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. <u>Methodology Synopsis</u>

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.