



## Chapter 5

### *Key Informant Interviews & Consultations*

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## 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.

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### 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.”*

*“professionals largely feel inadequate.”*

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### 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 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".

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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.

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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.



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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."*

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### 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.