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DUAL DIAGNOSIS PROJECT

Chapter 3

Queensland Profile of Dual Diagnosis

Queensland Government
Queensland Health

The University of Queensland

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 1st Priority Solutions & Strategies 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 2nd Priority Solutions & Strategies 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 3rd Priority Solutions & Strategies 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 4th Priority Solutions & Strategies 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 5th Priority Solutions & Strategies 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 6th Priority Solutions & Strategies 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.

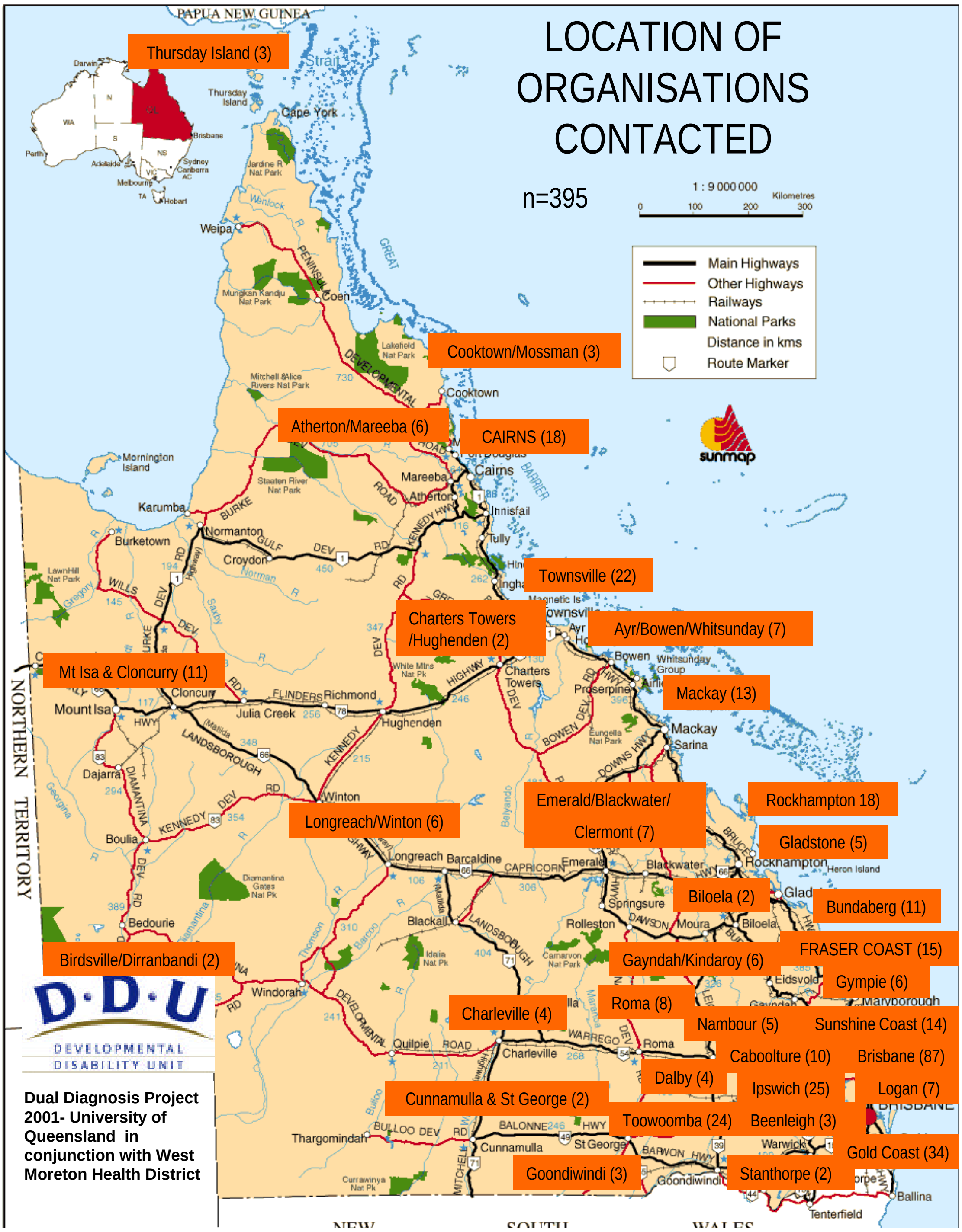
3.5 Stage One Findings

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.

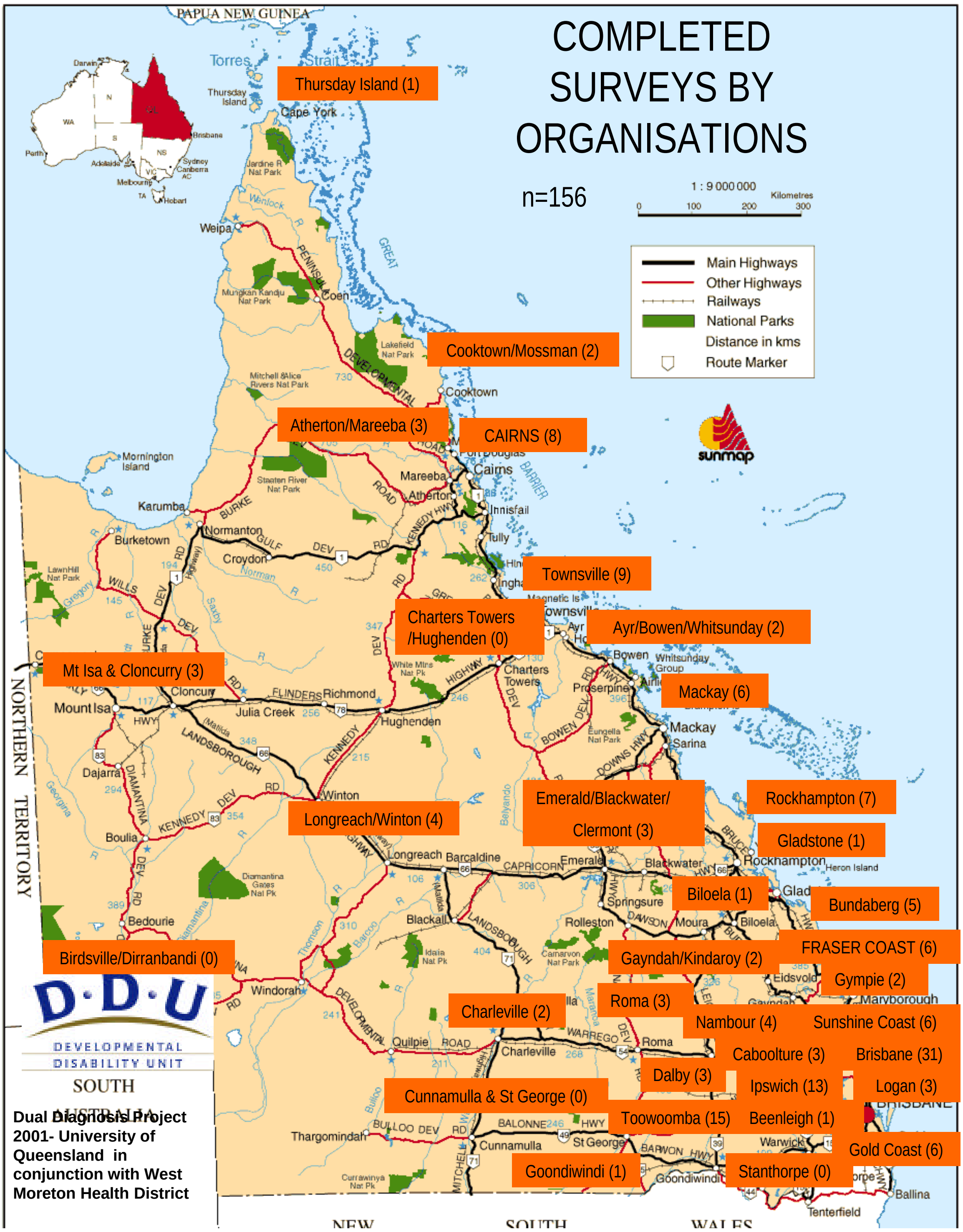
The Project Team was disappointed with this result in light of the telephone contact, information packages sent out and time spent explaining the Project rationale to potential survey participants. At the completion of the data collection stage, this Report has already stated that there were 145 agencies 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

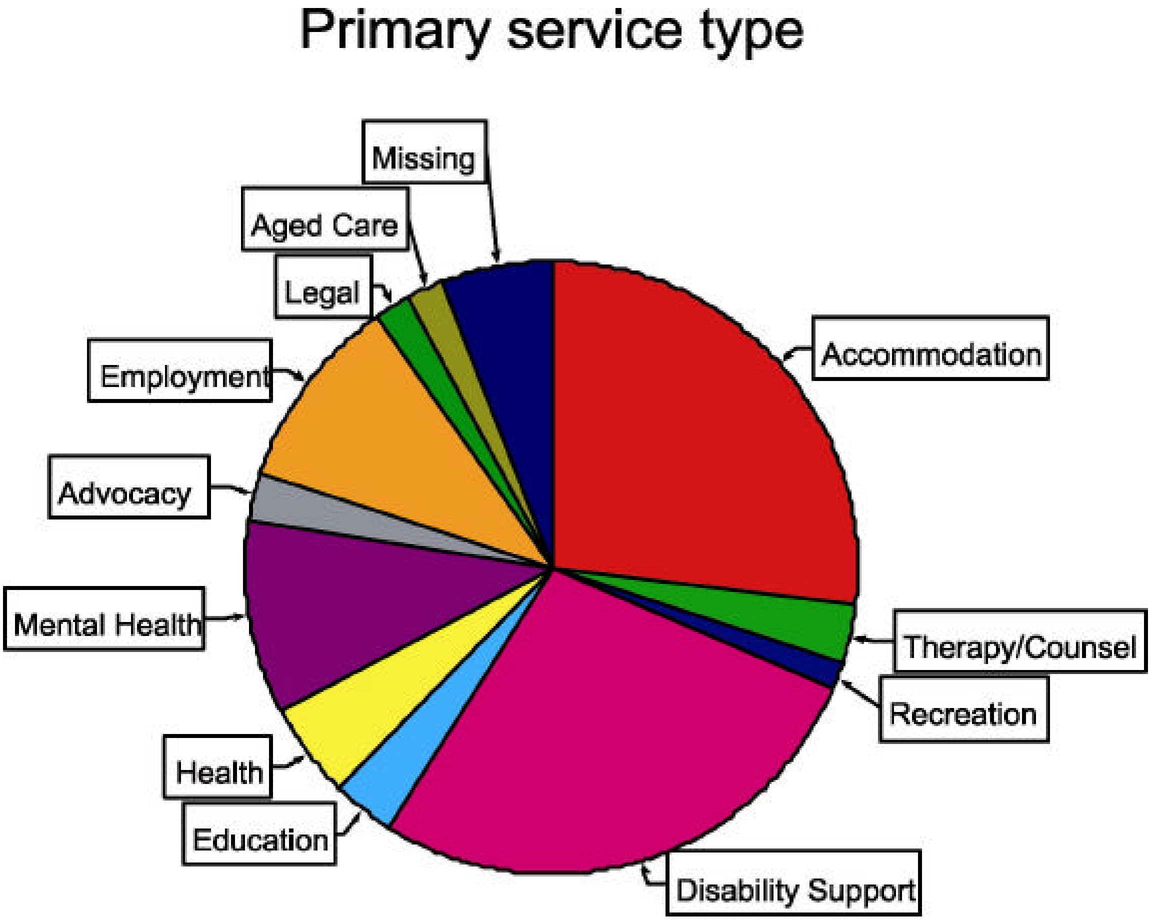


Table 7 Service Type Clusters

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.

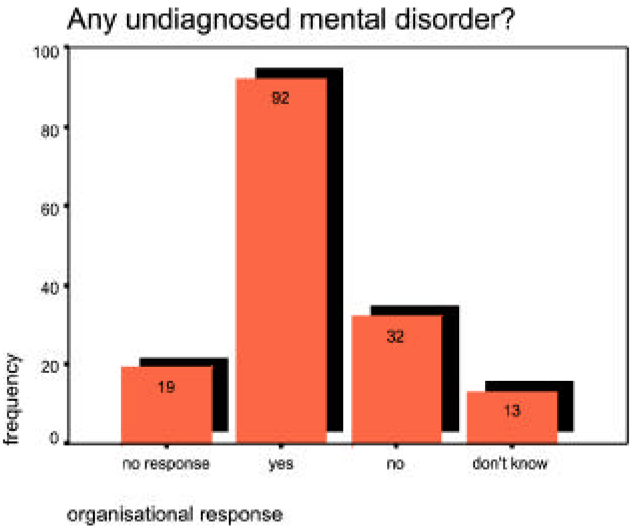
3.6.7 Services to Adults with ***Suspected but Undiagnosed*** Dual Diagnosis

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

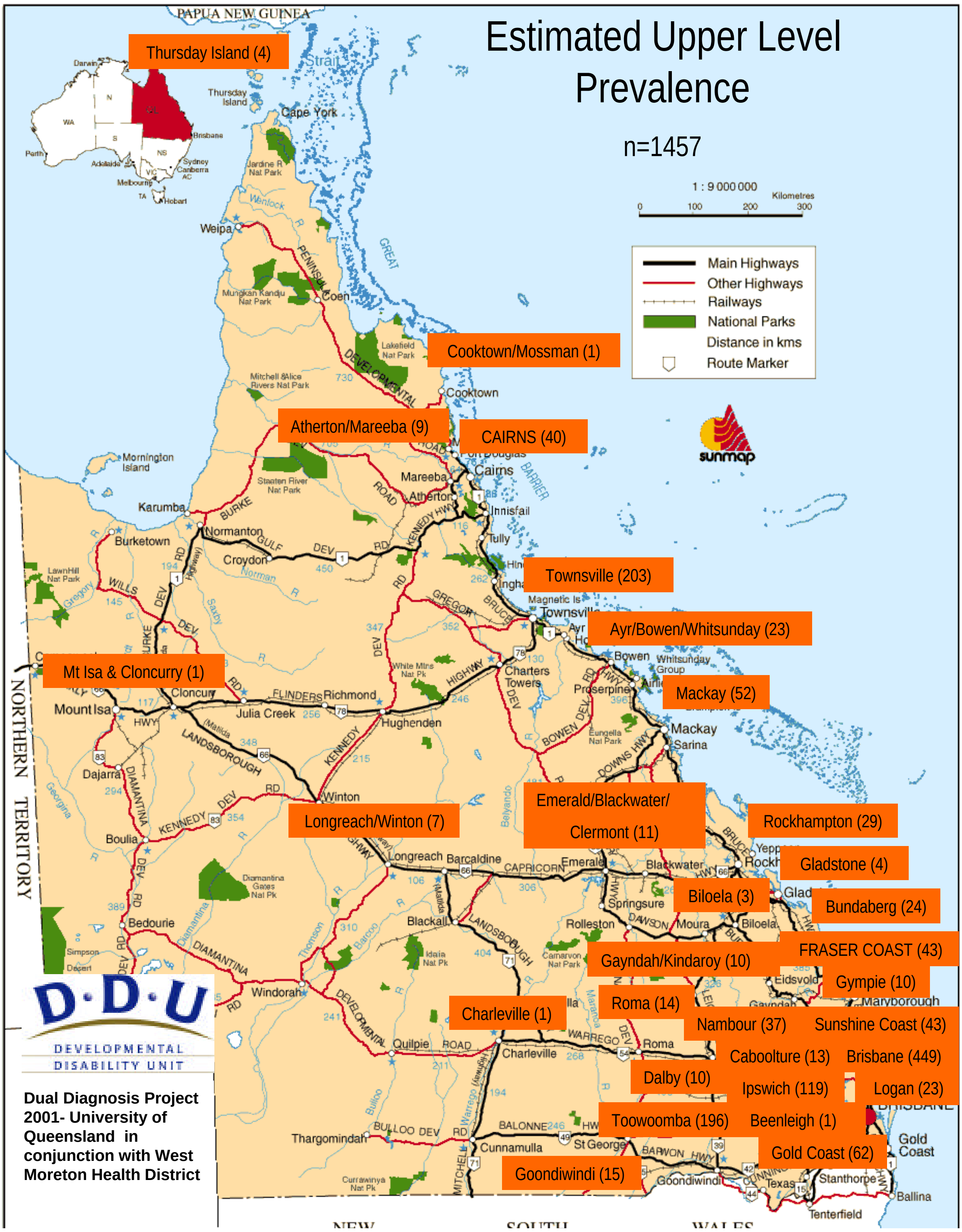
Agencies/organisations were asked to identify the clinical source of the dual diagnosis. Of the 202 adults with an intellectual disability who had a diagnosed mental disorder, Table 11 identifies the five sources of diagnosis that were most frequently provided. It should be noted, that some agencies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