3.6.1 Response Mode

There were only 50 questionnaires completed over the telephone. With considerable prompting and reminders (refer to above comments), the remainder were completed and returned to the Dual Diagnosis Project by mail and fax. Only a handful of questionnaires were returned using email.

Although the Project Team had originally anticipated that the questionnaire could be logically and quickly completed over the telephone, it quickly became clear that for many agencies/organisations, telephone completion was not practicable. Accordingly the majority of questionnaires were sent to the agencies/organisations for completion.

MAP 2 Location of Agencies/Organisations that Completed the Survey



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The majority of questionnaires were completed by the organisation/agencies, with:

- 161 questionnaires transmitted to the agencies/organisations by fax;
- 31 questionnaires emailed to the agencies/organisations; and
- 63 questionnaires mailed to agencies/organisations.

There were more than 800 phone calls made to agencies/organisations during the Project, both to initiate & follow up the questionnaires that had been distributed. More than 60 reminders were sent in the mail. Despite maximum effort being expended by the Project Team aimed at making contact with agencies through their medium of choice, only 16 responses were received from those reminders.

3.6.2 Agency Type

Agencies/organisations that participated in the Project can be clustered into ***11 different types of agencies/organisations*** across Queensland. Agency type was identified by asking participants "what service does your agency primarily provide?" A feature of this survey was the range of services provided under the one banner. For example, whilst an individual service might identify as primarily providing accommodation support, there were significant ***other*** services on offer under the same primary service.

Figure 2 demonstrates the ***major*** clusters of agency types surveyed. These included disability support (n=43), accommodation (n=42), mental health (n=16), employment (n=16), and mental health (n=11) services. These four major agency types account for 75% of respondents (n=117). The full range of primary services (n=32 different primary services as disclosed by participants) prior to clustering include: accommodation, therapy, recreation, lifestyle support, education, health and primary health, mental health, respite, advocacy, employment, hostel/boarding houses, psychiatric disability support, community access, legal, limited day programs, post school options/moving ahead, inpatient mental health, assessment, brokerage, community linking, aged care, hospitals, counselling, housing, HACC services, integrated disability, emergency support, family support, health education, case management, and financial counselling services.

The two largest service "types" were disability support (n=43) and accommodation (n=42). Disability support includes casework, lifestyle support, community access, networking and linking etc. Accommodation (n=42) includes housing, respite services, hostels, boarding houses etc. However, it appears that many of the actual "services" that are provided on the ground to adults with an intellectual disability, move far beyond what might be traditionally described as disability support or accommodation. For example, one large agency that provides a broad range of disability support services across Queensland identified its primary service as being "accommodation" whilst another similar agency considered its major service type to be family support. Both agencies shared many similarities in services provided and yet found it difficulty to identify *one* primary service. It is also important to note that there were multiple programmes or services being offered to adults with an intellectual disability regardless of the "theme" or nature of the funding sources.

3.6.3 Primary Service Provided by Agencies

147 agencies (94% of respondents) indicated 32 different primary service types. Only 6% (n=9) of the agencies that participated did not respond to this question. The eleven different cluster types that service type responses (n=147) have been collapsed into are shown in Figure 2 and Table 7.

Figure 2

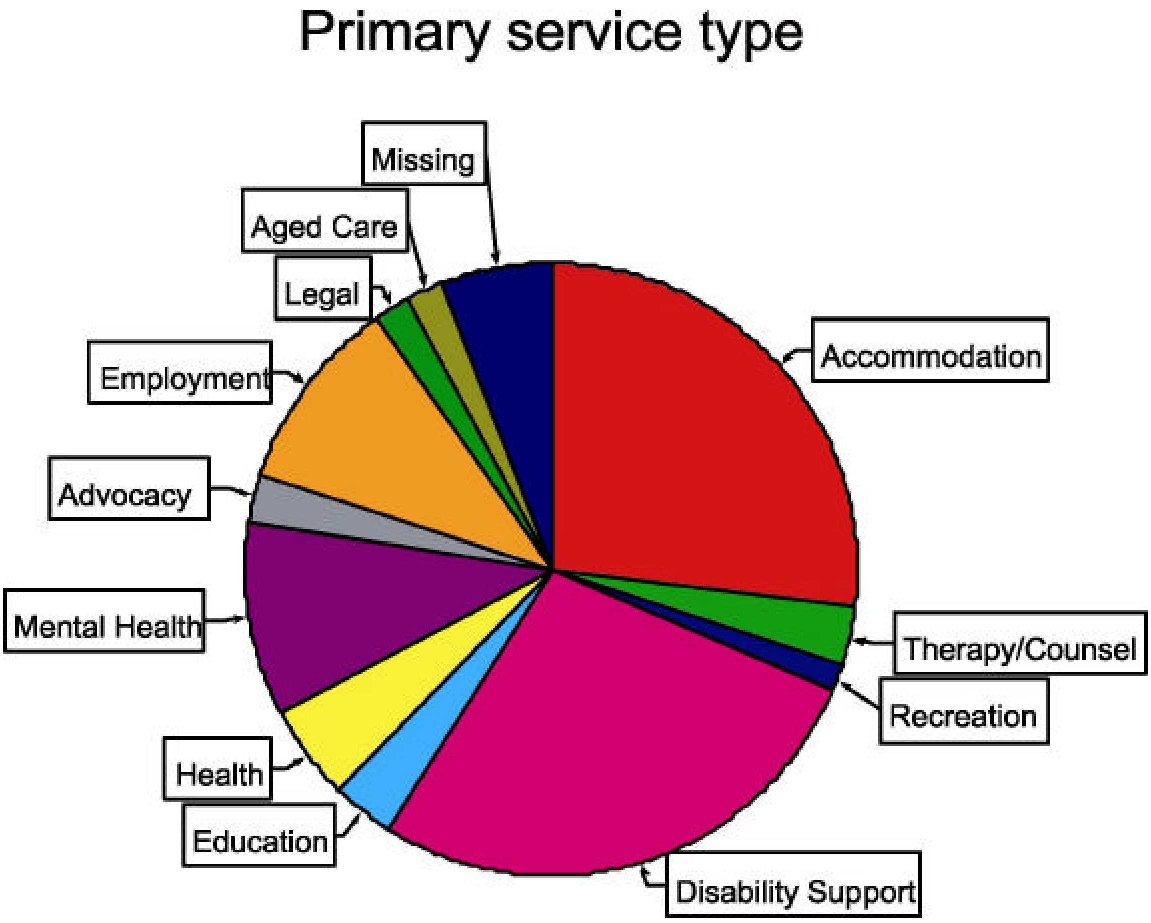


Table 7 Service Type Clusters

Service type	% of total n=156	Number of agencies n=147 “no” responses n=9
accommodation	27%	n=42
therapy/counselling	3%	n=5
recreation	1%	n=2
disability support	28%	n=43
education	3%	n=5
health	5%	n=8
mental health	10%	n=16
advocacy	3%	n=4
employment	10%	n=16
legal	2%	n=3
aged care	2%	n=3

3.6.4 Agency Funding Type

The variety of the “nature” or “type” of the organisations contacted means that agencies found it difficult to identify one major funding source. The majority of organisations had multiple funding sources. For example, one agency advised the Project Team that it operated with the assistance of more than 15 separate sources of funding and yet provided services under only one banner.

There were 16 different types of funding sources identified, including Commonwealth Health and Aged Care, Commonwealth Family Services, Department of Veterans' Affairs, Education, Project 300, Queensland Health, Private and fundraising, HACC and DSQ. Whilst acknowledging that respondents indicated more than one funding source, responses show that *at least one source of funding* received by agencies that responded (n=145), was provided by Disability Services Queensland. The predominant funding sources, in order of priority were:

- Disability Services Queensland (n=79);
- Queensland Health/Home and Community Care Program (n=43);
- Commonwealth ie Health & Aged Care/Family & Community Services (n=27); and
- private fundraising/donations (n=23).

Other sources of funding included Churches/Religious bodies (n=7), Queensland Education (n=2), and the Queensland Department of Justice (n= 2). Only 11 respondents failed to identify how their agency was funded.

3.6.5 Services to Adults with an Intellectual Disability

The 156 agencies/organisations that completed the Stage Two survey were questioned about the total number of adults with an intellectual disability that they provided services or support to. 54% of the agencies/organisations (n=84) advised that they provided services to 3,086 adults with an intellectual disability. 72 of the 156 respondents made no response.

A further 48 of the 156 agencies that responded to the survey (31%) were unable to specifically state the exact number of adults with an intellectual disability they provided services to. However, these agencies estimated that they provided services to approximately 4,110 adults with an intellectual disability.

The remaining agencies contacted (n=24) did not provide details or estimates although it was clear they did provide services to adults with an intellectual disability. In summary, the Project Team recorded that 132 agencies or 85% of respondent agencies (n=156), advised that they provided services or support to an estimated total of 7,196 adults with an intellectual disability.

7,196 adults with an intellectual disability is an estimated number comprising numbers of adults with an intellectual disability (n=3,086) and estimates of numbers of adults with an intellectual disability (n=4,110) who were provided services by the 132 of the agencies/organisations who responded to prevalence questions within the survey (85% of the 156 agencies).

3.6.6 Services to Adults with ***Diagnosed*** Dual Diagnosis

The Stage Two survey asked agencies/organisations to identify the number of adults with an intellectual disability who also had a ***diagnosed*** concurrent mental disorder, eg dual diagnosis. Where necessary, dual diagnosis was succinctly described. 59 agencies or 38% (n=156) were able to advise that they provided services to 227 adults with an intellectual disability who had been *diagnosed* with a concurrent mental disorder, eg a dual diagnosis.

An additional 45 agencies (29% of the 156) were unable to give an exact number of adults with a diagnosed dual diagnosis but did provide an approximation, ie an estimated number of adults with an intellectual with a dual diagnosis that have been ***diagnosed***. These agencies ***estimated*** that an additional 592 adults with an intellectual disability had a dual diagnosis (diagnosed).

The remaining agencies (n=52), 33% of the respondents to the survey (n=156) did not provide comments regarding undiagnosed or suspected dual diagnosis.

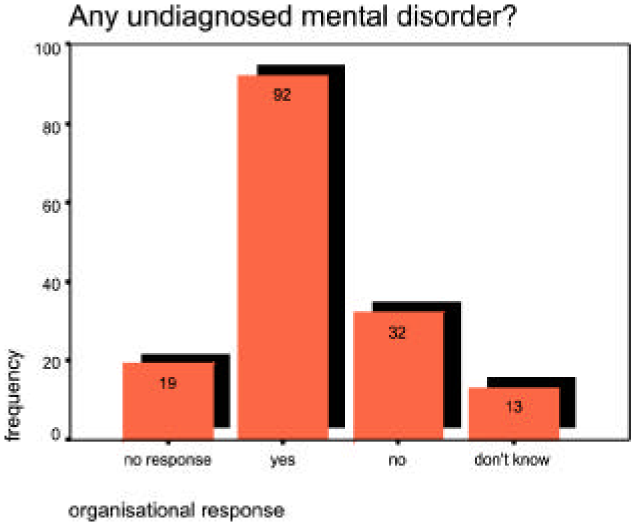
3.6.7 Services to Adults with ***Suspected but Undiagnosed*** Dual Diagnosis

Respondents were asked if they ***suspected*** that some adults with an intellectual disability that they provided services to, had a dual diagnosis ie, despite the absence of a formal clinical diagnosis. Figure 3 shows that 92 or 59% of the respondent agencies/organisations (n=156) said “yes” and 32 or 21% said “no”.

However, 32 respondents (21%) simply did not know (n=13) or failed to response to this question (n=19). Because the mental health system relies upon the individual or a carer recognising that a mental health assessment is necessary, failure to recognise signs or symptoms of a mental health problem may result in the problem being hidden. Alternatively, the individual may not reach the appropriate health professional or the mental health assessment may be flawed.

Mental health problems in adults with an intellectual disability can be under diagnosed or misdiagnosed. It is also interesting, that data analysis revealed that less than one third of organisations (31%) contacted (n=47), maintained formal policy or guidelines addressing service delivery to adults with a dual diagnosis. Failure to acknowledge the existence of dual diagnosis in agency policy and practice guidelines may contribute to the invisibility of mental health needs of adults with an intellectual disability.

Figure 3



Agencies/organisations were also prompted to advise whether they provided services to adults with an intellectual disability whom they ***suspected*** had a mental disorder, but had never been diagnosed. 27 of the 156 agencies (17%) advised that they suspected and could identify 240 adults with an intellectual disability who they ***suspected*** had a dual diagnosis, although these individuals had never been given a formal clinical diagnosis.

A further 51 of the 156 agencies (32%) could not provide exact numbers of adults with suspected dual diagnosis but did ***estimate*** that there were an additional 398 adults with an intellectual disability who they suspected had a dual diagnosis, although there had never been a diagnosis.

3.6.8 Lower Limits of Prevalence, ***Excluding Estimations***

Calculations of lower limits of prevalence ***excludes*** any estimates and uses ***only*** exact numbers of people with an intellectual disability, that were provided by agencies/organisations that participated in the survey. Using this approach, the lower limits of the prevalence of diagnosed and suspected dual diagnosis can be calculated as 15.1% (n=467) of 3,086 adults with an intellectual disability.

Table 8 Lower Limits of the Prevalence of Dual Diagnosis

This table uses only exact numbers provided by agencies/organisations and specifically excludes any estimates.

	Diagnosed **Dual Diagnosis**	***Suspected*** **Dual Diagnosis**	**Adults with an Intellectual Disability**
Number	227	240	3,086
Prevalence	7.4 % if 3,086	7.8% of 3,086	
Prevalence (lower limits)	**diagnosed (227) + suspected (240) = 467**		**15.1 % of 3,086**

Table 8 demonstrates that a total of 467 adults with a diagnosed or suspected dual diagnosis can be calculated when the exact number of adults with an intellectual disability who have a diagnosed dual diagnosis (n=227) and the exact number of those with a suspected dual diagnosis (n=240) were combined.

7.4 % (n=227) of the 3,086 adults with an intellectual disability that are provided services by respondents have a diagnosed dual diagnosis. An additional 7.8 % (n=240) have a suspected dual diagnosis.

This Chapter has already advised that 54% or 84 agencies/organisations (n=156) who participated in the survey, advised that they provided services to 3,086 adults with an intellectual disability.

3.6.9 Upper Limits of Prevalence, *Including Estimations*

By combining exact numbers and estimates provided by 104 agencies/organisations (67% of those that participated in the survey), upper limits of the prevalence of ***diagnosed and suspected dual diagnosis*** can be calculated. The total number of adults with an intellectual disability used is 7,196. This total is calculated by combing the exact number of adults with an intellectual (n=3,086) with the estimated number of adults with an intellectual disability (n=4,110) that participating agencies/organisations advised they provided services to across Queensland.

When exact numbers of adults with ***diagnosed dual diagnosis*** (n=227) and estimates of adults with a ***diagnosed dual diagnosis*** (n=592) are combined, the prevalence of diagnosed dual diagnosis (n=819) is 11.4% of the estimated 7,196 adults with an intellectual disability who were provided services by participating agencies/organisations in the survey.

When exact numbers of adults with ***suspected dual diagnosis*** (n=240) and estimates of adults with an intellectual disability who have a ***suspected dual diagnosis*** (n=398) are combined (n=638), the prevalence of suspected dual diagnosis can be calculated as 8.9% of the 7,196 adults with an intellectual disability who were provided services by participating agencies/organisations in the survey. Those with suspected dual diagnosis had never been provided with a formal clinical diagnosis.

Table 9 Upper Limits of the Prevalence of Dual Diagnosis

	Diagnosed Dual Diagnosis	*Suspected* Dual Diagnosis	Adults with an Intellectual Disability
Number	227	240	3,086
Estimate	592	398	4,110
TOTAL	**819**	**638**	**7,196**
Prevalence	11.4% of 7,196	8.9% of 7,196	
Prevalence (upper limits)	**diagnosed (819) + suspected (638) = 1,457**		**20.2 % of 7,196**

Table 9 demonstrates that upper limit calculations combine the total of the exact numbers of adults with a diagnosed or suspected dual diagnosis (n=467) and the total of the estimates of adults with suspected dual diagnosis (n=990) provided by agencies and organisations that participated in the survey. Using this approach ***a total** **of 1,457 adults with an intellectual disability that have either a dual diagnosis or suspected dual diagnosis can be identified.***

This means that the upper limits of the prevalence of dual diagnosis can be estimated as 20.2% (n=1,457) of the total number of adults with an intellectual disability that agencies/organisations provided services to (n=7,196), who had a diagnosed or suspected (but undiagnosed) dual diagnosis.

MAP 3 and Table 10 provide data that demonstrates how the lower and upper limits of prevalence have been calculated using a regional breakdown of the exact numbers and estimates of adults with both diagnosed and suspected dual diagnosis. Data is presented using a regional breakdown to prevent identification and protect confidentiality of information provided.

3.6.10 Clinical Source of the Dual Diagnosis

Agencies/organisations were asked to identify the clinical source of the dual diagnosis. Of the 202 adults with an intellectual disability who had a diagnosed mental disorder, Table 11 identifies the five sources of diagnosis that were most frequently provided. It should be noted, that some agencies gave multiple diagnostic sources when questioned about the source of diagnosis ie:

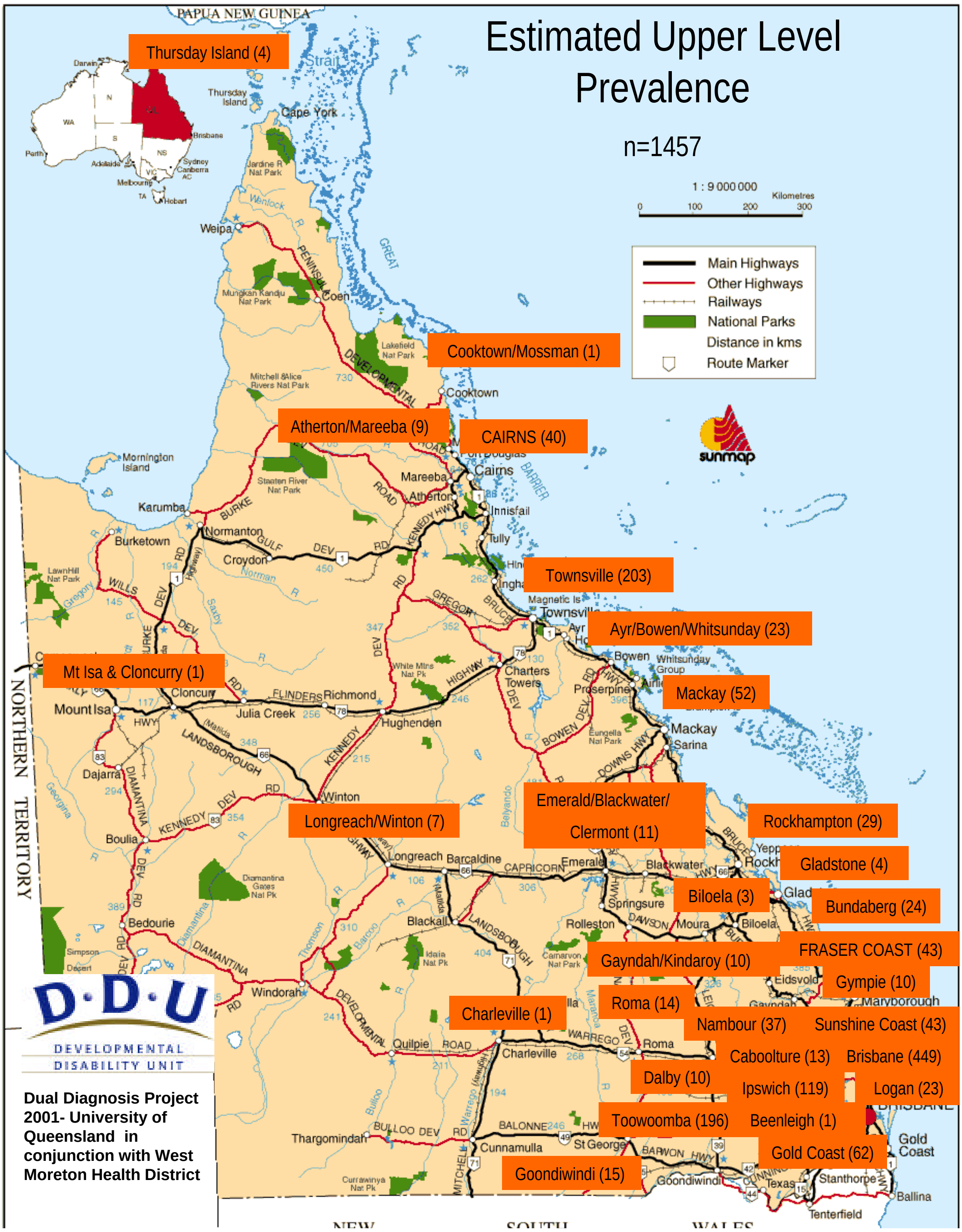
- 8 respondents cited 4 sources of diagnosis;
- 30 cited 3 sources;
- 68 cited 2 sources; and
- 134 cited only one source of dual diagnosis.

Table 10 Regional Breakdown of Prevalence of Dual Diagnosis (Diagnosed and Suspected) in Queensland

Location	Diagnosed DD	Approx Diagnosed DD	Suspected DD	Approx Suspected DD	Prevalence DD
Atherton/Mareeba	1	0	0	8	9
Ayr/Bowen/Whitsunday	15	0	4	4	23
Beenleigh/Beaudesert	1	0	0	0	1
Biloela	1	0	2	0	3
Brisbane	28	258	108	55	449
Bundaberg	4	10	0	10	24
Caboolture	4	0	2	7	13
Cairns	15	5	13	7	40
Charleville/Blackall/Augathella	1	0	0	0	1
Cooktown/Mossman	0	0	1	0	1
Dalby	1	2	4	3	10
Emerald/Blackwater/Clermont	1	3	0	7	11
Fraser Coast	4	10	10	19	43
Gladstone	4	0	0	0	4
Gold Coast	11	21	7	23	62
Goondiwindi	0	0	0	15	15
Gympie	2	0	4	4	10
Ipswich	25	35	7	52	119
Kingaroy/Gayndah	0	10	0	0	10
Logan	2	10	6	5	23
Longreach/Winton	4	0	3	0	7
Mackay	6	34	0	12	52
Mt Isa/Cloncurry	1	0	0	0	1
Nambour	19	7	8	3	37
Rockhampton	4	9	2	14	29
Roma	0	5	0	9	14
Sunshine Coast	2	8	28	5	43
Thursday Island	4	0	0	0	4
Toowoomba	34	115	8	39	196
Townsville	33	50	23	97	203
TOTAL	**227**	**592**	**240**	**398**	**1457**

MAP 3

Upper Limits of the Prevalence of Dual Diagnosis



Dual Diagnosis Project 2001- University of Queensland in conjunction with West Moreton Health District

Regardless, Table 11 clearly demonstrates that a range of clinicians and professionals are involved in the diagnostic process.

Table 11 Clinical Diagnosis Source

Psychiatrist	Mental Health Team	Psychologist	General Practitioners	Disability Services Queensland
86	70	35	24	7

In total, responses identified a total of 14 sources of diagnosis. In addition to the 5 most frequently cited diagnostic sources that are identified in Table 11, respondents also identified the following sources:

- Social worker (n=2);
- Neurologist (n=1);
- Institutions (n=1);
- Psychogeriatrician (n=1);
- Geriatrician (n=1);
- Centrelink (n=2);
- Developmental Disability Unit (n=1); and
- Schools (n=1).

3.7 Stage Three Contact: Focus Groups and Opinion Surveys

The Project Team conducted focus groups with dual diagnosis stake-holders in the Logan Health District and Fraser Health District. Opinion surveys were also mailed to dual diagnosis stakeholders in these districts, as well as within the Cairns Health District.

Focus groups and surveys sought opinions and views about:

- perceptions and views about dual diagnosis;
- current dual diagnosis knowledge & skills; and
- dual diagnosis education and training needs.

Logan & Fraser Coast districts were chosen because they were considered representative of metropolitan and non-metropolitan issues. Cairns was added when the Project Team learned of a dual diagnosis project that had developed in this area as a result of collaborative efforts of a number of Government and non-Government agencies. The Dual Diagnosis Project Team was advised in early 2002 that this group had secured some funds to employ a project officer.

Consultations targeted the five key groups prioritised by the Project Team: family members, consumers, direct support workers, managers and professionals. For each of the above five groups, 200 surveys were distributed either by post or in person during consultations or information sessions. There were a total of 1,000 surveys distributed across Queensland by the Project Team.

There was also an additional mail-out of 200 surveys that were sent to families in Far North Queensland, courtesy of the Far North Queensland Family Alliance.

3.7.1 Focus Group Responses

Despite considerable energy being expended by the Project Team, there was a disappointingly low attendance at focus groups:

- 51 family members;
- 16 direct support workers (BlueCare, Centacare, DSQ and community based services)
- 15 managers (service managers and regional directors); and
- 15 professionals (psychologists, case manager, speech pathologists).

There were no consumers who participated despite concerted effort being expended during the recruitment strategy. Regardless, the responses fit well with results from the Dual Diagnosis Forum hosted at the beginning of the data collection phase of the Project. Similarly, issues fit coherently with data gathered from key informant interviews.

"This is an important, emerging area of concern … If we do not tackle the issues systematically parallel to providing educational opportunities, the area will never become legitimatised. There must be clear commitment to developing the relationships between disability and mental health professionals at all levels".

This comment from a participant was greeted with general agreement. Generally, those who participated tended to target psychiatrists as requiring additional training in intellectual disability and dual diagnosis. Families suggested that General Practitioners receive information on the appropriate management of adults with a dual diagnosis. The following comments summarises the focus group content.

- **Direct Support Workers (n=16)**

Approximately half of the direct support workers (n=7) held a certificate in disability studies. Most (80%) had more than 3 years experience (n=12) working with people with disability. Between the 16 respondents, they reported that they were involved in supporting 11 clients with a dual diagnosis and 7 with an undiagnosed mental illness. All reported a better than average working knowledge of these consumers that they supported. Respondents reported that six of the identified 11 clients were being actively co-managed by disability and mental health services.

Of the direct support workers (n=16), all of them reported primarily learning about dual diagnosis on the job with half reporting (n=9) that they had received some skills from training and conferences. They also reported that they would like to know how to identify dual diagnosis (n=5), and to understand how to support people with dual diagnosis (n=5).

All respondents said they preferred videos and training opportunities as media for learning more about dual diagnosis, in sessions with other staff from other agencies (n=13). The best provider of dual diagnosis training was considered to be the employing agency (n=5), a university (n=4) and mental health professionals (n=5). One half of the respondents (n=8) considered that psychiatrists were in greatest need of dual diagnosis training.

- **Family Members (n=5)**

Family members included 4 mothers and 1 father. Two participants advised that their son/daughter had schizophrenia and two other participants discussed their experiences of depression. Only two people were formally diagnosed as having a dual diagnosis by a psychiatrist. Private psychiatrists, psychologists, and general practitioners were involved in the management of the mental health problems.

“I have no problems accessing services, but problems arriving at a diagnosis that is correct”.

“I'm not confident that my daughter requires professional medical assistance … I believe she needs social interaction and employment. I refer to professionals who have expertise in this area and are easily accessible/available”.

Parents advised that they had used their own experiences and books to obtain skills in dual diagnosis. They wanted more information on positive behaviour support, support services, schizophrenia, autism, and effective communication. They advised that videos were likely to be the most helpful medium through which to learn. Parents considered that psychiatrists, general practitioners, and direct care staff were in greatest need of dual diagnosis training. They did not rate their own training needs as being of a high priority.

- **Managers (n=15)**

Managers who responded came from disability services, mental health services, and community based services. Participants had between three and seven years experience in their sectors, and most (n=9) had tertiary qualifications. They managed services with up to 100 staff including direct support workers, professionals and administrative staff.

Only three participants identified 10 clients as having a clear dual diagnosis, and the rest identified a further 123 clients with an undiagnosed mental illness. Respondents identified only 6 clients who were being actively co-managed by disability and mental health services.

All respondents identified their primary source of knowledge about dual diagnosis as being learnt on the job, and all acknowledged that they would like to improve their knowledge and skills. Some of the requests for information included appropriate support models, assessment, recognising potential disability, awareness of types of mental disorder, and knowledge of medication and side-effects.

Participants opted for a range of media for training, and considered increasing their skills as important. Interestingly, managers indicated that skills in facilitating collaboration between key stakeholders in dual diagnosis was a key need. Overwhelmingly (100%), managers stated that psychiatrists were in the greatest need of dual diagnosis training.

“Eventually we will get the expertise to support people professionally with dual diagnosis”.

10 of the 15 managers stated that their staff learn about dual diagnosis through formal and informal avenues, but when examined, most of these opportunities appeared to be team meetings and on the job learning (n=13). Managers considered that staff were in need of training in managing behaviours, support clients with dual diagnosis, mental health systems, and "recognising the red flags" or signs of distress in clients. These clients provide the greatest stress to staff.

- **Professionals (n=15)**

“We are always wanting to know more to assist the clients”.

Professionals who responded came from a range of service types although the majority were working within government services (n=9). Those not working in government services, were from community-based services. The majority had formal qualifications including undergraduate degrees and higher degrees (n=13). Two respondents had diplomas that were associated with direct care responsibilities. Respondents had been working with people with disabilities for between one and seven years. The professionals reported working with 20 people with dual diagnosis and a further 39 clients that they suspected had undiagnosed mental illness. In general, they stated that they felt they possessed good to excellent levels of knowledge and skills about dual diagnosis, despite reporting that they exclusively learnt about dual diagnosis whilst “on the job”. Three professionals had learnt more about dual diagnosis through the Developmental Disability Unit.

Respondents requested more information and skills in assessment and treatment strategies, including types of symptoms and appropriate interventions. Their preference for training in assessment was in the form of workshops (n=10). Only four professionals had knowledge of assessment tools that were useful when working with adults who had or were suspected of having a dual diagnosis. Respondents considered that psychiatrists (n=8), managers (n=9), consumers and families (n=8), and also professionals (n=11) were in great need of training.

“Dual diagnosis is difficult but I believe that many professionals refuse to address or assess people with an intellectual disability. They appear to be unable or unwilling to address this area. They appear to be more at home to over medicate people rather than address the issue. Please note not all professionals are in this category but many are. Knowledge and a better understanding of intellectual disability might assist them with their ability to better diagnose people”.

“ I believe there is a lack of respect by some doctors towards people who do not have a medical background but do work in the disability and health care professions. It is very frustrating when a doctor states that the person with a disability is displaying behaviour on purely a behavioural basis despite good documentation it is more than likely a radical or psychiatric basis to the problem”

With regard to dual diagnosis training, professionals requested a range of media, provided primarily by mental health professionals (n=6) or the employing agency (n=4), attended by staff from disability and mental health services and other agencies (n=9). Professionals suggested that dual diagnosis training needed to occur in regional areas to enable non-metropolitan staff to attend. It was also suggested that a regional venue might allow family members and advocates to attend training.

4. Limitations associated with Prevalence Estimates

Attempts to estimate the prevalence of dual diagnosis in limited by a number of factors including:

- this Report only includes information provided by those agencies/organisations that responded;
- possible differences in the interpretation of questions by respondents;
- the incapacity of some respondents to provide correct or concise information;
- the inability of respondents to accurately recall information; and
- possible errors made when collecting and processing the data, including coding and data inputting.

4.1 Characteristics of Adults with an Intellectual Disability

There is limited availability and quality of data regarding adults with an intellectual disability within Australia. Reasons for this partly include wide variations in operational definitions, measurements, survey approaches, data sources and geographic locations. There is also considerable variation in the underlying concepts, definitions and classifications of intellectual disability adopted in Australia (AIHW, 1997)

Research on the number and characteristics of persons with disabilities has generated widely divergent estimates of the size of the disabled population. Differences abound because no single concept of disability is appropriate for all concerns and policy issues. Accommodating the diverse needs for data on this population group requires multiple definitions that deals both with the types of limitations, and with the severity of the limitations.

4.2 Survey Design

The Project Team was aware of limitations associated with the use of a survey as a data collection technique. Telephone-based surveys have a tendency to under-sample invisible populations. The potential for telephone under-coverage and non-response biases also represents a limitation of the results. However, telephone contact was deemed by the Project Team to be fast, efficient and cost-effective given the short timeframe available.

As with any survey, each respondent may interpret questions on the survey differently from other respondents, generating data that may be skewed due to user perceptions. The Project Team discussed this problem at the commencement of the Project and undertook a trial of the survey that aimed to identify problems so that this outcome could be minimized. The Project Team felt that this problem had been minimised by rewording any question that appeared to have ambiguity in its meaning but recognize that this factor can never be completely eliminated.

4.3 Proxy-Estimates and Case Ascertainment

Information provided to the Project Team, including exact numbers and estimates of the number of adults with diagnosed or suspected dual diagnosis relied upon the case ascertainment skills and abilities of the respondent agency/organisation. Although prompts were provided to respondents during telephone contact, many surveys were completed via non-telephone contact and returned to the Project Team via mail, fax and email. The case ascertainment capacity of respondents who completed the surveys was not identified, eg their confidence, skills and abilities to identify adults with a dual diagnosis is unknown.

It is highly likely that there are many adults with an intellectual disability known to these agencies who have a dual diagnosis and yet these agencies and organisations are unaware of these individuals' mental health needs. Dual diagnosis may be under-reported in the survey by respondent agencies because of the difficulties associated with the assessment and diagnosis of mental health problems in adults with an intellectual disability.

4.4 Non-Respondents

A major limitation associated with prevalence estimates within the Dual Diagnosis Project relates to the number of non-respondents. There were 239 agencies or organisations (60%) of those identified on the contact list (n=395) that did not participate in the survey. It is likely that the prevalence of dual diagnosis has been underestimated given that it is impossible to include estimates of prevalence from the non-respondents. It is also difficult to make generalisations because of the high level of non-respondents.

The estimates provided within this Chapter should not be regarded or considered to be "hard-and-fast" numerical measures. As a consequence, any conclusions drawn from the survey data must always be considered as an approximation of the true situation.

4.5 Reliability

As with any data, information and figures (eg exact numbers referred to) that were provided by the organisations and agencies raises the issue of reliability. Realistically, it is a difficult task for organisations and agencies to provide totally accurate information and figures. Logically, the Project Team must recognize that it is always difficult to produce totally accurate data.

It is unknown how and if agency/organisations collect data that they used to respond to questions in tthe survey, eg the number of adults with an intellectual disability that they provide services to. Respondents are unlikely to have collected data in a standardized manner and then used this data to inform their response. Responses provided to the Project Team as exact numbers, are likely to have been based upon estimates.

The survey could have been improved by instructing respondents to base their responses on records rather than personal knowledge. To determine the extent to which personal knowledge or estimates were used, the survey could have asked respondents to identify the source of their responses, eg asking them how did they calculate the number of adults with an intellectual disability that they provided services to.

4.6 Double Counting and Duplication

The avoidance of double counting or duplication was impossible to account for or address within the Dual Diagnosis Project. Double counting or duplication was possible at two levels:

- within a particular organisations/agency, eg where a person with an intellectual disability was seen a number of times within that organisation perhaps at the same venue or different venues;
- across data sources, eg where a person with an intellectual disability was seen by a number of different agencies/organisations.

Participants were guaranteed confidentiality therefore data provided about adults with an intellectual disability who were provided services by agencies/organisations, could not and did not identify personal details. Accordingly there is no guarantee that clients accessed more than one service and therefore double counting could have transpired.

Whilst upper limits of prevalence that are provided in this Chapter simply adds the data from the different agencies/organisations together to calculate totals, duplication is possible and likely. Accordingly, lower limits of prevalence have been calculated.

The methodology of the survey could have been improved and duplication/double counting minimised by limiting the period covered by the survey to a short timeframe, eg one month. Inclusion of questions about "services and support provided by another agency or organisations" may also have been helpful. However, nuances in these leading questions may not always be well understood and may not reliably reveal duplication or double counting.

5. Concluding Comments

It must be noted that the methodology of the Project contains flaws and limitations, particularly the reliance upon estimates. However, results from the Forum, the organisational surveys and the opinion surveys/consultations show organisations/services supporting adults with an intellectual disability are grappling with those people who also have a concurrent mental health problem. Agencies and organisations across the state of Queensland could identify adults with a dual diagnosis, both diagnosed and suspected. However, it is now clearer that expertise, support, and education or training opportunities, are very thin on the ground.

The prevalence of dual diagnosis provided within this Chapter, particularly the “upper limit” calculations, relies upon estimated numbers. These numbers need to be carefully considered in light of the limitations associated with the data collection that have been discussed in this Chapter. However, the estimated results do demonstrate that across Queensland there exists a sizable group of adults with an intellectual disability who are in need of expert mental health assessment and treatment. It is hoped that the Project findings will highlight the unmet mental health needs of adults with an intellectual disability. Support for ongoing research, both qualitative and quantitative in the dual diagnosis area would be a worthy outcome. The establishment of infrastructure for dual diagnosis education and training would, on the other hand, be welcomed by consumers, family members, carers, clinicians, professionals and a range of service providers in the community.

Chapter 4

Survey of Psychiatrists

Chapter 4 Survey of Psychiatrists

1. Introduction

This Chapter analyses trends in a survey of attitudes, opinions and beliefs held by Queensland Psychiatrists about adults with an intellectual disability. Psychiatrists have a pivotal role to play in meeting the mental health needs of adults with an intellectual disability. They are important gatekeepers to the mental health system because of their assessment and diagnostic responsibilities, therapeutic interventions and treatment recommendations, including psychopharmacology.

This Chapter provides an overview of the methodology, survey tool used, data collection and discusses findings from a survey sent through the Royal Australia and New Zealand College of Psychiatrists (RANZCP) to Queensland Psychiatrists and Psychiatric Registrars in mid 2001. Inclusion of the views of Psychiatrists was considered essential to the Dual Diagnosis Project.

2. Rationale and Aims

The Project Team considered that an attitude survey was the most effective and efficient approach to involve Psychiatrists in the Dual Diagnosis Project. The survey aimed to identify the views of Psychiatrists when the patient had an intellectual disability. Dual diagnosis education and training priorities were also to be determined and prioritised.

Attitudes, opinions and beliefs held by professionals can act as a barrier to effective clinical responses. There can be both direct and indirect effects upon patients. For example, attitudes can directly influence the clinician: patient relationship or more indirectly influence the person with an intellectual disability through effects upon their relationships with other people (Beckwith & Matthews, 1995).

Understanding what Psychiatrists perceive about adults with an intellectual disability and what they need in order to improve clinical outcomes in this group, has the potential to improve service responses to adults with an intellectual disability, and in particular those with dual diagnosis. Findings from the survey were also expected to be helpful in targeting dual diagnosis education and associated information strategies to a range of stakeholders, not just Psychiatrists themselves.

2.1 Attitudes

The terms “attitudes, opinions and beliefs” have related meanings therefore they tend to be used interchangeably. Commonplace definitions exist although social scientists have developed more complex explanations. The classic definition suggests that an attitude is a mental or neural state of readiness, organised through experience, exerting a directive or dynamic influence upon an individual’s response to all objects and situations with which it is related (Allport, 1935). More simply, whether favourable or unfavourable, attitudes are evaluative judgements that are expressed in thoughts, feelings and actions towards a person or an object. Attitudes are multi-dimensional, involving affective, behavioural and cognitive components.

Reasons for the Project Team's interest in the attitudes of Psychiatrists relates to the relationship between attitudes and behaviour. Although it might seem logical that attitudes can determine behaviour, the exact nature of the relationship is a subject of conjecture (Beckwith & Matthews, 1995). Research suggests that attitudes tend to be poor predictors of behaviour (Festinger, 1964) although attitudes can have behavioural ramifications (Beckwith & Matthews, 1995). A range of factors may influence the inconsistent relationship between behaviour and attitudes, including strength of the attitudes, accessibility in memory and relevance of the behaviour in question. However, attitudes may be more likely to determine behaviour if those attitudes were formed through familiarity or personal experiences (Fazio & Zanna, 1981).

Australian research has suggested that values are implicated in attitude formation. Values provide a structure for organising attitudes and have the following characteristics (Feather, 1991):

- consist of general beliefs about desirable behaviour and goals;
- involve goodness and badness and an "oughtedness" quality (unlike wants and needs);
- provide standards for evaluating actions, justifying opinions and conduct, planning behaviour, for deciding between different alternatives, engaging in social influence and presenting ourself to others;
- organised into hierarchies for any given person and their relative importance varies over time; and
- vary between individuals, across groups and cultures.

It is also worthy to note that concerns about mental health professionals expressed by consumers and carers may focus upon attitudes and values rather than deficits in knowledge and skills. The Report of the Evaluation of the National Mental Health Strategy (1997) advised that consumers and carers identified the attitudes of mental health professionals as the main source of stigma and discrimination that they experienced.

Whilst acknowledging that the relationship between attitudes and behaviour is complex, the Dual Diagnosis Project Team recognised that attitudes do play a role in the behaviour of clinicians and professionals. Attitudes and belief systems can ***influence*** behaviour. Understanding perceptions about people with an intellectual disability could provide information about current clinical challenges faced by Psychiatrists. The identification of misconceptions or problematic approaches could be identified and targeted for future interventions. Strategies for change would be driven by factual insight rather than conjecture. At this time, additional benefits included:

- promotion of the critical roles played by Psychiatrists in the mental health assessment and treatment of adults with an intellectual disability,
- assessment of the culture of psychiatry (the "mood") towards adults with an intellectual disability;
- scan of the clinical environment of Psychiatrists today when working with adults with an intellectual disability, as well as in the future; and
- individual opportunity to be involved, to voice a personal opinion, identify needs and gaps, anonymously and confidentially.

3. Survey Instrument

The survey instrument used was a 28 item self-administered questionnaire featuring multiple choice and open-ended questions. The questionnaire was comprised of five sections that sought:

Section 1:	Information about adults with an intellectual disability seen by the Psychiatrists within the last six months;
Section 2:	Responses to 18 statements of opinion regarding the management of adults with an intellectual disability (scored using Likert scales);
Section 3:	Recommendations regarding strategies for improving mental health and community based services for adults with an intellectual disability;
Section 4:	Demographic information regarding the respondents; and
Section 5:	Details regarding training and education needs, including preferred presentation mode and venue.

The tool used was derived from a questionnaire that was used to surveyed the attitudes of Psychiatrists to adults with an intellectual disability in Victoria during 1995 (Lennox & Chaplin, 1996). Revision of the Victorian questionnaire involved minimal changes to the original questionnaire including modified language and additional questions regarding training and education preferences. The questionnaire used in the Dual Diagnosis Project was trialed with staff from the Baillie Henderson Hospital, Toowoomba. This hospital was chosen because there are a number of adults with an intellectual disability living here.

4. Method

The questionnaire was mailed on two separate occasions to Psychiatrists and Psychiatric Registrars practicing within Queensland, with the assistance of the RANZCP (Queensland). The mail outs occurred approximately six weeks apart, during 2001.

The College was provided with the surveys and subsequently addressed each envelope to ensure confidentiality. The Project Team extend their sincere thanks to Dr Eileen Burkett and the RANZCP, for their assistance in the survey. The RANZCP advised that the survey was mailed to 306 Psychiatrists and 104 Psychiatric Registrars across Queensland. Eight surveys were returned due to incorrect addresses or had moved from known addresses. A total of 410 surveys were mailed on each occasion.

The survey did not specifically seek identifying details of respondents. However, respondents were given the choice of providing identifying details if they had a special interest in adults with an intellectual disability and were interested in further contact or follow-up.

Each questionnaire was accompanied by explanatory information regarding the purpose of the survey and the Dual Diagnosis Project. Brief information regarding the survey and the project was posted in the Royal Australia and New Zealand College of Psychiatrists (RANZCP) newsletter (included in Appendices). Data from the returned questionnaires was entered into a secure database. The SPSS statistical program was used to analyse the responses.

5. Results

The Dual Diagnosis Project team received 177 completed questionnaires, a response rate of 43% from the mail out (n=410). There were 140 responses (46%) from Consultant Psychiatrists (n= 306). 35 or 34% of Psychiatric Registrars responded (n=104). Only 2% of respondents (n=3) did not indicate their appointment status.

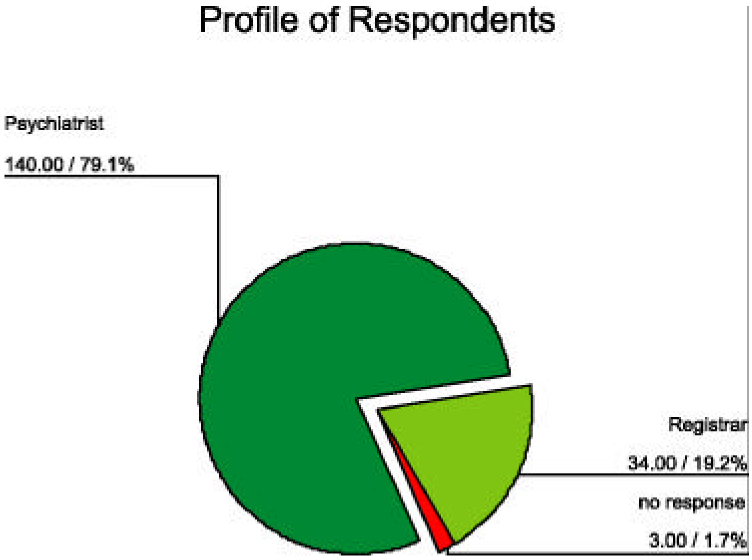
The response rate may have been influenced by the accuracy of the address list provided by the College. In particular, because of state wide training obligations, Registrars tend to be more mobile than Consultants. Another possible reason for the response rate may relate to failure by Adolescent and Child Psychiatrists to respond eg they may have considered a response inappropriate in light of the survey being targeted at psychiatric treatment of “adults” with an intellectual disability. Anecdotal evidence suggests that Adolescent and Child Psychiatrists could remain involved in the treatment of patients who move from childhood to adulthood because of limited alternatives for referral. Alternatively, interest in the topic, relevance of the topic to their practices and general problems associated with survey completion and return, may have had an impact upon response numbers.

5.1 Profile of Respondents

Results reported in this Chapter combine responses from Consultants and Registrars. It is however, important to recognise that the majority of responses reflect the views of Consultant Psychiatrists. Figure 1 demonstrates that 79% of respondents were Consultant Psychiatrists (n=140), with the remaining 19% of the sample comprised of Psychiatric Registrars (n=34).

The majority of the respondents were male (97 males). There were 73 female respondents. Six respondents did not indicate their gender. In recent years women have comprised approximately half of all medical graduates and similarly, a high proportion of applicants for psychiatric training are women (Adler & Mathieson, 1999). Consequently, female Psychiatrists may be under-represented in the sample.

Figure 1



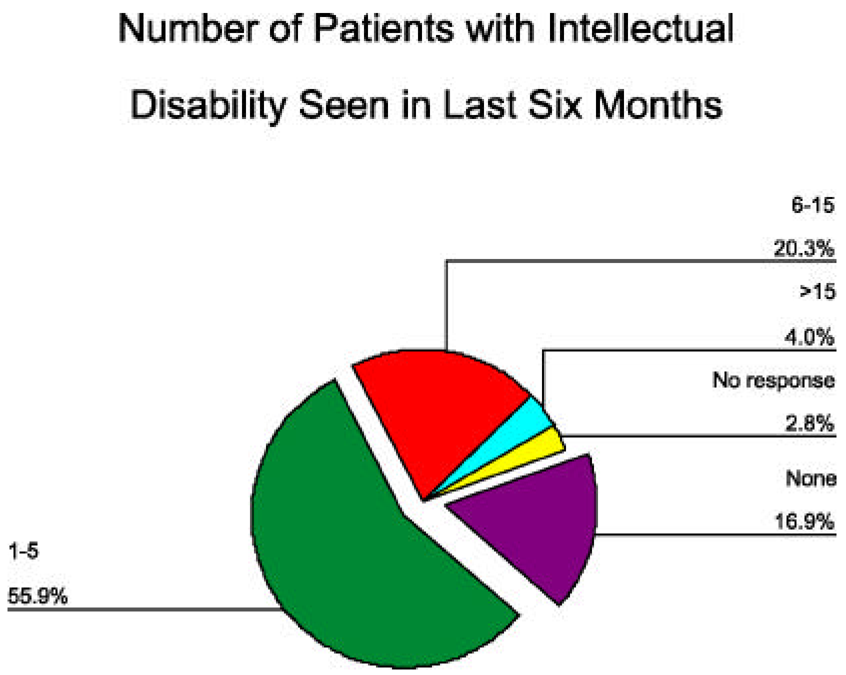
5.2 Clinical Contact with Adults with an Intellectual Disability

The majority of respondents were involved in the active treatment of adults with an intellectual disability and therefore were familiar with issues that the survey addressed. Figure 2 shows that 56% (n=99) of Psychiatrists had seen between 1-5 adults with an intellectual disability within the last six months. In fact, 20% (n=36) of the respondents had seen between 6-15 patients with an intellectual disability within this period.

Few respondents (n=7) had seen more than 15 patients with an intellectual disability (4%). The minority, 17% of respondents (n=30) had seen ***no*** adults with an intellectual disability, within the last six months.

Caseloads appear to reflect small numbers of adults with an intellectual disability although the respondents were not asked about total patient caseload. Movement from institutional care and the mainstreaming of inpatient services within acute general hospitals has led to much shorter lengths of stay, higher admission rates per bed, and a more acutely disturbed clientele than was previously the case (Adler & Mathieson, 1999). The referral of adults with an intellectual disability to Psychiatrists is likely to continue, if not grow, in response ongoing community care policies.

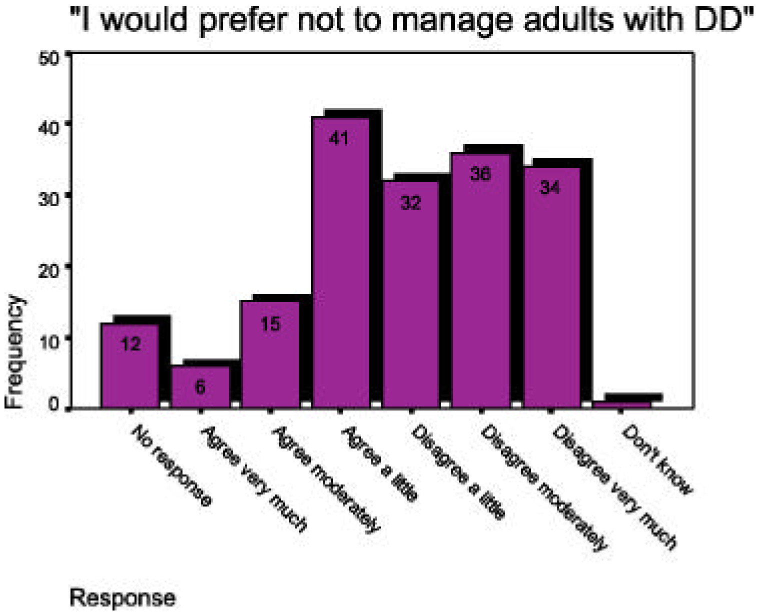
Figure 2



5.3 Attitude to the Management and Treatment of Adults with an Intellectual Disability

The survey showed that not only are the majority of the respondents actively treating adults with an intellectual disability, but they were also interested in managing and treating the mental health needs of adults with an intellectual disability. Figure 3 demonstrates responses to being asked if they preferred ***not*** to treat adults with an intellectual disability. 58% (n=102) disagreed. 35% of respondents concurred with the statement although of the respondents who agreed (n=62), only 23% (n=41) agreed a little.

Figure 3



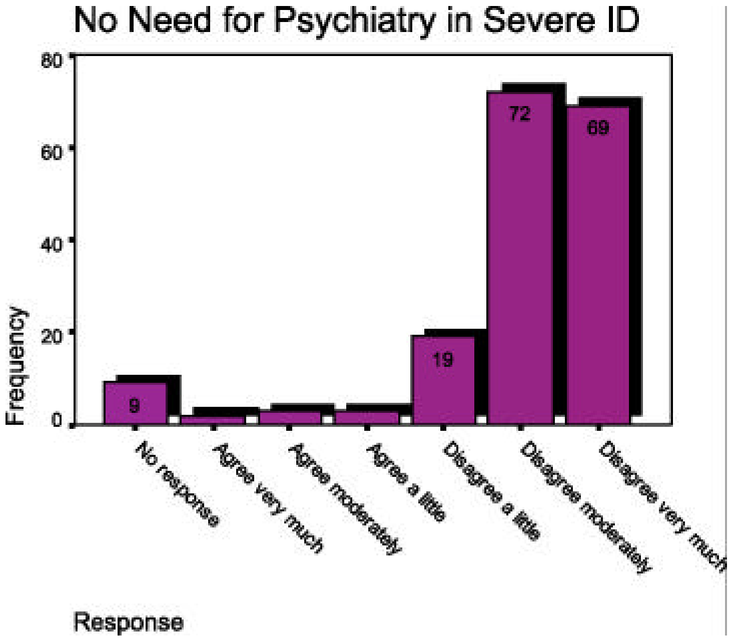
5.4 Relationship between Psychiatry and Intellectual Disability

Psychiatrists were questioned about their potential utility when treating adults with a severe intellectual disability. They were to respond to the statement, "there is seldom the need to investigate psychiatric symptoms in the more severely intellectually disabled".

Adults with a severe intellectual disability are likely to have high support needs, be reliant upon others for activities of daily living and experience communication problems. Patients with more severe levels of intellectual disability will have major difficulties when describing complicated, internal feelings therefore making diagnosis difficult (Deb et al, 2001).

Responses strongly affirmed the role of Psychiatrists when there was a severe level of intellectual disability. Figure 4 shows that 160 respondents (90%) acknowledged the need to investigate psychiatric morbidity in adults with a severe intellectual disability.

Figure 4



5.5 Consultation Setting

The majority of respondents saw adults with an intellectual disability within a ***public sector setting***. 32% (n=57) saw adults with an intellectual disability in a public setting sector as ***outpatients.*** However, 38% (n=67) of respondents indicated that they saw adults with an intellectual disability as ***inpatients***. One possible explanation for this difference is that Psychiatrists may be called to assess inpatients with an intellectual disability, perhaps in general wards or mental health settings, but may not necessarily take them on as outpatients.

Consultations in the ***private sector*** were quite different. 33% of respondents (n=58) had seen adults with an intellectual disability within the private sector as outpatients. There were only 4 respondents who had seen adults with an intellectual disability as inpatients (2%).

5.6 Common Diagnoses

Respondents were asked to rank the three most common diagnoses given to adults with an intellectual disability that they had seen within last six months. Diagnoses were listed in detail and were drawn from the DSM-IV. Figures 5,6 and 7 show the responses.

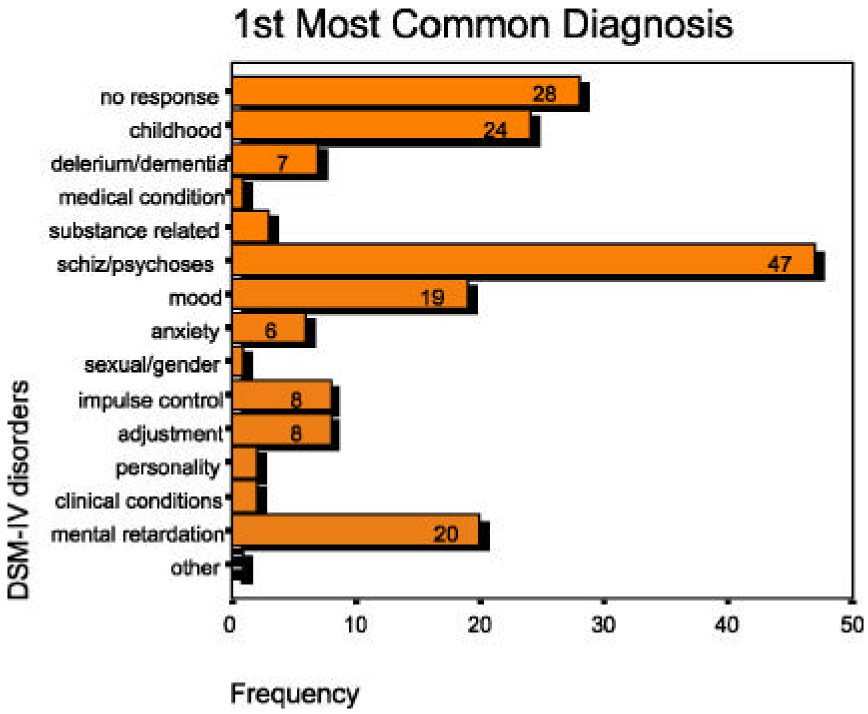
5.6.1 Most Common Diagnosis

The ***most common*** diagnoses were schizophrenia and other psychotic disorders. Figure 5 shows that 27% of respondents made this choice (n=47). In the general population, schizophrenia has a point prevalence of approximately 0.4% (Meltzer et al, 1995). The literature suggests that the prevalence of schizophrenia in adults with an intellectual disability is approximately 3% with lower limits of 1.3% through to upper limits of 3.7% (Deb, 2001).

The 11% of respondents (n=20) who indicated that "mental retardation" was the most common diagnosis are also of interest. Fundamentally this means that those adults with an intellectual disability had not received a psychiatric diagnosis because intellectual disability is not a mental disorder, despite inclusion within the DSM-IV and the ICD-10. Standardised classification systems, whether DSM-IV or ICD-10 are not always useful when assessing adults with an intellectual disability (Deb et al, 2001).

Mood disorders were another frequent diagnosis with 10% of respondents making that their first choice (n=19). The point prevalence of depressive disorder within the general population is around 2% (Meltzer et al, 1995), with a lifetime prevalence of between 6-17%. By comparison, depressive disorder in adults with an intellectual disability ranges between 1.3% and 3.7% (Deb et al, 2001a). People with an intellectual disability can be diagnosed with hypomania and mania although mixed affective states appear to be a more common presentation of bipolar disorder (Berney & Jones, 1988).

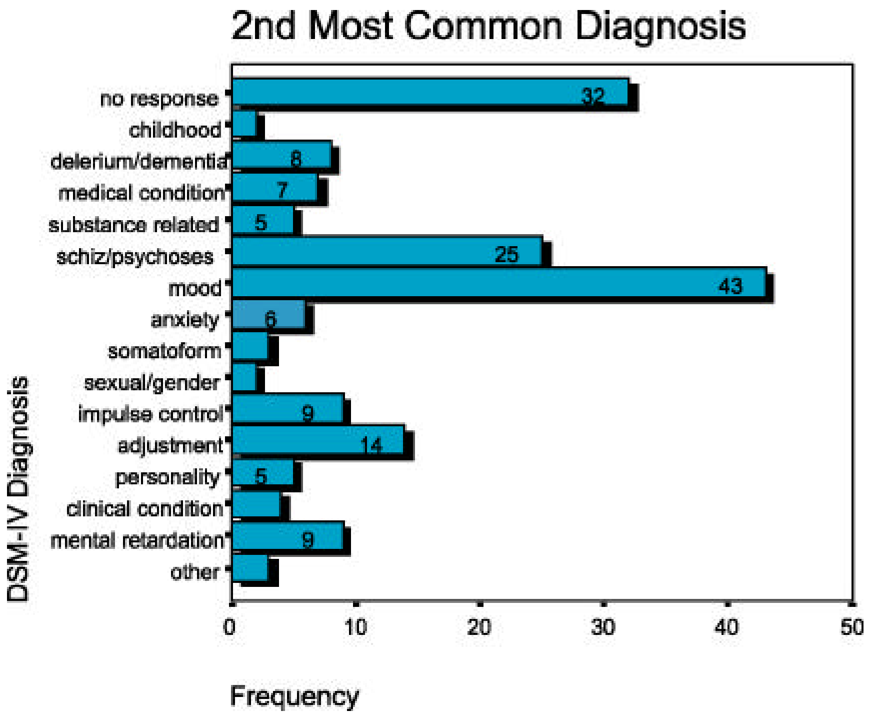
Figure 5



5.6.2 Second Most Common Diagnosis

Mood disorders emerged as the ***second most common diagnosis*** given to adults with an intellectual disability by the survey respondents. Figure 6 shows that twenty-four% of respondents made this choice (n=43). However, schizophrenia and other psychotic disorders was another frequent choice (14% or n= 25). 14 (8%) respondents suggested that adjustment disorders were the second most common diagnosis. Prevalence of this disorder in adults with an intellectual disability it not known (Deb et al, 2001).

Figure 6

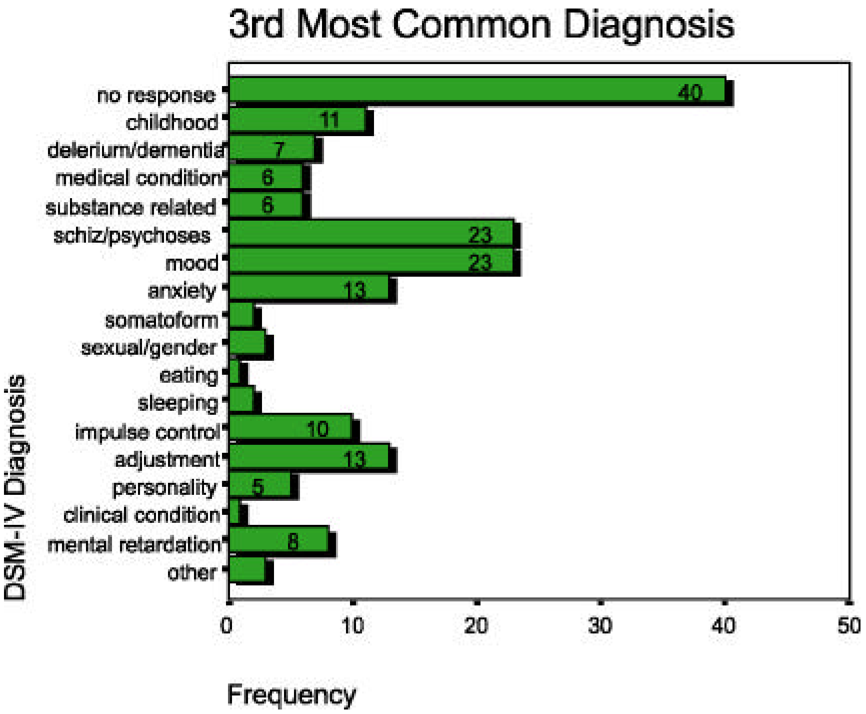


5.6.3 Third Most Common Diagnosis

The ***third most common diagnosis*** was shared by schizophrenia and other psychotic disorders *and* mood disorders. Figure 7 shows that 13% of respondents (n=23) chose the former and an additional 13% (n=23) chose the latter.

Anxiety disorders also featured frequently with 7% of respondents making this choice (n=13). There is minimal literature on the prevalence of neurotic and stress-related disorders in this population. However, adults with an intellectual disability experience increased exposure to stress and a range of risk factors associated with psychiatric morbidity, including biological, psychological and social factors (Deb et al, 2001).

Figure 7



Results should be considered with some caution as Figures 5,6 and 7 demonstrate that a large number of respondents made "no responses" when asked to prioritise the three most common diagnoses. For example, 16% (n=28) of the sample did not respond when questioned about most common diagnosis. Similarly, 18% (n=32) for the 2nd most common diagnosis and 23% (n=40) for the 3rd most common diagnosis.

The number of no responses could possibly reflect difficulties associated with the assessment and diagnosis of mental health problems in adults with an intellectual disability. It would be reasonable to expect that use of the DSM-IV for this population challenges clinicians. Alternatively, some patients with an intellectual disability being treated by some Psychiatrists simply may not have a diagnosis. It is beyond this survey to respond to these issues.

5.7 Training in Dual Diagnosis

Respondents were asked if they had attended dual diagnosis training within the last 12 months. The majority had received ***no*** training in dual diagnosis within this period (88%). Only 15 responded, "yes" to having attended dual diagnosis training. There were 6 "no" responses. However, 103 respondents did indicate interest in attending training in dual diagnosis (58%).

The survey also asked respondents if they had an ongoing interest in dual diagnosis and would they like to be contacted in regard to future activities. 55 (30%) provided their name and contact details. This interest in the mental health of adults with an intellectual disability was an encouraging finding within itself, given the virtual invisibility of this population within the current mental health and disability services systems.

Queensland Psychiatrists and Psychiatric Registrars are likely to have few formal opportunities or other methods of access to knowledge and information about the mental health needs of adults with an intellectual disability. Traditional methods for ongoing education including conferences, special interest groups or even “Grand Rounds” do not routinely address dual diagnosis within the Queensland setting and there are only rare opportunities across Australia. Whilst lack of awareness or even lack of interest is likely to be a key factor, the need exists to establish formal training mechanisms and links that both alert and upskill Psychiatrists in the mental health needs of adults with an intellectual disability.

5.8 Statements of Opinion

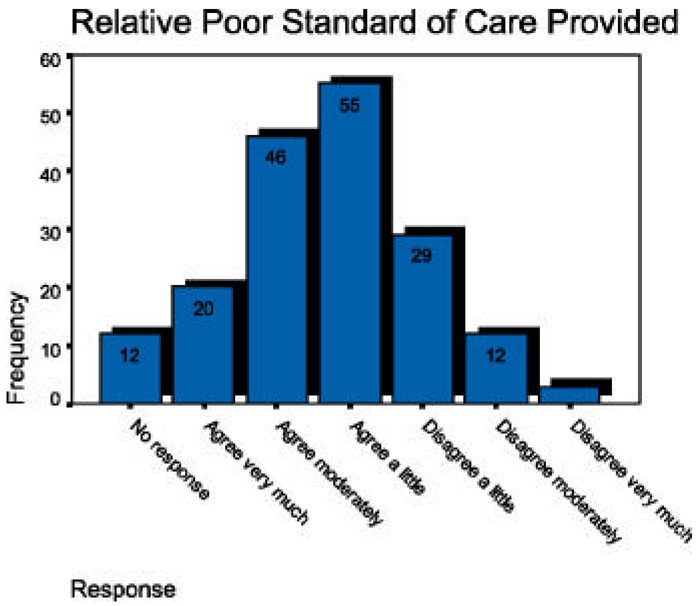
Statements of opinion regarding the psychiatric treatment and management of adults with an intellectual disability were presented in the questionnaire. Responses were recorded on a six point Likert scale that ranged from “very much agree” through to “very much disagree”.

5.8.1 *The survey asked: “Adults with dual diagnosis received a relatively poor standard of psychiatric care?*

Recognition of the mental health needs of adults with an intellectual disability is critical to the issue of quality of life. However, when respondents were questioned about quality of psychiatric care, the majority confirmed that the group received poor standards of psychiatric services.

Figure 8 shows that 68% (n=121) responded affirmatively to the survey question and only 23% disagreed (n=41). This response means that the majority of Psychiatrists believe that adults with an intellectual disability receive a poor standard of mental health care. Given that adults with an intellectual disability experience an increased prevalence of mental health problems when compared with the general population, this result is of major concern and calls for a concerted response by Government and service providers.

Figure 8

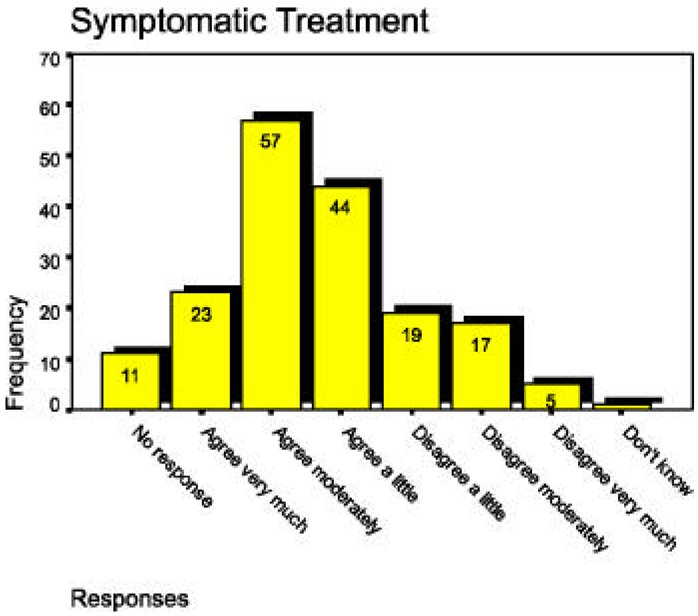


5.8.2 *The survey asked: "Psychiatric treatment of these adults is usually symptomatic, rather than based on diagnostic classification"*

Signs and symptoms of mental health problems vary considerably in adults with an intellectual disability for a variety of reasons that relate to the heterogeneity of this population. Communication abilities, as well as hearing, vision, memory and concentration skills impact the assessment process (Deb et al, 2001).

Figure 9 infers that majority of respondents believed that assessment and diagnosis of adults with an intellectual disability was based upon symptom management rather than diagnoses. 70% agreed with this statement (n=1twenty-four) with only 23% (n=41) disagreeing. This result may suggest that Psychiatrists need to develop skills and expertise in the assessment of adults with an intellectual disability

Figure 9

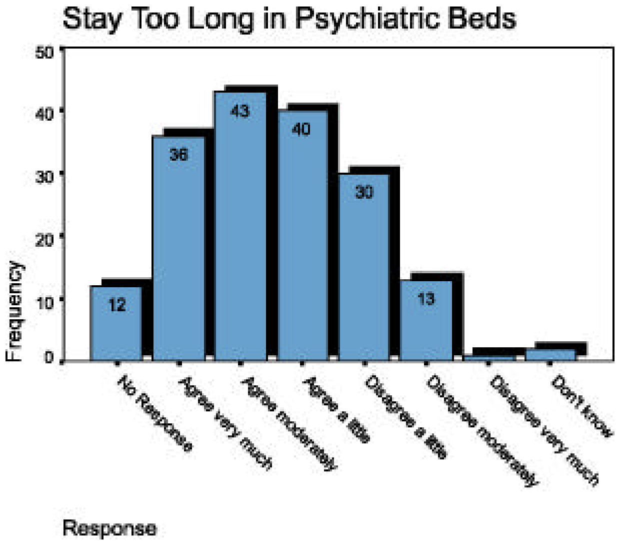


5.8.3 *The survey asked: "Adults with dual diagnosis commonly stay too long in psychiatric beds"*

Figure 10 shows that 67% of respondents believed that adults with dual diagnosis spent too much time in psychiatric beds (n=119). A minority of 25%, disagreed (n=44).

Anecdotal experience suggests that beliefs reflected within this finding are a major barrier to adults with an intellectual disability appropriately accessing the mental health system. For example, those with admission rights are often concerned that when an adult with an intellectual disability enters an inpatient facility, they become homeless and therefore chances of a timely discharge is unlikely.

Figure 10

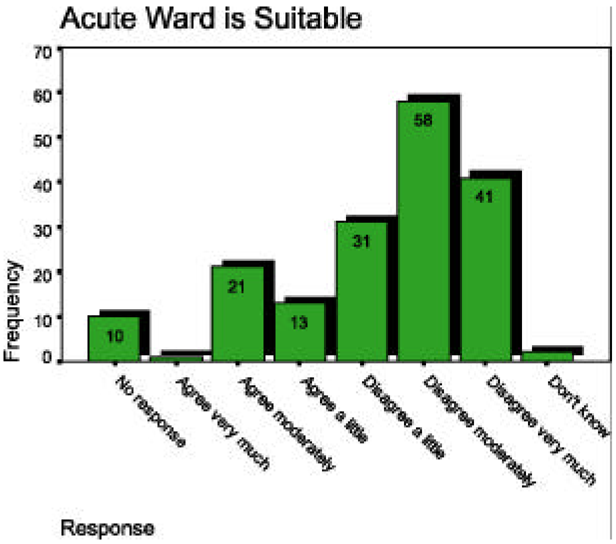


5.8.4 *The survey asked: "The acute admission ward is adequately suited to the needs of adults with dual diagnosis".*

The majority of respondents did not support the treatment of adults with an intellectual disability within the acute ward setting.

Figure 11 indicates that approximately 20% (n=35) believed that the acute admission ward was suitable whereas approximately 73% (n=130) of respondents did not. This finding may suggest that an alternative mental health setting is required when treating adults with an intellectual disability who have acute needs.

Figure 11

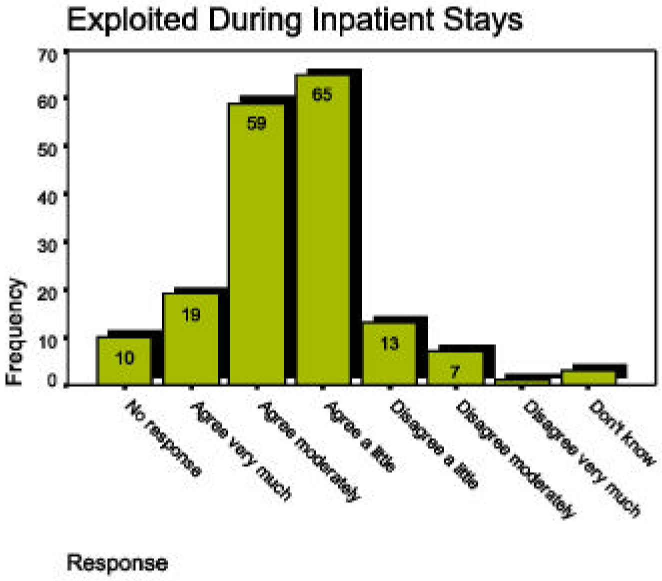


5.8.5 *The survey asked: "Adults with dual diagnosis are exploited by other patients during inpatient admission"*

Just over 80% of respondents agreed that exploitation occurred (n=143) during inpatient admission. Figure 12 shows there was minimal disagreement with this proposition (12% or n=21).

This response provides a possible reason as to why respondents believe that adults with an intellectual disability receive a poor standard of psychiatric care. Further, results shown in Figures 9, 10 and 11 suggest that respondents believe that inpatient mental health services have poor utility for adults with an intellectual disability.

Figure 12

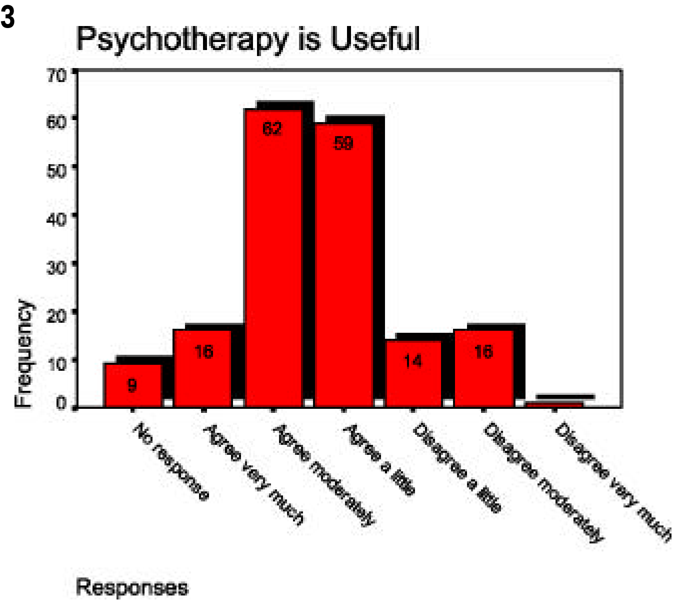


5.8.6 *The survey asked: "Individual supportive psychotherapy is a useful treatment".*

Psychiatric treatment ideally considers a range of therapeutic options including medication and non-medication approaches. Whilst the value of psychotherapy to adults with an intellectual disability is currently undergoing renewed interest within the UK, there is minimal interest here in Australia.

It is interesting to note that few respondents disagreed that psychotherapy could be of benefit to adults with an intellectual disability. Although only 9% of respondents strongly agreed (n=16), Figure 13 shows that 77% of respondents agreed with this statement (n=137). Only one respondent strongly disagreed about the value of psychotherapy in this population.

Figure 13

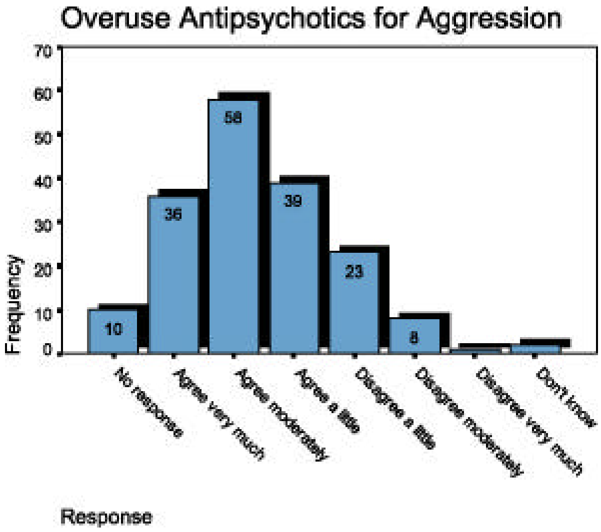


5.8.7 ***The survey asked:"Antipsychotic drugs are overused in the control of aggressive behaviour".***

The use of psychotropic medication to manage the behaviour of adults with an intellectual disability, particularly challenging behaviour, is a controversial issue that has been explored in Chapter 2 of this Report. Antipsychotic medication is an effective and valuable treatment within psychiatry. Rational psychopharmacology, however, is premised upon assumption that medication choice is linked to diagnosis. Aggressive behaviour is not a psychiatric diagnosis although challenging behaviour may be a sign or symptom of mental illness in adults with an intellectual disability.

Figure 14 shows that the majority of responses (75% or n=133) concur with the statement that antipsychotics are overused in the control of aggressive behaviour. Only 18% (n=32) disagreed. This finding may suggest that the prescription of psychotropic medication is ***not*** linked to psychiatric diagnosis when the patient has an intellectual disability.

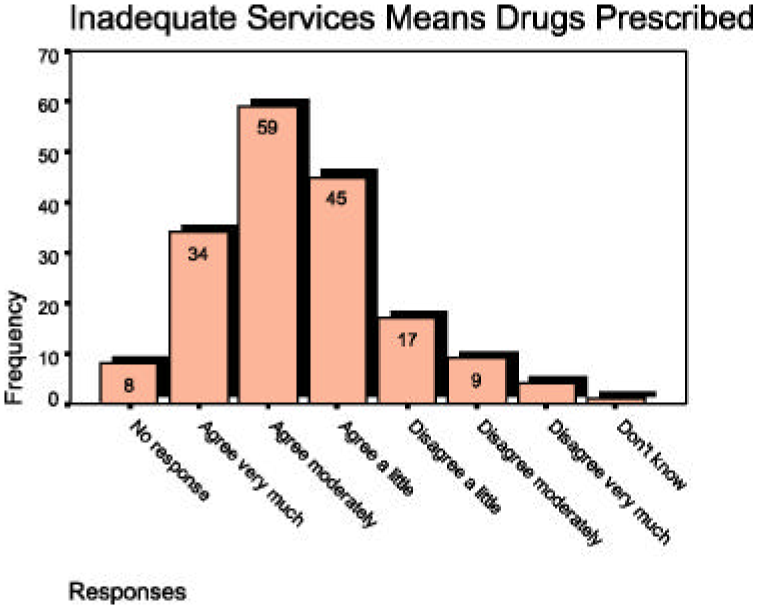
Figure 14



5.8.8 *The survey asked: "Inadequacy of community support services often make the prescription of antipsychotic drugs necessary".*

Figure 15 shows general support for the statement that psychotropics are prescribed to adults with an intellectual disability because inadequate community services are available to support this group. 138 respondents agree that antipsychotics were overused (78%), with 34 of that group, indicating that they strongly agreed. The minority (n=30) or 17% disagreed. This result reinforces concerns already raised in the survey (see Figure 14) regarding appropriate prescription of antipsychotics to adults with an intellectual disability.

Figure 15



5.8.9 *The survey asked: "It is easy to refer to and liaise with Disability Services Queensland (DSQ)".*

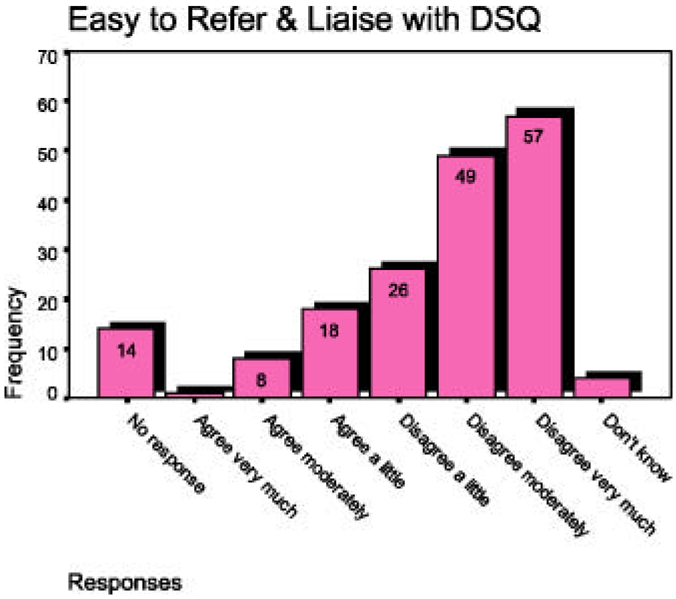
People with a dual diagnosis require a coordinated array of mental health, primary health and disability services. This need can be best met through the collaborative efforts of a range of government and non-government agencies. Unfortunately services that are currently available in most western nations (including Australia) are characterised by complexity, duplication, fragmentation, lack of coordination, polarisation and competition for resources (Baker & Intagliata, 1992).

The survey was interested in identifying the attitudes and views of Psychiatrists towards disability services. Figure 16 shows that 75% (n=132) of respondents did not believe it was easy to refer and liaise with Disability Services Queensland (DSQ). In fact, 32% (n=57) had significant levels of concern. Only 15% of respondents agreed with the survey question, eg that it was easy to refer and liaise with DSQ (n=27).

These responses have significant implications for those people with a dual diagnosis and also ramifications for disability service delivery. For example, Psychiatrists have already stated in the survey that adults with an intellectual disability receive poor standards of psychiatric care and that inadequate services results in over prescription of antipsychotics. Disability Services

Queensland is a major gateway to community services with more than 6,000 adults with an intellectual disability registered as consumers. If Psychiatrists are experiencing difficulty interacting with Disability Services Queensland, the needs of adults with a dual diagnosis are by default, seriously compromised.

Figure 16

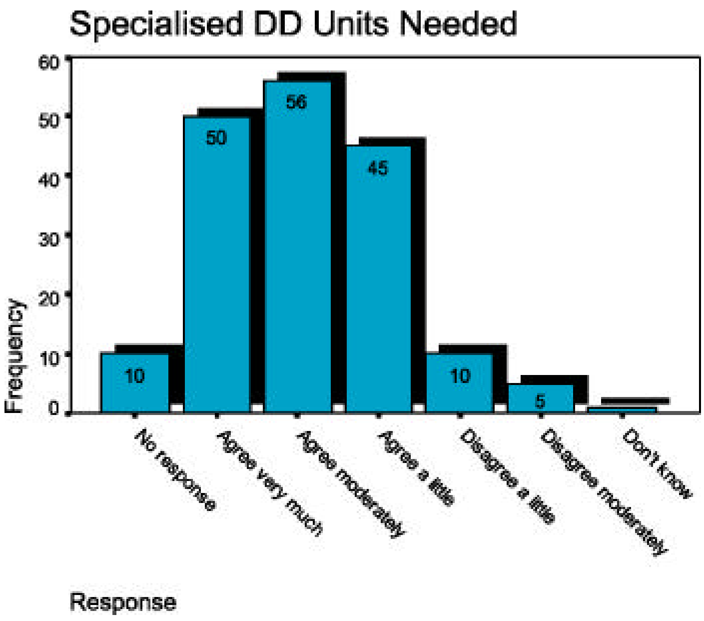


5.8.10 ***The survey asked: "Specialised psychiatric units for adults with dual diagnosis would provide a higher standard of care"***

The majority of respondents have already suggested that the needs of adults with an intellectual disability are not met within the acute admission ward (Figure 11) and that exploitation by other patients occurs during inpatient admission (Figure 12). It is therefore consistent with these beliefs that 151 respondents believe there is value in having specialised psychiatric units for adults with an intellectual disability (85%).

Only 9% of the respondents did not support the development of a specialist psychiatric unit (n=15). Figure 17 demonstrates the strong support for the development of this kind of service for adults with a dual diagnosis.

Figure 17

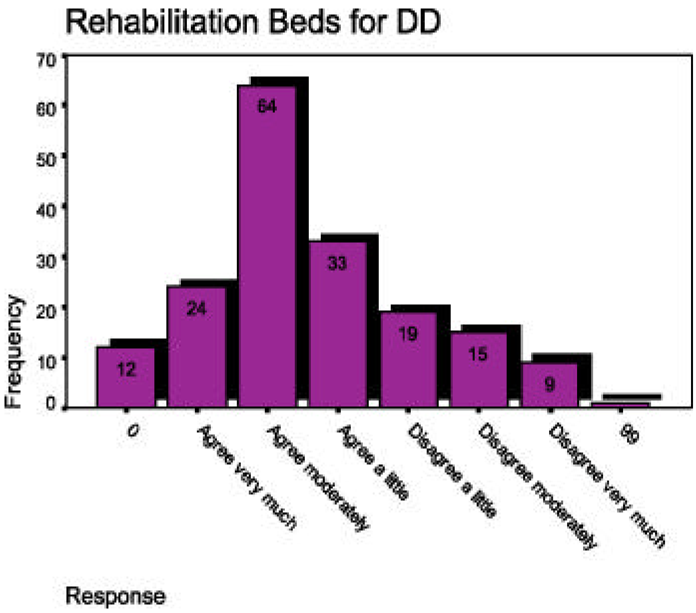


5.8.11 The survey asked: "Rehabilitation beds in psychiatric hospitals should be available for their management".

Contemporary deinstitutionalisation policies have dominated rehabilitation in recent years (McCulloch et al, 2000). Research suggests that psychiatric rehabilitation programs have a positive impact upon the lives of people with mental illness (Corrigan & McCracken, 1995). Potential benefits include symptom management, enhanced interpersonal skills and maintenance of independence. However, the utilisation of rehabilitation strategies can be compromised by insufficient training that results in deficits in clinical knowledge (Corrigan & McCracken, 1995).

Figure 18 shows that more than half of the respondents (n=124 or 70%) supported the use of rehabilitation beds within psychiatric hospitals for the treatment of adults with an intellectual disability. Only 19% (n=33) did not support the availability of rehabilitation beds for this population. These responses reflect the philosophically correct approach regarding equality of access to mental health care, eg adults with a dual diagnosis should be able to exercise identical rights of access to mental health services, as do the general population.

Figure 18



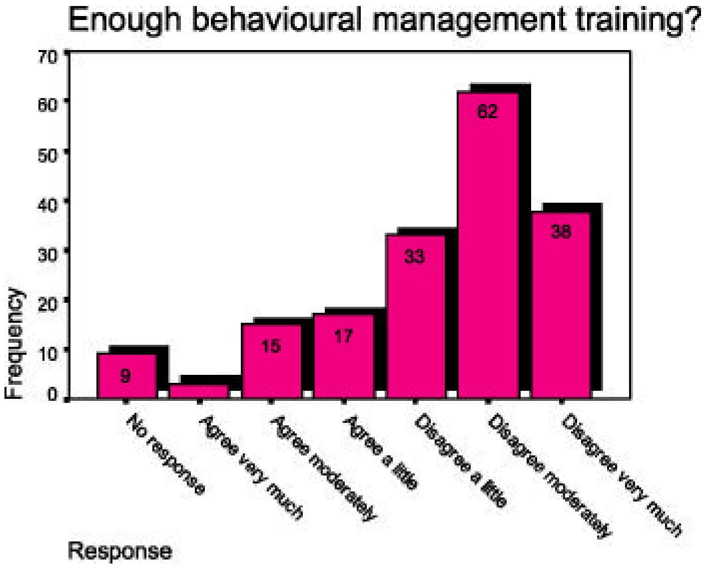
5.8.12 ***The survey asked: "Psychiatrists receive sufficient training in behavioural management of adults with dual diagnosis"***

Challenging behaviour is the major reason why adults with an intellectual disability are referred to Psychiatrists in the United Kingdom. The most likely determinant of help seeking behaviour is when adults with an intellectual disability display violent or aggressive behaviour that is directed towards others or goes beyond community tolerance (Borthwick-Duffy & Eyman, 1990).

There was broad agreement amongst respondents that they require training in the management of behaviour problems displayed by adults with an intellectual disability. This response is consistent with the profile of respondents already detailed, eg the majority of Psychiatrists (n=156) had received ***no*** training in dual diagnosis within the last 12 months (88%).

Figure 19 shows that 35 respondents believed there was enough training for Psychiatrists in behavioural management of adults with dual diagnosis (20%). However, approximately half of those, only minimally agreed. 75% (n=133) thought training in behavioural management was inadequate.

Figure 19

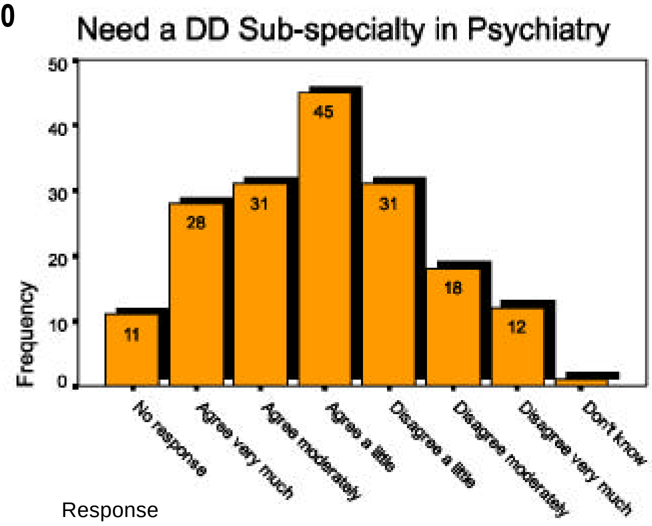


5.8.13 ***The survey asked: "The survey asked "A sub-specialty of psychiatry should be responsible for the treatment of adults with an intellectual disability'.***

Effective clinical outcomes for all patients with mental illness will depend upon the expertise, skills and training of clinicians involved. There is ongoing discussion within the RANZCP regarding the need for the development of a range of subspecialties although dual diagnosis is not mentioned (see Adler & Mathieson, 1999).

Figure 20 demonstrates the range of responses when respondents were questioned about the need for a dual diagnosis subspecialty. Although 59% of the respondents (n=104) were in favour of a training specialty, 45 (25%) only agreed a little. 35% were clearly not supportive (n=61). Given that the Royal College of Psychiatrists (UK) has run a successful sub-specialty in the psychiatry of learning disability since 1975, further discussion and consultation with the RANZCP regarding this issue is warranted.

Figure 20

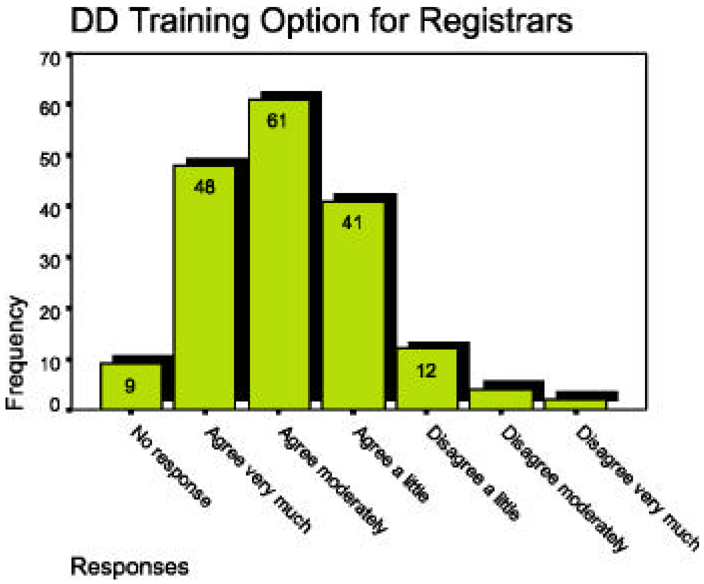


5.8.14 *The survey asked: "The psychiatry of dual diagnosis should be offered as a training option for all Psychiatric Registrars".*

Respondents appear to prefer this approach when compared to the mental health needs of adults with an intellectual disability being developed into a subspecialty of psychiatry.

Figure 21 shows that there was general agreement that training in dual diagnosis should be offered to Registrars. 85% (n=150) concurred with only 18 respondents (10%) disagreeing.

Figure 21



6. Improvement in Mental Health and Disability Services

Human services organisations, including health, mental health and disability agencies, tend to be organised to respond to an arbitrary set of causes (Patterson et al, 1995). Unfortunately the heterogenous nature of "people" means that their needs and requirements fit poorly into rigid categories or service provision. They are therefore left to struggle with their problems that don't fit well with the neatly organised and segregated human service systems (Patterson et al, 1995). This reality often reflects the lived experience of a person with a dual diagnosis. The frustration of carers to the rigid demarcation of organisations and agencies serving people with and without disabilities is discussed in Chapter 5 of this Report.

Psychiatrists were provided with an opportunity to respond to the context of service delivery. They were asked "how could mental health and disability services be improved?" The Psychiatrists and Registrars who responded covered a wide range of issues. Some responses suggest Psychiatrists were angry and frustrated. For example, one respondent said bluntly, "existing services avoid -reject-neglect". Another suggested "employ psychologists who know how to, and are willing to perform a behavioural analysis". Generally responses were positive and many provided constructive suggestions regarding realistic improvements in service delivery.

The diversity of responses clearly suggest that education and training alone will not be sufficient to improve the mental health of adults with an intellectual disability. Psychiatrists do not operate alone or within a vacuum. Quality mental health care for adults with an intellectual disability depends upon their expertise, in conjunction with other professionals, carers and a range of community based services.

Open-ended responses have not been prioritised by the Project Team but have been themed into the following eight categories. There is some overlap between these categories because of the inter-related nature of the issues addressed. A selection of responses, directly quoted from respondents, have been provided below:

6.1 Awareness

Psychiatrists and Psychiatric Registrars suggested that awareness of the mental health needs of adults with an intellectual disability was lacking within not only mental health services, but also disability services and other human services sectors. Respondents also indicated that clinicians and professionals with expertise or an interest in the area were isolated and unable to make contact with one another. There were also comments about the negative attitudes and views of society towards people with disabilities.

> “we should know each other”
> “reducing stigma in mainstream hospitals”
> “intellectual disability is a variation of normal and is not health endangering”
> “a compassion injection for people”
> “political will and courage”
> “not pondering to the lies and denial of the do-gooders and social influences”
> “education advocates for intellectual disability services….I have encountered strong objections from the advocates to their clients being referred to Psychiatrists”
> “awareness of the different needs of patients with a dual diagnosis”

6.2 Liaison and Collaboration

Many respondents acknowledged the policy directives that required agencies and clinicians to work collaboratively together. However, it was noted that when the patient had an intellectual disability, there was often a flight rather than fight response. Adults with an intellectual disability did fall through the gaps and it was the view of Psychiatrists that teams of professionals need to work together to meet the complex needs of this group of people.

> “ a greater willingness of each sector to work together”
> “dual case management for difficult cases”
> “a team approach is required”
> “minimising the gap between services”
> “adequate liaison between mental health and intellectually handicapped services”
> “clearer lines of liaison”
> “constructive liaison”
> “joint case management”

6.3 Specialised Services

The complexity of assessing and treating adults with an intellectual disability was acknowledged. The need for specialist dual diagnosis services was a repeated request.

> "create a new combined service delivery model"
> "special medical services to reduce the trauma of investigations"
> "better infrastructure for their care"
> "needs cannot be met by mainstream services because expertise is required"
> "adults with dual diagnosis deserve equal treatment to those adults with just psychiatric disorders….they deserve a specialist service….with the capacity to carry out the care plan"
> "specialised care coordination"
> "specific service….with a range of …therapeutic options would assist those patients that cannot be assisted by mainstream services"

6.4 Resources

There was much discussion about the need for community based services but there was very little available in reality. Psychiatrists appeared frustrated by lack of options when attempting to connect a patient with an intellectual disability with services available within their local community.

> "real as opposed to hypothetical supports"
> "I believe that Disability Services has been seriously under-resourced for years"
> "need funds and services in the first place"
> "twenty-four hour care about the state"
> "adequate resources to ensure appropriate settings and time for communication"
> "more resources, increase in services, eg increased support as alternative to inpatient admission"

6.5.1 Disability Services

Respondents were very concerned and often negative, about the capacity of Disability Services Queensland to respond to referrals for assistance. Many had the view that DSQ was under-resourced and unable to provide a suitable response when a patient with an intellectual disability was referred to them by a Psychiatrist.

> "they view psychiatric admission as placement"
> "it is currently a waste of time to haul a relationship with disability services as they opt out of any responsibility"
> "seem to lack internal medical information or Psychiatrist input"
> (need) "less stringent criteria from disability services regarding their involvement"
> "better resourced services provided by disability services"
> "acknowledge the medical model and psychiatric aspects"
> "improved non-hospital alternatives for crisis care"

6.6 Mental Health Services

Psychiatrists and Registrars admitted that mental health services staff required increased knowledge and expertise in the mental health of adults with an intellectual disability. Specialised service responses were requested.

> “specialised units for treatment”
> “dedicated beds”
> “formation of specialised dual diagnosis teams that can provide the extra effort and expertise required”
> “dedicated liaison, increased knowledge and access to support services for dual diagnosis patients amongst mental health staff”
> “place it firmly in the HEALTH Department because it is a health issue”
> “there are the rare doctors who take an interest, they should be encouraged and identified”
> “training of staff in psychiatric units”

6.7 Education

There was general consensus that education and training of Psychiatrists in dual diagnosis was required. Many respondents argued that dual diagnosis education and training needed to involve a range of professionals, including those from mental health and disability services.

> “more education of Psychiatrists”
> “specialty terms” (for Psychiatrists)
> “patients could be better managed in the community if more trained case managers were available”
> “training of disability workers and mental health staff – about dual diagnosis but also about each other”
> “improved education and training – better training for nursing staff and medical staff and allied health professionals”
> “shared education and resources (DSQ and Mental Health)
> “more training in the RANZCP course”
> “units of specialised expertise”

6.8 Carers

Some respondents were concerned about the role of carers, particularly ageing family members. In addition to improved support and respite, Psychiatrists suggested that this group would also benefit from dual diagnosis education and training.

> “real respite services for ageing parents of these patients”
> “more support and education for carers”
> “take the burden off family members”

7. Dual Diagnosis Training and Education Needs Analysis

The survey concluded with open-ended questions designed to elicit comments from Psychiatrists and Registrars regarding training and education needs, including preferred presentation mode and venue. Full responses were considered in detail and then themed into the following five categories. The order that the categories are provided in reflect the frequency of the response, eg training falling within the diagnostics category was the most frequently requested category.

7.1 Diagnostics

Respondents prioritised training and education in the assessment and diagnosis of mental disorders in adults with an intellectual disability. They specifically asked for training that would assist them to recognise depression, psychosis and mood disorders. The management of anxiety and relevance of psychotherapy was raised. Respondents commented on problems with the variation in the presentation of mental disorders in this population. There were requests for interview techniques that were suitable for people with limited verbal expression or communication problems.

7.2 Behaviour Management and Treatment

Respondents indicated they had skills and techniques that were suitable for the management of problem behaviours, eg aggression or violence. However, approaches suitable for the general population were often unsuited to the complex needs of adults with an intellectual disability. Psychiatrists requested assistance with tailoring known techniques. They also wanted information about or access to additional clinical strategies that reduced challenging behaviour. Respondents also requested knowledge and advice that could be provided to carers, both paid staff and family members.

7.3 Pharmacotherapy/ Psychopharmacology

Respondents were interested in accessing rational prescribing guidelines or best practice recommendations that specifically addressed the needs of adults with an intellectual disability. Respondents requested indications for psychotropic use when managing and treating challenging behaviour.

7.4 Information in “General”

Respondents requested information and advice regarding service options for adults with an intellectual disability. Psychiatrists clearly wanted to know not only ***what*** existed, but also ***how*** to access these options. Other responses suggested that they needed to understand how to collaborate with existing service delivery systems as many suggested they were unable to access needed services. Respondents said that they needed to interact more with disability and other services but lacked opportunities to do so.

Related to the need for "information" was the acknowledged need that clinical practice with adults with an intellectual disability should be evidence based. Respondents requested advice on where to go for contemporary and best practice management and treatment when working with adults with an intellectual disability. Many advised they were interested in knowing about current innovations in the intellectual disability field. Others asked for opportunities to interact with other experts.

7.5 Other Training Needs

A small number of respondents also identified the followed topics for future education and training:

- childhood and adolescents with dual diagnosis - behaviour management - psychopharmacology
- substance abuse – alcohol and drug abuse
- ageing of adults with an intellectual disability – dementia – identification and treatment of other mental disorders
- comorbidity – management of epilepsy and mental disorder

7.6 Training Medium Preferences

Respondents were questioned about preferences for dual diagnosis training and education opportunities. They were encouraged to nominate more than one choice. Preferences for dual diagnosis education and training mediums, in order of priority included:

Seminars (< 1 day):	86 responses
RANZCP meeting presentation:	68 responses
Workshops (> 1 day):	53 responses
Video:	50 responses
Lecture series:	46 responses
Computer based learning:	39 responses
Manuals/policy documentation:	29 responses
Audio tape:	25 responses

Responses to prompts about dual diagnosis training and education options suggest that the preference exists for didactic, expert presentations. This preference may reflect the need for contact with experts in the area of dual diagnosis or desire for evidence based approach. The tendency to choose multiple options for training and education may also suggest that Psychiatrists prefer a multi-faceted approach.

The range of preferences chosen suggest that educational and training strategies may need to adopt a blended approach, eg where a number of options are melted into one training event or perhaps a series of events. However, it should be noted that only one respondent chose the following options: Workshop (1/2 day), Conference and RACGP program.

7.7 Training Presenters

Respondents were asked to indicate preferences for “who” should deliver the dual diagnosis education and training. More than one response was encouraged. Responses, in order of priority included:

• Mental health and disability professionals	112 responses
• Developmental Disability Unit	45 responses
• RANZCP	43 responses
• University of Queensland Department of Psychiatry	43 responses

Only a small number of respondents failed to provide a preference (n=18) and most respondents chose more than one preference. It is interesting to note that multiprofessional and multiagency dual diagnosis education and training was the preferred choice. This response is consistent with previous responses of respondents reported within this Chapter where Psychiatrists indicated that they needed opportunities to liaise and interact with both mental health and disability professionals. It is also encouraging that Psychiatrists appear to acknowledge that the treatment and management of adults with a dual diagnosis necessitates shared clinical and professional expertise, eg there are valuable contributions to be made by the mental health ***and*** the disability sectors.

7.8 Training Needs

Respondents were asked to nominate, “those with the greatest need for dual diagnosis education and training”. Multiple choices were encouraged and responses have been prioritised:

• Direct care staff/nurses	127 responses
• Professionals	102 responses
• Consumers/families	78 responses
• Managers of services	77 responses

Other responses included “all of the above” (n=5); general practitioners/physicians (n=4); politicians (n=4); Disability Services Queensland (n=2); education staff (n=1); and “those involved with care” (n=1). Only 5 respondents did not respond.

Responses suggest that Psychiatrists consider the treatment and management of adults with a dual diagnosis as requiring a collaborative approach. Respondents prioritised the needs of direct care staff/nurses and professionals. However, they also highlighted the needs of consumers and family members, as well as managers or administrators of services. A responsive education strategy must have a wide-ranging focus.

8. Discussion and Concluding Comments

Survey trends show that approximately three quarters of respondents consistently express concerns about the psychiatric management and treatment of adults with an intellectual disability.

Most Psychiatrists and Registrars who participated in the survey ***were*** treating and managing adults with an intellectual disability despite anecdotal suggestions from disability and other community workers, that they cannot engage the services of these specialists.

Numbers of adults with an intellectual disability who were recently seen by Psychiatrists were small, but the majority of respondents had seen adults with an intellectual disability within the past six months. The impact of continued deinstitutionalisation and problems associated with the management of challenging behaviours within the wider community may increase referrals of adults with an intellectual disability to Psychiatrists and mental health services. Referrals are more likely to increase, rather than decrease, in the future.

The majority of Psychiatrists and Registrars believe that existing mental health services have limited utility for adults with an intellectual disability. Most respondents suggested that adults with an intellectual disability received a poor standard of psychiatric care, that they failed to benefit from acute admission, and they were exploited during inpatient stays. Again, there is majority agreement that specialist services should exist for this group.

Most Psychiatrists and Registrars advised that their approach to management of adults with an intellectual disability was based upon consideration of symptoms, as opposed treatment being based upon diagnoses. There is a large number of respondents who admitted that they overused antipsychotics when managing aggression. Further, the majority of respondents believed that the inadequacy of community services influences the over prescription of antipsychotics to this group of people.

There was general consensus amongst survey respondents admit that they lacked appropriate knowledge and expertise in treating and managing this vulnerable population. They agreed that Psychiatrists required training in behavioural management of adults with an intellectual disability. Most of the respondents were interested in redressing lack of skills. Although some saw value in the development of a psychiatric subspecialty, there was wider agreement that dual diagnosis training options should be made available to Psychiatric Registrars.

Major training and education needs related to the assessment and diagnosis of mental health problems in adults with an intellectual disability. Many respondents appeared eager to access general information about dual diagnosis but more specifically, they requested assistance with behavioural management and best practice guidelines that guided psychopharmacological treatment. The survey results prioritised the need for evidence-based knowledge about dual diagnosis.

In addition to knowledge gaps, the survey findings revealed that Psychiatrists required a range of learning formats. Expert presentations were requested and seminars (one day or less) were preferred. Time constraints mean that “blended” training opportunities that addressed a number of skill deficits in one educational event should be sought. Respondents request multiprofessional presenters for training events. This response may reflect the fact that Psychiatrists are increasingly working as members of multidisciplinary teams that involve a range of professionals. Alternatively, the complexity of managing and treating adults with an intellectual disability may infer value in the involvement of a range of professionals.

Changing Psychiatrists’ attitudes, opinions and beliefs about adults with an intellectual disability may not significantly alter how psychiatry treats this group. Training and education alone will also be an insufficient stimulant for change. The Dual Diagnosis Project reveals that there are many barriers to effective mental health care for adults with an intellectual disability. Regardless, adults with a dual diagnosis will benefit from Psychiatrists who are well-trained and sensitive to the mental health vulnerabilities of this population. Other important collaboration partners in any education and training strategy for Psychiatrists should also include key stakeholders from the disability and mental health sectors. The needs of general practitioners, who also play an important role in the assessment, treatment and management of adults with an intellectual disability was not addressed by this survey. Further research, with Psychiatrists and general practitioners should remain on the agenda if quality mental health of adults with an intellectual disability is pursued.

The survey revealed that Queensland has a number of Psychiatrists who are already interested in the mental health of adults with an intellectual disability. The level of interest was indicated by the fifty-five Psychiatrists (30%) who provided identifying information and indicated an ongoing special interest in dual diagnosis. Further contact with this group should be made so that their interest can be nurtured and sustained. The needs of those Psychiatrists and Registrars who did not participate in the survey needs to also be factored into future dual diagnosis educational and training opportunities. Ongoing collaboration with the RANZCP should be pursued.

Chapter 5

Key Informant Interviews & Consultations

Chapter 5 Key Informant Interviews & Consultations

1. Introduction

This Chapter summaries views about the needs of adults with dual diagnosis that emerged within interviews and consultations that involved two groups:

- paid and unpaid carers, including some family members; and
- senior managers, bureaucrats from a range of Queensland government and non-government agencies.

Training and education needs of service providers, carers and consumers were also canvassed during the interviews and consultations. Responses have been themed and are summarized in this Chapter.

Participants in the interviews and consultations had not been surveyed by the Project Team in the process detailed in Chapter 2 of this Report. The Project Team deemed it important to make contact with these key informants because their views might differ from those who had already participated in the Project. It is encouraging that views were consistent. Despite considerable effort to engage consumers, there were no participants. It is hoped that their views have been captured during the Project.

2. Rationale and Limitations

The key informant technique was chosen because of its relative simplicity and inexpensive character. The technique aimed to connect the Project Team on a face-to-face basis with individuals drawn from selected community based agencies and organizations who had not had the opportunity to participate in other data gathering activities associated with the Dual Diagnosis Project.

All participants were asked to comment on contextual issues or constraints impacting service delivery to adults with dual diagnosis, service gaps, and to comment on dual diagnosis education and training needs of staff. A schedule of questions and prompts were developed by the Project Team to ensure there was a consistent framework used for all of the interviews conducted with key informants.

The major limitation to material presented within this Chapter relates to the built in bias towards the individual or organizational perspectives of participants. Despite careful collective analysis, this Chapter may not provide an accurate appraisal of Queensland wide dual diagnosis service issues, gaps and education and training needs. Another limitation relates to the fact that the mental health needs of adults with an intellectual disability are certainly discussed but the direct voice remains silent.

3. Participation

The Dual Diagnosis Project team identified key informants after considering the range of government and non-government agencies through group discussion. Priority for contact was accorded to major service providers to adults with an intellectual disability or adults with mental health problems. Consequently, contact was made with primarily three types of organisations:

- charitable and religious;
- parent/consumer; and
- government.

A total of 32 key informant interviews were undertaken. Some of these consultations took the form of focus groups where a number of individuals would meet with Project Team members. Other consultations were on an individual basis or with two or three individuals from one agency. A full list of key informants who were consulted is included in the Appendices.

Project Team members and the Chief Investigator completed the interviews. The number of consultations was restricted by the availability of participants and also the short timeframe of the project. It is acknowledged that there are likely to be agencies, service providers and individuals who should have been consulted. The Project Team, given increased resources and time, would have liked to have consulted more widely but this was not possible.

4. Results

With the permission of participants, detailed notes were recorded during the interviews and discussions. The contents of the notes were collectively considered by the Project Team. Content was collapsed into themes and then summarised. The themes that featured through the interviews and consultations were not prioritised by the key informants and have not been ordered in any particular way by the Project Team. Responses are summarised below. Comments that appear in italics are presented verbatim from the interviews.

4.1 Skills, inadequacy and anxiety

Participants suggested that all dual diagnosis stakeholders, regardless of whether they were professionals or paid carers, were desperate for simple information, advice, assistance, information and support. The operative word was “desperate” in so far that participants repeatedly stressed how anxiety provoking it was to work with adults with a dual diagnosis. Some suggested they felt like they were operating within an isolated void or vacuum. Many suggested that they or their staff, were unaware of where to go for assistance or expert direction. Others suggested that a minimal skill based existed “out there”.

> *“people do the best they can and don’t know much.”*
> *“there is a lack of knowledge all round.”*
> *“we are not looking for miracles”*
> *“we are just looking for an opportunity for problem solving.”*
> *“prrofessionals largely feel inadequate.”*

4.2 Resources

There was general acknowledgement between participants from the government and non-government sectors that both health and disability service sectors were chronically under funded and under-resourced. Similarly, there was strong consensus in all interviews and consultations that that consumers with an intellectual disability, with or without the complications of mental health problems, had complex needs that challenging service delivery.

Participants commented on the inflexibility of funding packages and funding that was provided to support adults with an intellectual disability to live in the community. A major source of concern was that funding did not include the education and training of carers.

> *"everyone is stretched."*
> *"intense amount of resources going into a few individuals."*
> *"need flexible funding arrangements so that people are not strangled by their money constraints."*
> *"I'm sure I'm not the only service provider who has been left to deal with [these] situations, but the toll it took on staff and resources of the service in general has certainly shaped how we will approach service delivery to this group in the future."*

4.3 Collaboration

Participants commented on the lack of collaboration between health and disability services. Many stressed the need to develop working relationships across and between government and non-government agencies. Lack of cooperation, poor communication and tense relationships between agencies had major negative repercussions upon adults with an intellectual disability who tried to access mental health services. Entry and access was often compromised. Adults with an intellectual disability did not fit the eligibility criteria for mental health services and disability services felt unable to adequately deal with complex behaviours that they believed related to mental health problems.

> *"need workable relationships."*
> *"look at the person as a human being not squashed into society's systems."*
> *"building and maintaining good relationships."*
> "people are not getting a service of any kind, barely finding housing and food, let alone support of any kind."

4.4 Stereotypes, fear and demonisation

Participants in consultations and interviews described the experiences of a range of clinicians and professionals who were asked to work with adults with an intellectual disability. Some participants suggested that many professionals seemed to be out of their depth eg unsure of how to respond to someone with an intellectual disability. Others agreed and suggested that some were "out of their comfort zone".

Many stakeholders (professionals, carers and service providers) appear to carry negative and erroneous stereotypes about people with an intellectual disability and people with mental disorders. Belief systems had powerful impact upon services that were provided or refused to adults with a dual diagnosis. These beliefs are commonly transformed into fears that are also held by the public. Fears increase when faced with physical or mental health comorbidity ie dual diagnosis.

Some participants suggested that there is a difference between what professionals or clinicians knew was politically correct and what they did in reality. Some professionals were unaware of the politically correct philosophy of working with people with disability (normalisation, social role valorisation, the developmental model, the least restrictive alternative, dignity of risk, choice etc).

> *"too scary for everyone."*
> *"powerful values attitudes are in action here."*
> *"an adolescent in a non-urban centre was demonised in local media as a "monster".*

4.5 Evidence

Participants suggested that interventions or treatment provided to adults with an intellectual disability was frequently driven by good intentions and a desire to help, rather than evidence based medicine. Consultations suggested that the mental health of many adults with an intellectual disability was compromised by lack of awareness and ignorance. Some clinicians and professionals were unaware of research-based evidence about dual diagnosis or lacked awareness of how they could expediently access such.

Of serious concern was the suggestion by many participants that there exists a persistent and erroneous belief system shared by many (clinicians, professionals, carers and consumers) that adults with an intellectual disability *do not* develop mental disorders. This belief was a major barrier to service and treatment access.

> *"recognition by all parties that people with intellectual disabilities CAN have mental illness."*
> *"we are flying by the seat of our pants most of the time."*
> *"we need to pass the knowledge on."*
> *"the literature points to high co-morbidity but we don't see it here."*

4.6 Signs and symptoms

Variation in the presentation of the mental disorder in adults with an intellectual disability was of concern. Although signs or symptoms of mental disorder in adults with an intellectual disability were identified by a range of people, participants suggested that many psychiatrists were uninterested in the population. Others suggested that general lack of awareness of psychopathology in adults with an intellectual disability had ramifications for all stakeholders eg whether you were the consumer, parent or paid staff.

The phenomena of diagnostic overshadowing was often described in consultations. For example, many participants were frustrated when clinicians or professionals attributed alleged signs or symptoms of mental disorder as simply being an expression of intellectual disability.

Many participants also described the frustration of managing with challenging behaviours. Some shared guilt over the use of psychotropic medication. Others were angry regarding problems getting an accurate assessment and therefore objective diagnosis that either ruled out or in, dual diagnosis.

> *"dual diagnosis is labeled as behaviour."*
> *"sticky diagnosis."*
> *"no pressure or expectation of accuracy of the diagnosis."*
> *"people are denied being well"*
> *"boundaries are black and white – between intellectual disability, challenging behaviours and dual diagnosis."*
> *"need to know how to record behaviours to convince psychiatrists that dual diagnosis exists."*
> *"ability to have a correct diagnosis, correct treatment and medication."*

4.7 Entry and eligibility

Participants described the frustrations associated with making referrals. Although some problems appeared to relate to language/terminology problems (see language/discourse comments below) significant communication barriers were also evident. Communication problems appeared to develop into what was described as "turf battles" when seeking assistance for adults with, or suspected of, a dual diagnosis.

Services were accused of inflexibility and the maintenance of gate-keeping roles that specifically excluded those in need. Adults with a dual diagnosis, or suspected dual diagnosis did not fit eligibility criteria. The degree of difficulty often required advocacy. Commonly, adults with a dual diagnosis were in no-man's land, fell through the gaps and failed to access required assessment or treatment.

> *"inter-departmental wars have to stop."*
> *"criminal justice is the only way into the mental health system."*
> *"people become "yoyos" between services.*
> *"people are "literally locked out of services" because they have intellectual disability.*
> *"nobody wants them."*
> *"no collaboration or ownership by anyone."*
> *"they should be offering services to whoever walks in the door, not putting them in pigeonholes."*

4.8 Language and discourse

Participants described numerous scenarios where there were different or conflicting concepts used to describe dual diagnosis. Different agencies also appeared to operate from different philosophical stances that did not "fit" when the consumer had a dual diagnosis or intellectual disability.

The language of disability and mental health was considered to share some concepts but in the same way, was also considered to be very different. Disability agencies appeared to have difficulty understanding common terms or concepts used within mental health services and vice versa. For example, mental health services provides "clinical" services but disability services does not (eg provides "services") and yet psychologists were employed within both agencies.

Unknown or unfamiliar terminology appeared to exacerbate existing antagonism between the health and disability sectors, add to confusion about dual diagnosis and reinforce the politics of "difference." This has major negative ramifications on service access for adults with a dual diagnosis that is well documented in "entry and eligibility".

> *"culturally different way of approaching support and even understanding their problems"*
> *"mental health services see disability services as promulgating a "pure" disability model"*
> *"there are different models of disability which affects our language and approach to support"*
> *" disability services operate on subsistence and crisis: food shelter and care. We operate from a clinical model of casework and triage."*

4.9 Treatment

Participants suggested that treatment or interventions were very limited and often based on inaccurate diagnosis. Where stakeholders were dogged about getting the required service, they described the exhausting process of advocacy required. For example, because of the fragmented and ad hoc nature of service delivery, consumers and their carers often had to "face" a multitude of professionals or medical practitioners with the same problem or stories.

> *"they change the diagnosis, and they change practitioner, and change medications which can be dangerous."*
> *"a mother talked about her son and lack of diagnosis even though he has many labels."*
> *"cannot find a psychiatrist who will make a firm diagnosis."*

4.10 Isolation, remoteness and children

Consultations highlighted the concerning plight of children and adolescents who appear to be often locked out of services. The transition from childhood services, dominated by paediatricians through to adult services, appears to range from non-existent to confusing.

Life in rural or remote areas, was also of concern as services were even thinner on the ground than in the metropolitan experiences. Those supporting people living in rural or remote areas described isolation and loneliness, trying to do the best without the right services or support.

> *(about a child living in a remote community, without respite, housing or schooling) "… he is climbing the walls…movement from council to shift them… doesn't solve anything …in ten years time, if he is still alive, he will be a statistic for us. What can be done for him now!"*
> *"seems to be no-one to help parents of children with profound behavioural or mental problems."*
> *"need a DDU for children who will end up there anyway as soon as they turn 18 years old."*
> *"no adequate and safe respite for children so they end up in a motel with staff."*

4.11 Support and expertise

Access to “expertise” in dual diagnosis was clearly desired. The need existed regardless of professional or clinical background eg parents required the support as much as medical practitioners or direct care staff. Some participants suggested that a central unit with whole of state outreach that would provide skills and training was relevant to dual diagnosis.

> *“shadow staff or mentoring”*
> *“crisis response protocols”*
> *“General Practitioners need extra skills.”*
> *“family inclusion.”*
> *“provision of highly trained specialist staff to conduct statewide forums and panels.”*

5. Conclusion

A common thread that emerged through consultations, regardless of whether the participant had a clinical or non-clinical background, was the need for training and education in dual diagnosis. Participants identified a range of training needs, acknowledging that they were not well prepared for the mental health problems experienced by adults with an intellectual disability. Needs shared by participants in the disability sector and participants in the mental health sectors included:

- mental health in intellectual disability awareness training that addressed signs and symptoms of mental disorder;
- general awareness about intellectual disability;
- working with challenging behaviour including safety issues;
- assistance with eligibility disputation including improved collaboration between sectors;
- access to evidence based care and general information about dual diagnosis;
- education between mental health and disability sectors regarding the philosophy of service provision to adults with an intellectual disability.

There existed general feeling amongst participants that the numbers of adults with suspected dual diagnosis was increasing. Some suggested deinstitutionalisation and community care policy would continue this trend. One participant put the situation bluntly, *“the problem is only going to get worse, it won’t go away....we have to work together to do something about it”.*

Participants also appeared to be keen for education and training initiatives that involved interagency cooperation. Joint training was considered to be a particularly valuable and relevant process of engaging the disability and mental health sectors. In particular, some suggested dual diagnosis training and education was a potential solution for interagency communication and eligibility battles. Whilst the majority of participants were supportive of structured and formal education and training strategies eg formal lectures and workshops, others felt there was significant value to be derived from informal get togethers and network meetings to address dual diagnosis if they involved the disability and mental health sectors.

Chapter 6

Discussion & Recommendations

Chapter 6 Discussion and Recommendations

1. Introduction

This Chapter is comprised of two related parts. ***Part One*** of this Chapter provides concluding comments on the Dual Diagnosis Project. Service developments for adults with a dual diagnosis in other Australian states and the international experience, specifically the UK and USA are also briefly considered. Concluding comments are then followed by ***Part Two*** of this Chapter that outlines the Dual Diagnosis Project Team's recommendations. An executive summary and concise list of recommendations contained in this Chapter can be found in the Foreward of this Report.

Part One

2. Global Perspective

Over the last twenty years, services for adults with an intellectual disability in western society have undergone constant transformation. A range of community-based services continues to evolve and emerge within different settings and facilities. Unfortunately life in the community can be compromised by unmet mental health problems. There is growing evidence that mental health problems are more prevalent in this group when compared to the general population, and are a primary reason for failure to adapt to community living (Bouras & Holt, 2001). Mental disorders and mental health problems may severely limit the functional capacity of adults with an intellectual disability, their quality of life generally and more specifically, adaption to the ordinary experiences and stresses of life within the community (Reiss, 1994).

In the same way that adults with an intellectual disability are a diverse group, the history of service development and the nature or characteristics of the services that support and assist this group, varies considerably between countries. Whilst there is significant interest in this population in the USA, Scandanavia and Western Europe, the development of specialist services for adults with a dual diagnosis are more advanced within the UK and The Netherlands (Chaplin & Flynn, 2000).

Most western nations have developed separate service systems to deal with disability and mental health. When assessing the needs of adults with an intellectual disability, the separate services systems have therefore tended to try to artificially separate the disability aspects of presenting problems from their mental health needs. This approach has not been successful, resulting in people becoming lost within systems. The UK is the exception to this rule (Holt et al, 2000). The national approach by the UK may account for the more advanced development of specialist dual diagnosis services and models. Service provision to adults with a dual diagnosis within the UK, the USA and Australia is briefly overviewed below.

2.1 United Kingdom

Service delivery to adults with an intellectual disability within the United Kingdom (UK), is by comparison to Australia, very different but worthy of careful consideration. Health authorities and social services across the UK differ in the ways in which they provide services to meet the needs of adults with a dual diagnosis. The type of service provision available varies between localities in response to the autonomy of each regional authority to design services to meet the needs of their local populations. The fact that these agencies do not always work effectively together as partners in care is an additional hardship. Old-fashioned demarcations persist between professional staff and barriers divide health and social services.

Ongoing reforms to the UK National Health Service have attempted to encourage patient-centred care that focuses upon being responsive to need (The NHS Plan, 1999). Despite major injections of funding and resources, the interface between community support teams that support adults with an intellectual disability and mainstream psychiatric services remains problematic (Bouras & Holt, 2001). Consistency of service provision remains an issue as models of care appear to reflect community profiles and therefore differ considerably across the UK. The following dual diagnosis service delivery models have been identified (Bouras & Holt, 2001):

- separate specialist psychiatric services within institutional/hospital settings;
- community based specialist services integrated with mental health services;
- community specialist psychiatric services integrated with both mental health services and learning disability services;
- separate “challenging” behaviour services as part of a specialist learning disability service (learning disability is a UK term that is interchangeable with intellectual disability).

Perhaps the most outstanding feature of services provided to adults with a dual diagnosis across the UK is the central role of Psychiatrists. A working group of the Royal College of Psychiatrists (1996) summarised the approach succinctly, “enabling people with learning disabilities to use ordinary mental health services is a complex and demanding task requiring input from specialists in the psychiatry of learning disability.” The Project Team consulted with an Australian based but UK trained Psychiatrist, who specialised in learning disability psychiatry. This Consultant Psychiatrist advised the Project Team that there were four key elements operating within the UK that produced and maintained highly trained Psychiatrists with expertise in intellectual disability:

- specialist training curriculum that was monitored by the Royal College of Psychiatry (RCP);
- the active involvement of the RCP in learning disability policy and related agenda;
- Consultant Psychiatrists posts in Learning Disability Psychiatry across the UK; and
- Professorial Chairs in the Psychiatry of Learning Disability.

This Psychiatrist also suggested that the profile of adults with a dual diagnosis was enhanced by the fact that the RCP had an active group of Psychiatrists who were intellectually robust and academically oriented. In contrast, the Psychiatrist suggested that because there was no equivalent structure or approach within Australia, mental health services to adults with an intellectual disability were compromised. Further, any training relating to dual diagnosis, of Psychiatrists in Australia in a sporadic or piecemeal fashion.

UK Consultant Psychiatrists who have specialised in learning disability, are employed by National Health System (NHS) Trusts that are centrally regulated by the Department of Health. Distribution of mental health services across the UK is uneven, with inconsistencies between Trusts in the range of mental health services provided and also quality. Unlike Australia, there are very few Psychiatrists working in private practice in the UK (McCulloch et al, 2000). There is variation in how each NHS Trust provides services to adults with an intellectual disability, but specialist inpatient treatment and assessment units are a feature of dual diagnosis services in the UK. Further, specialist teams that work across agency boundaries have been established to work with this population.

2.2 USA

Similar to Australia, separate service structures exist within the United States of America (USA) for disability services (known as mental retardation services) and mental health services. USA federal and state governments also provide separate or complimentary services. These separate systems have contributed to diffusion of responsibility and jurisdictional disputes (Fletcher et al, 1999). Conflicts between these two service systems appear similar to those already described in this Report. When compared to the UK, the USA lacks specialised dual diagnosis services. However, when compared to Australia, the USA has more developed and well-resourced service infrastructure.

Whilst a comprehensive array of specialist dual diagnosis services does not exist in every US state, University Affiliated Programs (UAP) have been established under the auspices of the Developmental Disability Assistance and Bill of Rights Act. These UAPs, now called Centres of Excellence in Developmental Disabilities Education, Research and Services, are located in major cities and can be found in every state and territory in the USA. The Centres provide interdisciplinary academic, professional and community training. Staff of these centres are also involved in diagnosis, evaluation and treatment. Specialist inpatient mental health treatment and assessment units also operate on an ad hoc basis across the USA. These programs link clinicians, professionals and academics. They focus upon providing clinical services and are involved in teaching and education activities at the undergraduate and postgraduate levels.

3. Australian Perspective

The closure of institutions and the consequent movement of adults with an intellectual disability to the community resulted in generic services being expected to take ongoing responsibility for the primary health care, mental health care and disability support needs of this group. Although the disability service provision sector continues to grow, the mental health needs of this population have not received due attention. Responses to the mental health needs of adults with an intellectual disability have not only been limited by economic constraints, but also by widespread lack of formal recognition and acknowledgement that:

- adults with an intellectual disability living in the community ***DO*** have increased risk of mental health problems;
- mental health needs are complex and are often unmet by generic services;
- disability agencies and mental health services experience communication and collaboration difficulties;
- neglect of mental health needs of this population compromises quality of life; and
- professionals, clinicians, staff, carers, consumers – dual diagnosis stakeholders need support, expert assistance, training and education.

State governments within Australia have only recently begun to formally respond to the needs of adults with a dual diagnosis. Initiatives across Australia have tended to develop on a state-by-state basis that has resulted in isolated and uncoordinated service development. For example, the Dual Diagnosis Project Team attempted to make contact with each state to identify dual diagnosis initiatives. The task was made difficult when government agencies contacted (both disability and mental health) did not respond to Project Team requests for information. Some states failed to respond to the request.

When contact was made with some state initiatives, it was immediately obvious that agencies or organisations involved in service provision to adults with a dual diagnosis were generally not aware of dual diagnosis developments or activities in other states. There were no mechanisms set in place for networking or sharing of expertise or resources across the states or between agencies.

Brief information provided below does not comment on dual diagnosis services delivery across all Australian states. Although the Project Team made contact with government service providers in each state, not all states responded. Accordingly, comments provided below on state initiatives should *not* be considered to provide a conclusive list of ***all*** dual diagnosis services and initiatives taking place across Australia.

3.1 Victoria

The most active state in regard to dual diagnosis appears to be Victoria where a range of innovative developments have been established. In addition to the development of a collaborative document entitled, “Protocol between Intellectual Disability Services and Psychiatric Services’” that guides service responses to adults with a dual diagnosis, a number of projects have been developed by the Victorian Government’s Department of Human Services.

The Department of Human Services Disability Branch established the ***Gippsland Dual Disability Evaluation Project*** in the late 1990s (Chesters et al, 1998). This project was designed to conceptualise and analyse a model of service delivery for adults with a dual diagnosis. The Report of this project confirmed that sole reliance upon generic services did not result in optimal outcomes for people with a dual diagnosis. The Project identified the need for appropriate service models, adequate funding, well-trained personnel, dual diagnosis training programs and coordinated service delivery.

The Project Team was also advised of the ***Northern Region Dual Diagnosis Project***. Although there were no Psychiatrists employed, two mental health professionals are involved in assessment in the northern metropolitan region (Disability Branch). The Project Team was advised that referrals are made to other services discussed below where Psychiatrists are employed.

The Department of Human Services, through the Mental Health Branch, funds the ***Victorian Dual Disability Service (VDDS).*** The VDDS is a state-wide specialist service that commenced operating in 1999. This service is based at St. Vincent’s Hospital Melbourne. One full time Psychiatrist, a full time Psychiatric Registrar and other mental health professionals are employed.

The VDDS service model provides assistance to generic services in servicing this population to improve their performance and aims to complement existing structures and service delivery mechanisms. It does not attempt to offer an alternative model of direct care eg provision of clinical services. It aims to improve the provision of mental health services to adults with dual disability across the state through:

- primary, secondary and tertiary consultation to consumers and service providers; and
- specialised training and education for mental health professionals.

The VDDS prefers not to undertake direct responsibility for case management. The preferred modus operandi is to complete case assessments in conjunction with Area Mental Health Services (AMHS) staff who undertake the primary treatment role. Joint assessment with mental health staff facilitates the transfer of skills during the process. Tertiary consultancy and advice takes place on a regular basis with staff from AMHS. Because the VDDS is funded by mental health priority is accorded to responding to their needs. The VDDS does receive a number of requests from other organisations (Disability Services, GPs, private Psychiatrists) but the VDDS has a limited capacity to respond.

The **Centre for Developmental Disability Health Victoria (CDDHV**) is also involved in the provision of clinical services to adults with a dual diagnosis although to a limited extent. CDDHV coordinates a General Psychiatric Clinic for Adults with Developmental Disabilities (three sessions per fortnight) and a Psychiatric Clinic for Older People with Developmental Disabilities (one session per fortnight). These services are provided by a full time Psychiatrist who is employed by the CDDHV. This Psychiatrist advised the Project Team that many people with a dual diagnosis access forensic services or are seen by Psychiatrists in private practice in Victoria who have an interest in people with an intellectual disability.

The CDDHV is a joint initiative between the Departments of Community Medicine and General Practice, Monash University and General Practice and Public Health, The University of Melbourne. The Centre is funded by the Disability Services Branch of the Department of Human Services but is managed by Monash University. The objectives of the CDDHV are:

- to improve the quality of health care available to people with developmental disabilities throughout Victoria
- to promote the awareness of health care issues of people with developmental disabilities amongst medical and other students, medical and other health professionals and service providers throughout Victoria.

The CDDHV provides clinical Services to adults with an intellectual disability, is involved in the delivery of educational programs, and has undertaken a number of research initiatives. Of particular relevance to the Dual Diagnosis Project is the Centre's development of dual diagnosis assessment guidelines (GAP MAP) for use by GPs and mental health professionals.

The CDDHV has also completed a training package for these professionals in the use of GAP MAP. The GAP MAP (Global Assessment of Psychopathology - Managing the Assessment process). This tool was developed by Jenny Curran, a Psychiatrist and Caroline Mohr, a clinical psychologist working together at the Centre for Developmental Disability Health Victoria (CDDHV) in 1999. It is a guide to assessment for health professionals and carers to follow when they are concerned that a person with an intellectual disability, who has disturbed behaviour, may have a mental health problem. The CDDHV provides GAP MAP training that addresses:

- mental health for adults with an intellectual disability;
- how to write behavioural descriptions;
- addressing carer concerns and safety issues;
- medical review;
- maximising information reliability in assessment using checklists and rating scales; and
- a guide to diagnosis and treatment of the most common psychiatric disorders.

A fourth Victorian initiative is also of some interest. ***The Monash University Centre for Developmental Psychiatry & Psychology (CDPP)*** was established in 1989. This Centre has a mandate to provide research and teaching in the field of developmental psychiatry and psychology with a particular focus on child, adolescent and family mental health. There is close affiliation with the clinical services provided by the Monash Medical Centre Child and Adolescent Mental Health Service.

Special areas of interest include mental health in children with developmental and intellectual disabilities, pervasive developmental disorders, school refusal and truancy, sexual abuse and trauma, anxiety and depression. The CDPP and the University of New South Wales are currently investigating psychopathology in young people with intellectual and developmental disabilities. Current research activities included the Australian Child and Adolescent Development study, the development of an autism screening tool and an investigation of anxiety in children with intellectual disability. However, the CDPP focuses upon children and adolescents although research outcomes will have some relevance for adults with a dual diagnosis.

3.2 New South Wales

The Centre for Developmental Disability Studies **(CDDS)** began operating in 1997. This Centre operates through the University of Sydney where a Foundation Chair of Developmental Disabilities was created. The CDDS creates and disseminates knowledge that can improve the lives of people with developmental disabilities. In addition to research activities, the CDDS is involved in teaching and clinical contact with people with developmental disabilities.

Although this Centre carries out some research and educational outreach that addresses the needs of those who have a dual diagnosis, there are no formal or dedicated dual diagnosis services within this state. For example, Associate Professor Stewart Einfeld is a Psychiatrist and Clinical Associate with the CDDS. Dr Einfeld and Dr Seeta Durvasula (also from the CDDS) have experience in working with people with developmental disability and challenging behaviour. Both avail themselves to respond to queries that doctors and others may have about medical issues related to disability.

Late in the life of the Project, the Team became aware of other local dual diagnosis initiatives developing within New South Wales. For example, the South Western Sydney Area Health Service, Area Mental Health team has a Clinical Nurse Consultant working in the dual diagnosis area (developmental disability and mental illness). Difficulties in making contact or networking with clinicians and project workers is a significant barrier to dual diagnosis service development and enhancement.

3.3 South Australia

The South Australian government has been proactive in responding to the needs of adults with a dual diagnosis through the Intellectual Disability Services Council (IDSC). The IDSC is the lead agency for people with an intellectual disability in South Australia. In 1995 recurrent commonwealth funds of approximately $70,000 were made available through the Commonwealth State Disability Agreement to address dual diagnosis within South Australia. These funds were used to establish a steering committee and appoint a project officer in 1996. Initially this committee was involved in the allocation of brokerage funds to support service provision to individual adults with a dual diagnosis. The committee was also involved in collaboration with agencies in policy development relevant to adults with a dual diagnosis, as well as cross-agency dual diagnosis training.

Additional funds allocated in 2000 enabled the IDSC to appoint a half time Psychiatrist to supplement the Social Worker who had been appointed to the project officer position. The Project was subsequently renamed the Dual Disability Program (DDP). The DDP continues to operate from the Specialist Intervention and Support Service (SISS) that was formed in 1997.

The Dual Disability Program provides face-to-face consultations for people with an intellectual disability who have suspected or diagnosed concurrent mental disorder. In addition to clinical contact, secondary consultations are provided to IDSC workers who are requiring assistance to work with a person who has a dual diagnosis. Services from the team are accessed through the IDSC case manager. These teams are also involved in research and provide training for IDSC and other agencies that work with people with a dual diagnosis. In 2001 the DDP maintains focus upon interagency responses to the needs of adults with a dual diagnosis through the provision of training and education initiatives, such as “Working in Partnership” workshops. The Program is also actively involved in dual diagnosis training that addresses the needs of Psychiatrists and trainee Psychiatrists.

Despite these initiatives there is room for improvement. A recent publication by the IDSC, “Development Priorities for People with Intellectual Disability 2002”, outlines a range of unmet needs and includes a set of proposals that outlines possible responses. Key priorities cover a wide range of needs relating to children and adults but also include recommendations addressing the needs of adults with a dual diagnosis. Specific recommendations made regarding the extension, development and expansion of specialist services, include:

- healthcare plans and support in country areas;
- response capacity for those with dual disability of intellectual disability and mental illness;
- Intensive intervention for those with extremely challenging behaviours.

3.4 Tasmania

In Tasmania, OPTIA INC, a non-government agency supporting adults with an intellectual disability has developed a “Dual Diagnosis Outreach Program”. OPTIA INC has negotiated with a Sydney based Psychiatrist, Dr Peter Wurth, to run a dual diagnosis clinic. OPTIA pays for Dr Wurth to fly from Sydney to Hobart to complete the dual diagnosis clinic on an “as required” basis. Dr Wurth consults with staff and adults with a dual diagnosis, when funding is available. This Consultant Psychiatrist has a private practice in Sydney. Dr Wurth has an interest in the area but the bulk of his practice is within general adult psychiatry.

The Project Team was also aware of the work of two registered nurses employed by the Department of Community Health Services in Hobart. These nurses were conducting a small scale study into models of care and models of nursing for adults with a dual diagnosis. Outcomes of this project however, were unable to be identified.

3.5 Western Australia

In Western Australia, the Disability Services Commission (DSC) and the Mental Health Services of the Department of Health have formally responded to the needs of adults with an intellectual disability who require access to services provided by both departments through the development of a protocol. The "Protocol Between the Disability Services Commission and the Department of Health: People with Intellectual Disabilities and Mental Health Disorders: Guidelines for Service Providers" was established in February 2002. The Protocol is modeled on the Victorian government's document, "Protocol between Intellectual Disability Services and Psychiatric Services", Human Services, Victoria, June 1994. The purpose of this protocol is to enable the departments to meet the needs of these consumers and ensure that they receive the services most appropriate to their needs in as smooth and coordinated a manner as possible.

Additionally, the Disability Services Commission (DSC) and the Metropolitan Mental Health Services (Department of Health) established a high level interagency committee in April 2001. This committee specifically meets to address the needs of adults with an intellectual disability who have concurrent mental health problems. Both government and non-government agencies representing disability and mental health service provision are involved at a senior level.

The Disability Services Commission (DSC) also advised the Project Team that a proposal exists to extend the DSC Specialist Clinical Psychology Service to people with mental health disorders (ie people with a dual diagnosis of intellectual disability and mental health disorders). The extended service would be made available to adults aged 18 years and over who have an intellectual disability and/or autism living in the Perth Metropolitan Area serviced by the Metropolitan Services Coordination Directorate. This proposal involves enhancement of a current service that consists of two specialist clinical psychology positions where one focuses upon challenging behaviour and the other on positive parenting/behavioural family interventions.

The proposal requests funding for one specialist Clinical Psychology position with specialist knowledge and skills in assessment and community based treatment of mental health disorders in people who have an intellectual disability. The proposed service would provide:

- assessment and intervention for adults with an intellectual disability who are considered to have a mental illness. This service would be involved in the provision of early interventions to prevent the breakdown of the person's place of work or home;
- consultancy and training to families, carers and service providers to enhance functional and adaptive skills and to support the individuals with mental health disorders in their own homes, communities and places of work; and
- a multi disciplinary service that will involve collaboration with DSC Local Area Coordinators, social workers, medical officers, clinical psychologists, medical specialists and other agencies including non-government organisations.

The proposed position would be working in direct partnership with the planned DSC sessional consultant Psychiatrist, sessional clinical Neurologists and the Western Australian Metropolitan Mental Health Service (WAMMHS). The position would also be involved in the provision of expertise and consultation interagency committee established between the Western Australian Metropolitan Mental Health Services and the Disability Services Commission (refer above comments).

3.6 Queensland

In Queensland, mental health treatment and rehabilitation services are provided by primary health care providers and specialised mental health services. Formal service infrastructure across Queensland that holistically and specifically addresses the needs of adults with a dual diagnosis is virtually non-existent. Some services and agencies contacted by the Project Team advised that they respond to the needs of adults with a dual diagnosis out of “goodwill” rather than having a funded or formal policy brief to serve this group. However, it should be noted that Queensland Health, Mental Health Services and Disability Services Queensland have updated an existing protocol and are trailing/evaluating the new version in four locations (two metropolitan and two non-metropolitan) across Queensland. This protocol guides a collaborative service response, between Mental Health Teams and Disability Services Queensland, when a consumer has an intellectual disability and diagnosed or suspected mental health problems.

The Project Team could only identify ***three*** services operating ***solely*** to meet the needs of adults with a dual diagnosis that operate in Queensland. None of these services holistically address whole of lifespan issues for adults with a dual diagnosis. Two of these, ARROS (non-government) and the Developmental Disability Unit Clinic (University) operate with large waiting lists due to limited resources.

- ***ARROS*** (At Risk Resource and Outreach Service) – is an outreach and support service for young people with an intellectual disability aged 15 to 25 years of age that is funded by Families, Youth and Community Care Queensland. ARROS provides assistance to a small number of consumers who are homeless, at risk of being homeless and also experiencing mental health problems. This service operates only in the Northern suburbs of Brisbane and auspiced by another non-government agency, the Community Living Program.

- Dual Diagnosis Unit (Jenner House), Wolston Park Hospital, West Moreton Health District – a hospital based, inpatient tertiary mental health service serving Health districts within Queensland Health. The service targets those adults with concomitant intellectual disability and mental disorder, who exhibit aggressive or violent behaviour that cannot be managed within an integrated mental health service. Jenner House provides specialist assessment, extended inpatient services on a medium to long-term basis, that enables people with a dual diagnosis to receive treatment and rehabilitation. The referring service retains responsibility for ongoing care and support consequent to successful treatment and rehabilitation.

  Some Queensland Health districts also provide non-hospital based extended inpatient mental health units that are intended for people with a chronic mental disorder and associated disability who cannot maintain independence within the community. Adults with a dual diagnosis may access these Community Care Units although clinical services are not specifically tailored to meet their complex needs. These Community Care Units comprise cluster style housing that is community based and substitutes for hospital based extended inpatient treatment. Eligibility criteria, treatment and services parallels Jenner House as described above. It is possible for adults with a dual diagnosis to move from Jenner house to a Community Care Unit through to community based living options.

- Developmental Disability Unit Clinic – a clinic operating at the Mater Hospital Brisbane. Dr Nick Lennox sees adults with an intellectual disability one day per week. Dr Paul White, Consultant Psychiatrist and a Psychiatric Registrar from Wolston Park Hospital provide limited psychiatric sessions to the Clinic specifically for adults with a dual diagnosis.

The Dual Diagnosis Project team also visited and consulted with some clinical staff from the St Vincents Hospital at Robina, on the Gold Coast. This hospital is an innovative collaboration between Queensland Health and the non-profit Sisters of Charity organisation. The hospital provides public mental health inpatient facilities including 16 beds for adults with a dual diagnosis. The Team was advised by consultation participants that demand for dual diagnosis inpatient services was so low that these beds had been used for other needs. Consultations with other dual diagnosis stakeholders suggested an alternative explanation, eg criteria for admission was problematic. Some agencies advised the Project Team that adults with an intellectual disability with suspected mental health problems had been refused admission or presenting psychopathology had been reduced to “challenging behaviour” or that the person did not warrant admission for assessment or treatment.

Many Queensland services advised the Project Team that they felt unable to cope with the complex needs and challenging behaviours that adults with an intellectual disability can display. Many were unsure of how to proceed in supporting the needs of those with intellectual disability. Co-existing mental health problems exacerbated pre-existing lack of confidence. Key informant interviews and consultations with stakeholders revealed the following “shared” experiences when working with adults with an intellectual disability with a diagnosed mental disorder or suspected mental disorder:

- inadequate skills and knowledge in understanding dual diagnosis;
- under-funding and resource constraints;
- lack of collaboration between agencies or service providers;
- negative stereotypes of the consumers/clients;
- conflicting professional language/discourse;
- difficulty in identifying mental health problems;
- restricted cross service system entry eg eligibility problems;
- limited treatment and interventions;
- isolation and remoteness; and
- need for expert dual diagnosis support and expertise transfer.

These outcomes need to be carefully considered in regards to not only the obvious training and education ramifications, but also policy, practice and strategic planning.

4. Psychiatry and Intellectual Disability

"Psychiatry does not take a lead role for adults with an intellectual disability, and neither does any other key discipline eg clinical psychologist…hope expressed that an individual professional with expertise can single handedly lead psychiatry out of its Dark Ages, in relation to intellectual disability"

This comment to the Project Team from an Australian Psychiatrist was shared in the context of the shortage of Psychiatrists with expertise in the area of intellectual disability. The small number of Psychiatrists with an interest in intellectual disability is a significant barrier to dual diagnosis service development within Australia.

The Project Team are only aware of two Psychiatrists in Australia who work in the area of dual diagnosis in dedicated positions, on a full time basis. Similarly, the Team is only aware of one Psychiatric Trainee (Registrar). One Psychiatrist is based in Adelaide, with the second Psychiatrist (and Registrar) in Melbourne. Chapter Four of this Report, the survey of Queensland Psychiatrists, showed that Psychiatrists working in adult psychiatry ***DO*** see adults with an intellectual disability but they too lack access to relevant training, believe that specialist services should be available and are concerned about support available for this group in the wider community. Psychiatrists have a critical role in maintaining the health and well-being of adults with an intellectual disability. They need to be persuaded, encouraged and supported to work with this population.

In Australia, few specialist services exist that concentrate on the provision of mental health care to adults with an intellectual disability. When psychiatric admission is required, acute mental health units within the hospital system are expected to respond. Difficulties associated with assessment, diagnosis and treatment may challenge even the experienced clinician. Too frequently admission is declined or quality treatment compromised. Australia needs multidisciplinary teams of intellectual disability specialists with a range of professional backgrounds. A Psychiatrist must be a member of such a team.

5. Policy

The Dual Diagnosis Project highlights the need for an integrated and collaborative approach. Policy and legislative development should not only cut across local, state and national boundaries but local boundaries as well. Demarcation and disputation between professionals, agencies, mental health and disability services, medical professionals and carers are only some of the experiences raised in consultations and key informant interviews.

Mental health and disability services must learn to work together to focus upon the needs of the person with the intellectual disability, rather than demarcated service issues. "Mental health and well-being" will only be achievable when stakeholders, in particular mental health and disability services, adopt a genuinely collaborative approach. They must move beyond traditional professional or agency boundaries and clearly aim to address the needs of the individual who is under scrutiny rather than meeting their own agendas (Kitson, 1996).

Adults with an intellectual disability often require "care" throughout their entire lifespan. Those individuals who experience the additional burden of mental health problems, may require additional support and assistance to access appropriate services and then maintain lifestyles that maximize mental health and well-being as well as physical health and well-being. Few carers, whether paid or unpaid, would disagree that care is a complex, inter-professional process that is undertaken by a variety of staff, both clinical and non-clinical (Sharp & Kilvington,1993). However, the Dual Diagnosis Project cannot prescribe the best way or “how” care can be most effectively and efficiently provided.

Perhaps the next National Mental Health Plan could be lobbied to be more inclusive of the mental health needs of adults with an intellectual disability. Perhaps a national approach could assist with linking isolated but committed dual diagnosis stakeholders together – to learn together and from one another, to share resources and ideas, and to support one another through training or education initiatives. In the interim, cross-boundary, inter and intra disciplinary, team based specialist services for adults with an intellectual disability are only a vision. Education and training initiatives can assist in networking. Research activity also needs to be stimulated within Australia to ensure models of service delivery are evidence based.

6. Diagnosis Networks/Associations

There are no formal dual diagnosis support or educational networks established within Australia to link stakeholders together. The Association for the Scientific Study of Intellectual Disability (ASSID) has state branches and does recognise support interstate collaboration and dual diagnosis themes feature at conferences. The International Association for the Scientific Study of Intellectual Disability (IASSID) maintains a Mental Health Special Interest Research Group (SIRG) that meets regularly with events addressing dual diagnosis always well attended. Whilst some academics and clinicians from Australia do attend IASSID and the Mental Health SIRG when limited budgets allow, participants have on occasion voiced concerns that they are “preaching to the converted”. The inference is that those with responsibility and the power to make changes eg the bureaucrats and politicians, would benefit from exposure to the growing evidence base about the negative effects of mental health care neglect of this population.

The USA hosts the National Association for Dual Diagnosis (NADD) that operates “chapters” in most large cities. These chapters are comprised of interested dual diagnosis stakeholders, including paid and unpaid carers, professionals, and interested others, who meet to provide support and share information. Conferences are a regular feature aimed at providing varied professional and clinical education opportunities. NADD encourages interaction and collaboration between agencies and stakeholders. Medical practitioners and Psychiatrists are actively engaged, in addition to other professionals, carers, staff, consumers etc. This organisations maintains a website and a substantive dual diagnosis resource collection.

In the UK, the Association for Mental Health in Mental Retardation is an active association that provides well-planned conferences and educational opportunities. Similarly, the European Association for Mental Health in Mental Retardation, that includes some of the eastern nations, recently hosted a conference in Berlin therefore linking the “east” with the “west”. Both Associations have published excellent resource material and host one day and half day dual diagnosis education and training events during the year for “local” members. These associations attract Psychiatrists and other medical specialists, as well as allied health professionals, disability service providers and other interested stakeholders including family members and carers.

7. Education and Training

Consumers with a dual diagnosis and their carers need to have confidence that the clinicians and professionals they seek treatment from have appropriate expertise in the mental health problems of adults with an intellectual disability. Although mental health treatment that is generally available to the broader population would benefit adults with an intellectual disability, such effective treatment needs to translate from theory through to practice. The Project reveals wide general consensus amongst stakeholders, that access to quality dual diagnosis education and training is critical to the health and wellbeing of adults with an intellectual disability. Few had training in the recognition and treatment of adults with a dual diagnosis.

The Project suggests that although a number of stakeholders who participated were providing well-intentioned care, this occurred because there were few alternatives. There were no others services to pick up the needs of the consumer group, and few opportunities for these services to upskill or seek expert assistance. In the UK, a recent government report (DoH, 2001) provided a snapshot of direct care and professional staff who support adults with an intellectual disability:

- estimated 75% of staff are unqualified;
- difficulties in recruitment and retention of professional and care staff;
- low status among the workforce;
- few recognised accredited training qualifications;
- little attention to workforce planning;
- variable involvement of service users and carers in training or planning.

Outcomes from the Dual Diagnosis Project share views and perspectives discussed in this UK report. Findings clearly demonstrate the need for both paid and unpaid carers who support adults with an intellectual disability to:

- have access to quality training and education opportunities with an understanding that ongoing as opposed to “one-off” learning will be required;
- possess skills in networking, liaison and partnership with the different sectors or agencies involved in service provision to adults with a dual diagnosis, particularly primary health care, mental health and disability services;
- understand the need for and participate in multidisciplinary or interdisciplinary teams that may work across agency or service provider boundaries; and
- be sensitive to cultural and philosophical underpinnings of service delivery such as normalisation, the least restrictive alternative, autonomy, choice etc.

The Project highlights that service providers share a general lack of knowledge, training and confidence when consumers have a dual diagnosis. Knowledge and skill deficits may be at a very fundamental level. For example, health, mental health and disability staff (government and non-government) lacked knowledge about even basic characteristics and features of intellectual disability. Professional behaviour and attitudes may be shaped and modified by enhancing knowledge, training and skills as well as organizational practices (Hatton & Emerson, 1993). Training and education is also important in regard to maintaining morale and commitment to the complex needs of adults with an intellectual disability who have a dual diagnosis or a suspected dual diagnosis.

Research evaluating the impact of education and training in the disability field has tended to concentrate upon the effect of behavioural principles for people with challenging behaviour (Carr et al, 1990). Staff training in relation to mental health issues has received minimal attention within the literature. However, some training has been found to be effective in increasing staff knowledge and impacting practice (Allen et al, 1997).

8. Conclusion

This Report has stressed the reality that adults with a dual diagnosis have complex behaviours that pose significant challenges to both clinicians and non-clinicians. Project outcomes demonstrate that the majority of services provided to adults with an intellectual within Queensland are NOT saturated with those who have a concurrent mental disorder. However, despite acknowledged methodological and practical limitations associated with the Project, contact with 156 Queensland agencies providing services to adults with an intellectual disability estimated that there were 1,353 adults with a dual diagnosis or suspected dual diagnosis.

Out of approximately 7,000 adults with an intellectual disability that were served by these agencies, it was then estimated (upper limits of prevalence) that more than 20% had a “dual diagnosis”. Managers, staff and professionals associated with these services, clients and their families and carers, described unmet need for adults with a dual diagnosis. Although the numbers of adults with an intellectual disability are estimates and more likely an underestimation, there is little doubt that this small group of Queenslanders consume vast resources and place enormous pressure upon government and non-government services.

The Dual Diagnosis Project is a rich descriptive source of information on the needs of consumers with a dual diagnosis, their carers **and** services and agencies that support them. Findings from the Project enhances understanding of the number of adults with a dual diagnosis within Queensland, and the need for a more formalised prevalence study. The Project also demonstrates the increasing demands that adults with a dual diagnosis, or suspected dual diagnosis, will continue to place upon Queensland services and agencies, within disability, health and other sectors.

Specialised dual diagnosis services are a scarce and often unknown entity within Queensland. Adults with an intellectual disability must attempt to access generic health and mental health services, often with poor outcomes. Many rely heavily upon disability services professionals who often have minimal or absent mental health expertise. Despite the best of intentions, inadequate assessment or diagnosis of mental health problems are common results. Even where a diagnosis or assessment suggests a mental health problem exists, entry or access to clinical and therapeutic services are never guaranteed.

Responses to the various surveys and consultations organised by the Project Team clearly show that there is a high level of concern evident within the broader Queensland community regarding the capacity of mainstream mental health and disability services to “deliver” and cope with the mental health problems experienced by adults with an intellectual disability. Concerns are exacerbated by the limited capacity of many services, agencies and carers to cope with complex and challenging behaviour. Challenging behaviour is a common reason why a mental health consultation is sought and yet, often the very reason why mental health services are refused. The challenging behaviour of adults with an intellectual disability places major demands upon services

(Dudley et al, 1999). Many clinicians and professionals lack the skills to differentiate between challenging behaviour and mental illness. Treatment and intervention is often compromised by diagnostic problems and dilemmas. Understanding psychopathology in adults with an intellectual disability can be a daunting task.

There is obvious need for well planned and resourced education and training in dual diagnosis. Recipients of dual diagnosis training and education should not be limited to Psychiatrists and other clinicians such as psychologists. All service providers and carers need to participate in training events, including consumers. However equally critical is the development and implementation of a coherent conceptual framework to guide service development and delivery. This is the rationale behind two sets of Project recommendations: Gaps in Dual Diagnosis Skills and Knowledge of Clinicians, Professionals, Carers and Other Stakeholders; and Gaps in Service Delivery to Adults with a Dual Diagnosis, their Carers and Other Stakeholders. Without a coherent conceptual framework of service provision to adults with a dual diagnosis, education and training will only have limited success. Their mental health needs of adults with an intellectual disability often need to be met by disability and mental health professionals working collaboratively together. Logically, joint training and educational opportunities should take place.

In recent years, Australia has had access to the growing evidence base regarding the mental health needs of adults with an intellectual disability. Most concur that this group are at increased risk of mental illness when compared to the general population (Moss et al, 1997). Regardless, there is great international disparity regarding best practice within this field and various western nations are at stages of development as they attempt to meet the needs of this population. The Dual Diagnosis Project attempted to describe how Queensland services and agencies were responding to the mental health needs of this group of people. Outcomes from the Dual Diagnosis Project can inform and enhance service development or enhancement as well as guiding state-wide dual diagnosis training and educational strategies.

The health care and mental health care needs of adults with an intellectual disability needs to be prioritised by both government and non-government services within Queensland. Obviously, there is huge room for improvement, and a timely, prompt response is required. It is the hope of the Developmental Disability Unit that not only will Queensland Health rise to the challenges presented in this Report, but their colleagues in Disability Services Queensland and other government agencies will also come on board. After all, adults with an intellectual disability are one of the most vulnerable groups within contemporary Australian society. Their overwhelming needs are undeniable and deserve response.

9. Recommendations

The Developmental Disability Unit encourages the Queensland Government to carefully consider the Recommendations that are detailed in Part Two of this Chapter. Recommendations are multidisciplinary in nature. For convenience, possible solutions and strategies have been divided into ***two sets of complimentary recommendations*** that address:

- Gaps in Dual Diagnosis Skills and Knowledge of Clinicians, Professionals, Carers and Other Stakeholders; and

- Gaps in Service Delivery to Adults with a Dual Diagnosis, their Carers and Other Stakeholders.

Key areas of need that the recommendations are embedded within include:

- clinical practice including assessment, diagnosis and treatment/management;
- training and education;
- networking and multi-agency collaborative practice;
- research activity; and
- an evidence based care approach.

Part Two

Recommendations: Gaps in Dual Diagnosis Skills & Knowledge of Clinicians, Professionals, Carers & Other Stakeholders.

The training and education needs of a the range of dual diagnosis stakeholders needs to be prioritised by not only the Queensland Health Mental Health Services, but also Disability Services Queensland and other government agencies, including Queensland Education. Similarly, strategic responses should not be limited to government sectors, but also embrace the non-government sectors. A holistic approach, that adopts the biopsychosocial approach to understanding health, and specifically mental health and well-being must be adopted. There are four critical domains that stakeholders require dual diagnosis training and education within:

- effective assessment and diagnosis;
- effective communication (with consumers, their carers, other professionals);
- effective treatment & interventions; and
- effective networking & cross agency collaboration.

Recommendation 1: Evidence-Based Approach to Dual Diagnosis

Queensland Health, Mental Health Services must ensure that clinical and professional decisions about the mental health of adults with an intellectual draw upon and reflect the emerging evidence-base about adults with a dual diagnosis. Clinical decisions and service delivery should be based upon knowledge, rather than *ad hoc* experiences.

Services provided to adults with an intellectual disability need to draw upon and reflect the growing body of research and evidence about dual diagnosis. Specifically service development within Queensland should:

- form part of "frontier" scientific research, working with colleagues across Australia and other western nations to improve understanding of the causes and effects of mental health problems, and to enable improvements in the prevention, diagnosis and treatment of mental disorders and mental health problems in adults with an intellectual disability;
- be actively and purposefully involved in both evaluation and assessment of new technologies and existing practices, through access to and familiarity with up to date information that reflects contemporary developments and changes in the field of intellectual disability/dual diagnosis; and
- adopt and encourage an interdisciplinary and cross-agency approach that enables health, mental health care and disability professionals to work cooperatively and collaboratively to ensure all disciplines contribute to maintaining the mental health of adults with an intellectual disability.

Recommendation 2: Highly Skilled Dual Diagnosis Mental Health Clinicians

Queensland Health, Mental Health Services must allocate appropriate resources and commit to supporting continuous training, education and learning opportunities tailored to the needs of the range of clinicians, professionals and carers involved in assessing, treating and maintaining the mental health of adults with an intellectual disability. Dual Diagnosis education and training must be implemented to ensure the result is a highly trained and skilled mental health workforce.
Dual diagnosis education and training needs to be inclusive of clinical skills and also a wider range of competencies, including the ability to:

- comprehend problems and issues arising from the perspective of the consumer or carer, and to be an effective communicator;
- understand and access human services holistically ie health, disability and other social services fitting together to meet consumer need;
- work in teams using a multidisciplinary or interdisciplinary approach, with the capacity to cross agency or organisational boundaries;
- identify mental health and broader health needs and understand the opportunities for mental health and health promotion as well as treatment and care;
- collaboratively involve other carers, family members, relatives and the consumer in decisions and choices involving their services, support, treatment or care.
- provide individual training and education initiatives should be tailored to meet the needs of general practitioners and Psychiatrists.

Recommendation 3: Cross Agency Dual Diagnosis Education, Training and Ongoing Learning Opportunities

Queensland Health, Mental Health Services needs to collaborate with Disability Services Queensland to facilitate or provide, and actively promote the importance of a range of informal and formal dual diagnosis education and training opportunities for a range of stakeholders. Cross agency and interagency dual diagnosis training initiatives should be implemented.

Cross agency dual diagnosis education, training and learning opportunities must broadly target stakeholders from government and non-government services including: professionals and service providers, paid and unpaid carers and consumers ie medical practitioners (Psychiatrists, GPs and other medical officers), professionals and clinicians (nurses, psychologists, social workers, therapists), direct care staff (residential care officers, lifestyle support workers and other staff including managers involved in the provision of direct care services), family members and relatives; and consumers.

Recommendation 4: Promotion of Mental Health in Intellectual Disability

Queensland Health, Mental Health Services should fund the Developmental Disability Unit to develop dedicated resources that facilitate improved and better understanding of the complex needs of adults with a dual diagnosis amongst members of the broader community. The needs of adults with a dual diagnosis or suspected dual diagnosis, cuts across a wide range of community agencies and services providers including primary health care providers, education, police, human services etc.

Mental health promotion activities within the broad community needs to be inclusive of the needs of dual diagnosis consumers who are often "invisible" in health promotion campaigns. Community groups and services would benefit from a broad and improved understanding of the needs of people with an intellectual disability so as to overcome any lingering prejudice and enable adults with an intellectual disability to make appropriate use of services on an equal basis with community members.

Recommendation 5: Clinical and Professional Dual Diagnosis Leadership

Queensland Health, Mental Health Services should collaborate with Disability Services Queensland and jointly fund the appointment of a:

- Psychiatrist to provide clinical services to adults with an intellectual disability;
- dual diagnosis education and training coordinator (full time lecturer/senior lecturer); and
- clinical psychologist (full time lecturer/senior lecturer).

These three positions should be located within the Developmental Disability Unit. These positions would make substantial contributions to mentoring and supporting dual diagnosis stakeholders; the provision of education and training initiatives; research; and clinical services.

Queensland government must ensure that the clinical and professional workforce permanently maintains and supports experts in dual diagnosis. Health, mental health professionals and disability professionals must have adequate access to clinicians and professionals who can provide appropriate training and education that addresses the mental health needs of adults with an intellectual disability. Additionally, these experts should provide support to the clinical and professional workforce, in addition to the provision of clinical services.

Recommendation 6: Dual Diagnosis Development Fund

Queensland Health, Mental Health Services should initiate, establish and fund a Dual Diagnosis Development Fund that would resource and support a range of initiatives aimed at enhancing clinical, educational and research capacity across Queensland.

It is recommended that Queensland Health approach Disability Services Queensland and Queensland Education for joint commissioning of this fund, including major shared contributions and oversight responsibilities. This initiative should be located within the Developmental Disability Unit, but overseen by a committee approved by Ministers of all three Government Departments.

The establishment of this fund would contribute to the much needed recognition of the valuable role that needs to be played by the academic and research communities in creating and supporting through an evidence based care approach, appropriate dual diagnosis services, including education and training activities and resources.

Recommendation 7: Dual Diagnosis Training and Educational Resource Package

Queensland Health, Mental Health Services should fund the Developmental Disability Unit to develop a Dual Diagnosis training and educational resource package. This educational resource package would embrace a multidisciplinary/interdisciplinary approach but would be used to train and educate key dual diagnosis stakeholders ie Psychiatrists/general practitioners, professionals, paid and unpaid carers and consumers.

The mental health care needs of adults with an intellectual disability are commonly managed by Psychiatrists and General Practitioners. These medical specialists need access to succinct and relevant training and educational resources that ensure they have the necessary skills to undertake assessment, diagnosis and treatment of mental health care problems experienced by adults with an intellectual disability. GPs and Psychiatrists would require the dual diagnosis and educational resources package to be tailored specifically to meet their needs.

In general, the dual diagnosis training and resource package should be developed to enhance skills, knowledge and expertise in (Bouras & Holt, 1997):

- recognition of signs and symptoms of mental health problems in adults with an intellectual disability;
- treatment methods, including therapy and psychopharmacology;
- problem solving approaches when faced with behavioural problems or challenging behaviour;
- networking with other staff, professionals and key resources; and
- liaison and collaboration with key stakeholders eg mental health services and disability services.

Recommendation 8: Dual Diagnosis Information and Support Network for Professionals and Paid Carers

Queensland Health, Mental Health Services should collaborate with Disability Services Queensland to establish and trial a Dual Diagnosis Support Network. This network should aim to link the range of professionals and paid carers. Service providers, working within the government and non-government sectors need to be encouraged to interact together, share resources and information and therefore enhance conjoint problem solving approaches.

The Queensland Government needs to increase the help and support professionals and carers receive from both government and non-government services so that they are able to be effective in enhancing the mental health of adults with an intellectual disability. Service providers face complex problems and challenges while they are supporting an adult with a dual diagnosis. Their specific needs include:

- quality and practical information regarding dual diagnosis;
- insight into the nexus between mental health services and disability services;
- better assessment of their own needs;
- improved access to support services; and
- advice regarding services eg eligibility and access details.

Recommendation 9: Information and Support Network for Consumers, Families and Other Unpaid Carers

Queensland Health, Mental Health Services should fund the Developmental Disability Unit to establish an Information and Support Network for carers and consumers with a dual diagnosis.

The network would link unpaid carers supporting adults with a dual diagnosis and also provide regular opportunities for interaction and information sharing. Networking and information exchanges will never negate the important need for contact with competent and experienced professionals but carers and consumers would benefit from effective collaboration and problem solving. Carers and consumers need access to networks that provide them with the opportunity to share information, strategies and support when caring for an adult with a dual diagnosis.

Recommendation 10: Carers and Consumers Contributing to Dual Diagnosis Education and Training Initiatives

Queensland Health, Mental Health Services should ensure that dual diagnosis education and training initiatives actively involve the contribution of consumers and their carers. Funding should be provided to ensure consumers and their carers have an integral and effective role in the design and delivery of dual diagnosis education training to all stakeholders. Whether those receiving training or education in dual diagnosis are clinicians, professionals or managers, they will benefit from the opportunity to hear directly from adults with an intellectual disability about their experiences and expectations.

Carers have dual diagnosis training and education needs but they can also be an effective training resource. Adults with an intellectual disability and their carers need to be actively supported and encouraged to participate in the development and implementation of training and educational initiatives.

Recommendations: Gaps in Service Delivery to Adults with a Dual Diagnosis, their Carers & Other Stakeholders

Quality multi-disciplinary specialist services are urgently required to meet the needs of adults with an intellectual disability who have a dual diagnosis or a suspected mental health problem. Ideally, services provided to adults with an intellectual disability should be locally based and either co-located or closely linked with generic mental health services.

Queensland mental health services aim to provide seamless services to those people who have mental health problems. Although the provision of appropriate services is a challenge for the general population, seamless services for adults with an intellectual disability clearly means that:

- organisational boundaries should never impede consumers;
- planning and provision of services and support is practical, realistic and workable;
- roles and responsibilities are clearly defined;
- multidisciplinary teams (or representative members), from different agencies come together to provide high quality services for consumers and make the best use of the specialist skills and experience of the clinicians/professionals/staff involved; and
- there is support in working across organisational boundaries.

The model of service delivery most appropriate for adults with a dual diagnosis involves cross-boundary team working functions. The complex needs of this population are compromised by the lack of a shared vision and shared commitment across agencies. There is a tendency for clinicians, professionals and service providers to be unaware of what “rules” are in operation or concurrently what their professional obligations are to adults with an intellectual disability. A serious but direct effect is the harsh reality that when an adult with an intellectual disability requests mental health services, the service response tends to focus upon the agency resources or relationships rather than the concrete needs of the person needing assessment or treatment.

The Dual Diagnosis Project identified many tensions between service providers regarding the mental health needs of adults with an intellectual disability. There were few suggestions that the majority of agencies and service providers, whether mental health services or disability services, were prepared to substitute functions or responsibilities in the interests of “seamlessness” or client needs. Although the Project Team was made aware of a number of key initiatives where seamlessness and client needs ***were*** put ahead of organisational agendas eg the Cairns and District Dual Diagnosis Group, there is definite room for improvement. A background theme in many of the recommendations listed below argues for strategies and initiatives that promote linkages and bridgework between key stakeholders, particularly mental health services and disability services.

Recommendation 1: Health Care Equality

Policy and program development or activity across the Queensland Government should consistently ensure adults with an intellectual disability enjoy the same right of access to mainstream health services, mental health services and disability services as is experienced by the general population when in pursuit of reasonable quality of life, specifically in regard to health status. Specifically, this policy approach should form part of local policy and practice within not just mental health services, but all Queensland Health Districts, including hospitals. Mechanisms, such as the dual diagnosis protocols developed by Queensland Health Mental Health Services, with Disability Services Queensland should be adequately funded to ensure trialing and evaluation is both practicable and realistic.

Recommendation 2: Collaborative Focus Upon Care

Queensland Health, Mental Health Services needs to work collaboratively with Disability Services Queensland to meet the mental health needs of adults with an intellectual disability. Collaboration will require a new focus and cultural shift within government and non-government services that recognises the importance of developing and enhancing skill development within and between health, mental health and disability staff.

Opportunities for collaboration need to occur at the coalface through to policy and senior bureaucrat levels. Mental health policy and services provided to adults with an intellectual disability need to aim to provide services through collaborative arrangements by stakeholder agencies rather than exclusionary approaches that attempt to make unitary responsibility eg where one agency is solely responsible.

The needs of adults with a dual diagnosis, or a suspected dual diagnosis clearly cut across agencies, rather than being able to be allocated to one sole agency of responsibility. Mental health services provided through Queensland Health *and* disability services provided through Disability Services Queensland need to re-focus the orientation of services provided to adults with an intellectual disability. In particular, at the point of initial access, where eligibility is determined or referrals are made to "appropriate services", the focus must be upon care and the needs of the individual and their carers. Despite philosophically appropriate policy and practice manuals that exist in both services sectors, services are not consumer focused or client focused.

Recommendation 3: Cross-agency Dual Diagnosis Service Development

Queensland Health, Mental Health Services must encourage community based agencies and service providers to work collaboratively together to meet the needs of adults with a dual diagnosis, and their carers. Services need to reflect multidisciplinary teamwork– assessment, treatment, support, case management & coordination, education, training, mentorship & referral.

The Mental Health Program should provide non-recurrent funding opportunities that encourage and induce government and non-government agencies, services and organisations to join together to develop services to meet the needs of adults with a dual diagnosis. Funding or additional resources should aim to:

- maximise contributions & potential of each agency to provide services to adults with a dual diagnosis;
- stretch boundaries of participating agencies and make them need to the needs of adults with a dual diagnosis; and
- support and encourage the development of a new kind of professional eg who is able to work comfortably & to interact simultaneously within many disciplines.

Recommendation 4: Funding Injections to Enable Mental Health through Meaningful Day Activities

Queensland Health, Mental Health Services needs to work collaboratively with Disability Services Queensland to ensure active steps are taken to enable and encourage the development of a wider range of daily, recreational or leisure opportunities that take place within appropriate community-based settings. People with an intellectual disability are living in sub-optimal conditions therefore it is of little surprise that their mental health, as well as physical health and well-being is being severely compromised. "Meaningful" day activities can make a significant contribution to improving quality of life, can help to tackle social exclusion, and most importantly, encourage the promotion of mental, social and emotional health and well-being Government and non-government service providers require substantial injections of recurrent funds to enable this recommendation to be realised.

The Office of the Public Advocate Queensland has sole responsibility for systems advocacy. The Public Advocate recently highlighted the deep-rooted and historic legacy of neglect in regard to the way people with impaired capacity are supported. In the Annual General Report of the Office of the Public Advocate (2001), this Office argued that Queensland would require the injection of an additional $125-$150 million per year to reach the national per capita average.

Although a range of factors combine to stop adults with an intellectual disability from participating in ordinary community activities, economic restraints are often the underlying denominator. Where employment is not possible, meaningful day activities or leisure and recreation appears to be considered a rare luxury and often fails to be embedded within daily routines. Lack of meaningful or interesting day activity contributes to boredom, anxiety and stress and may increase the likelihood of mental health and or challenging behaviour problems developing.

Recommendation 5: Tertiary Clinical Outreach Service

Queensland Health, Mental Health Services needs to provide enhanced funding to the Developmental Disability Unit so that a Dual Diagnosis Clinical Outreach Service can be provided on a state-wide basis. This Dual Diagnosis Clinical Outreach Service would support Psychiatrists, general practitioners, professionals, disability service providers and unpaid carers and consumers across Queensland. The Mental Health Program should seek collaborative supportive funding from Disability Services Queensland to enhance this initiative.

All adults with an intellectual disability should enjoy equitable access to generic mental health and disability services. However, research has clearly demonstrated that adults with a dual diagnosis challenge service delivery (see Bouras et al, 1994). Specialist, tertiary services need to be planned, developed and delivered. These specialist services should operate at a tertiary level eg consult with, work with and support generic services eg primary health care services to continue to provide quality evidence based care to adults with an intellectual disability.

The Developmental Disability Unit, working collaboratively with the Wolston Park Hospital is an excellent example of tertiary consultancy services that can work effectively together to support generic health and disability services to support and assist adults with a dual diagnosis living in community settings. However, the DDU is chronically under funded in the provision of specialist dual diagnosis services. Waiting lists acknowledge demand and unmet need.

The Queensland Health Mental Health Program should recurrently enhance the funding of the DDU to enable recruitment and employment of staff for the Clinical Outreach Services, including:

- one sessional Psychiatrist;
- one sessional clinical psychologist;
- one sessional social worker; and
- a part time administrative support.

Recommendation 6: Dual Diagnosis "Triage" Positions

It is strongly recommended that each Queensland Health District employs at minimum, one full time professional or clinical position designated with Dual Diagnosis Mental Health Advocacy and Liaison or dual diagnosis "triage" responsibilities. This position would adopt a local level advisory role for adults with an intellectual disability entering the mental health system and mental health staff working with that individual. Other responsibilities would include:

- networking and liaison responsibilities to maintain communication links with disability services at a local, middle management and senior level;
- familiarity with disability discourse, relevant protocols and policies;
- consultation and networking with primary health care services, particularly general practitioners in the local area;
- regular in-service dual diagnosis training that involves mental health and disability staff; and
- access to literature, information and resources relevant to dual diagnosis.

Recommendation 7: Multidisciplinary and Cross-Disciplinary Professional Practice

Queensland Health, Mental Health Services and Disability Services Queensland need to adopt cross-disciplinary and multidisciplinary practice as the model of professional service delivery required to meet the needs of adults with an intellectual disability who have a dual diagnosis or suspected dual diagnosis. The multidisciplinary approach required needs professionals recruited and trained who are able to have a wide rather than narrow focus of the mental health needs of adults with a dual diagnosis and therefore, have the capacity to look beyond their discipline "over the walls."

Interdisciplinary practice is a preferred model of care emerging within the literature (McCallin, 2001). The model is best understood as professionals with distinct discipline specific training working together for a common purpose eg mutually supportive relationships. Multidisciplinary in nature, the contribution of each discipline is understood as being "different" and yet at the same time complimentary.

Collaborative professional practice that crosses traditional professional boundaries is increasingly demanded in the contemporary context of human, health and disability services. This is a response to policy and legislative demands for cooperation and integrated or seamless care pathways. The complex needs of adults with a dual diagnosis require professionals from a range of backgrounds, who need to work together to provide cohesive care within an environment that reflects specialisation, rationalisation, maximisation and avoids duplication (Leathard, 1994).

Recommendation 8: DDU based Dual Diagnosis Colloquia

Queensland Health, Mental Health Services has a unique opportunity to develop an initiative that will ensure a “leading Australian voice in dual diagnosis” emerges in the Queensland setting. Funding of a Dual Diagnosis Colloquia would contribute to the development of dual diagnosis services and initiatives that are high quality, evidence-based and continuously improving. Although brief details are provided below, funding needs to be drawn from key stakeholders making this initiative truly collaborative and co-operative.

Queensland Government should establish the Dual Diagnosis Colloquia as a centre of excellence to contribute to improvements in services to adults with an intellectual disability who have a concurrent mental health problem. The main responsibility for this Colloquia would be the promotion of evidence based practice across Queensland, to guide and address current service delivery problems and challenges to this complex client group.

Outcomes from the Colloquia will ensure improved approaches to the measurement of quality services that emphasizes improved outcomes for adults with a dual diagnosis, informed by quality research and therefore evidence based care. The establishment of this initiative would demonstrate that the Government is genuine about raising standards and improving quality of services for adults with a dual diagnosis living in Queensland.

Responsibilities

The colloquia would operate as a forum that encouraged the development and dissemination of expertise in dual diagnosis across Queensland. Characteristically multifunctional, the forum could achieve a range of activities including:

- education and training initiatives for professionals & carers tailored to meet individual audience needs;
- collation of and distribution of evidence based information, advice and support to dual diagnosis service providers across Queensland including tertiary medical & health related support;
- website development and maintenance including an online discussion network and clearing house for relevant, current evidence based research;
- coordination of brokerage funds to support service provision to adults with a dual diagnosis;
- policy, program and protocol development regarding collaborative interactions and initiatives that meet the needs of dual diagnosis stakeholders;
- generation of and support the development of collaborative partnerships;
- problem solving and non-adversarial resolution of cross-agency problems; and
- research activity and outcome distribution.

Location

Colloquia should be located in a neutral environment that provides appropriate status eg university setting. The Developmental Disability Unit, an independent academic unit with a mission to improve the health status of adults with an intellectual disability, is the ideal site for the Dual Diagnosis Colloquia.

Funding

Funding to establish the Colloquia should be collaboratively contributed by stakeholders. Specific roles, responsibilities and activities of the Colloquia could therefore be further negotiated with stakeholders. The model described could be implemented in a “staggered” approach eg role and responsibilities could be introduced over a number of years as funding became available.

However, the minimum staffing profile at commencement of the Colloquia would have to include: a full time Project Officer (AO 6) who would assume project responsibilities and key teaching role in addition to a full time Psychiatrist.

Chapter 7

Appendices & References

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Appendices

(a) Project Information Sheet

(b) Psychiatrists Survey

(c) Organisational Survey

(d) Opinions Survey

(e) Direct Support Workers Opinions Survey

(f) Families Opinions Survey

(g) Managerial Opinions Survey