1. Introduction and Background to the Project

The World Health Organisation defines mental health as "a state of emotional and social wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively or fruitfully, and is able to make a contribution to his or her community (CDHAC 2000: 3).

The Australian National Mental Health Strategy states that "mental health is not simply the absence of mental illness but describes the capacity of individuals and groups to interact with one another and their environment in ways that promote subjective wellbeing, optimal development and use of mental abilities (cognitive, affective and relational) (CDHAC 2000: 3).

Dr Stephen Moss (2000), co-author of the PAS-ADD Checklist (Psychiatric Assessment Scale for Adults with Developmental Delay), highlights the close links between quality of life issues, mental health and mental illness:

> Those factors which influence our quality of life also influence the likelihood that we are going to get mentally ill…Basically what we are all doing through life is attempting to achieve a balancing act between the resources that we have to bring to bear on the world and the pressures that the world is putting on us. The extent to which we achieve that balance is a measure of the extent to which our quality of life is high, and to which we are at risk from the common mental disorders. We have so many resources that we never think about them unless perhaps two or more of them fail at any one time. We've got our physical health, our intellect, which…allows us to have coping strategies to be able to cope with a whole range of things. We have our parents, our spouses, our children, our high level of financial status (hopefully), the esteem we get from our jobs, and our friends in society in general. That's a huge number of resources.

Practice experience, research and analysis undertaken at Community Living Program (CLP) have generated significant knowledge and understanding of the mental health and well being issues that shape the lives of people with learning difficulties. This knowledge and information illustrates a picture in harsh contrast with the above definitions and descriptions of mental health, well being, and quality of life. For many people with learning difficulties, achieving that all-important balance between the resources they have to bring to bear on the world and the pressures that the world is putting on them, is a chronic and relentless struggle. A struggle in which the pressures of the world often overwhelm the depleted resources available to the individual.

CLP research describes people with learning difficulties "as people in struggle" (O'Connor and Fowkes 2000). Significant features of their struggle are:

- Marginalisation, objectification, and disenfranchisement from a society that values intelligence, beauty, material wealth, and power.
- Over-representation in many areas of social disadvantage, including poverty, homelessness, psychiatric disability, the criminal justice system, victims of crime, unemployment and health problems.
- Living with being told throughout their lives that they are failures, and battling to develop the characteristics of a competent self in spite of this.
- Fighting to be their own person and make their own decisions, to be potent, to feel hope and optimism.

- Negotiating the everyday. Struggling everyday to understand what is going on around them, to understand what people are saying, to make themselves understood and, above all, to not appear different.
- Experiencing loneliness, rejection, lack of friendship, lack of respectful and caring intimate relationships, and lack of love.
- Experiencing violence, exploitation, abuse, victimisation (10, 22, 23).

Not surprisingly, the chronic and relentless stress of living this daily struggle leads people with learning difficulties to experience a greater risk of a range of mental health issues. In recent years, practice, observation and discussion has led CLP workers to become increasingly aware of the impact mental health and well-being issues have on the lives of the people they work with. Through the Dual Diagnosis Project, CLP aims to further develop its understanding of mental health issues in the lives of people with learning difficulties. In turn, this knowledge will inform organisational practice responses and professional development programs for working with people with learning difficulties who experience poor mental health and well-being.

MENTAL HEALTH PROBLEMS AND MENTAL DISORDERS

To facilitate the development of our knowledge and understanding of the mental health issues that affect the lives of people with learning difficulties, the Dual Diagnosis Project Framework incorporates the distinction between 'mental disorders' and 'mental health problems', as identified by The Commonwealth Department of Health and Aged Care (2000: 3):

Mental Disorder:
A mental disorder is a diagnosable illness (of which there are different types and degrees of severity) that significantly interferes with an individual's cognitive, emotional or social abilities. An individual must meet particular diagnostic criteria before a mental disorder can be diagnosed. The diagnostic process involves "the recognition of clinically relevant symptomatology, the consideration of causes that may exclude a diagnosis of another condition, and the application of clinical judgement" (125).

Mental Health Problem:
These are defined as more common mental complaints that interfere with an individual's cognitive, emotional or social abilities, but to a lesser extent than a mental disorder. Mental health problems are less severe and of shorter duration than mental disorders, and include the temporary mental ill health temporarily experienced as a reaction to life stressors. Mental health problems may develop into mental disorders.

2. Methodology

(A diagrammatic representation of the Project Framework is outlined on page 6).

The CLP Dual Diagnosis Project utilised four research tools:

1. **Literature Review**
2. **Worker Interviews**
3. **Focus Group**
4. **CLP Collaborative Project**

1. LITERATURE REVIEW

Key national and international research addressing mental health and dual diagnosis was reviewed to inform a knowledge base and understanding of key issues, practice methodologies and trends. Areas of information addressed include:

- Mental health and well being
- Demographics and prevalence
- Non-identification and underreporting
- Risk Factors
- Assessing dual diagnosis
- Diagnostic tools and processes
- Interventions and treatment methods (Prevention; Early Intervention; Crisis Intervention and Ongoing Support)

2. WORKER INTERVIEWS

27 service providers with experience working with people with dual diagnosis issues participated in interviews of 1-1 ½ hours duration. 8 of these were CLP workers, and 19 workers from a range of external services, including:

- Adult Guardian
- Alina Families Program
- At Risk Resource and Outreach Service (ARROS)
- Brisbane North Lifestyle Support Service
- Centacare Northwest Lifestyle Support Services
- Community Living Program (CLP)
- Community Mental Health, Brisbane Forensic Mental Health
- Community Mental Health, Redland Health Service
- Disability Services Queensland (DSQ) Wacol
- DSQ Wooloowin
- DSQ Mt Gravatt
- Endeavour
- Ipswich Community Access Disability Service (ICADS)
- Greenmeadow Court
- Nundah Community Enterprise Cooperative
- Women With Intellectual and Learning Disabilities – Sexual Violence Prevention Service (WWILD-SVP)
- Queensland Wattle League
- University of Queensland Developmental Disability Unit (DDU)
- Youth & Family Services (Logan City) Inc

The purpose of these interviews was two-fold:

1. To prepare workers for meaningful participation in the Dual Diagnosis Focus Group, ensuring all participants had a shared understanding of the parameters and language of the Focus Group; and
2. To gain detailed information around individual service provider's practice experience and knowledge. The conversational interview setting was more conducive to eliciting this information than a group environment.

Service Provider Questionnaire (see Appendix A)

A questionnaire was developed to structure the interviews and gather the following information:

- Agency context
- Prevalence of dual diagnosis
- Types of Mental Health Problems and Disorders
- Assessment tools and processes
- Prevention responses
- Early Intervention responses
- Crisis Intervention and Ongoing Support responses
- Skills and Knowledge Development
- Program/Policy Development

3. FOCUS GROUP

An all-day Focus Group was run on 8 August 2001 at Warilda Conference Centre. This aimed to:

- Facilitate sharing of information between workers.
- Hear other agencies experience, analysis and expertise.
- Catalogue the skills, knowledge and resources necessary for good practice responses to dual diagnosis.
- Document the implications of good practice responses for program and policy development (at agency and government level).
- Highlight the training needs and systems necessary for long term learning and skill development.

The Focus Group was attended by 14 participants from the following organisations:

- Alina Families Program
- At Risk Resource and Outreach Service (ARROS)
- Brisbane North Lifestyle Support Service
- Centacare Northwest Lifestyle Support Services
- Community Living Program (CLP)
- Disability Services Queensland, Wacol Area Office
- Endeavour
- Ipswich Community Access Disability Service (ICADS)
- Queensland Wattle League
- University of Queensland Developmental Disability Unit (DDU)
- Women with Intellectual and Learning Disabilities – Sexual Violence Prevention Service (WWILD-SVP)

Case study (see Appendix B)

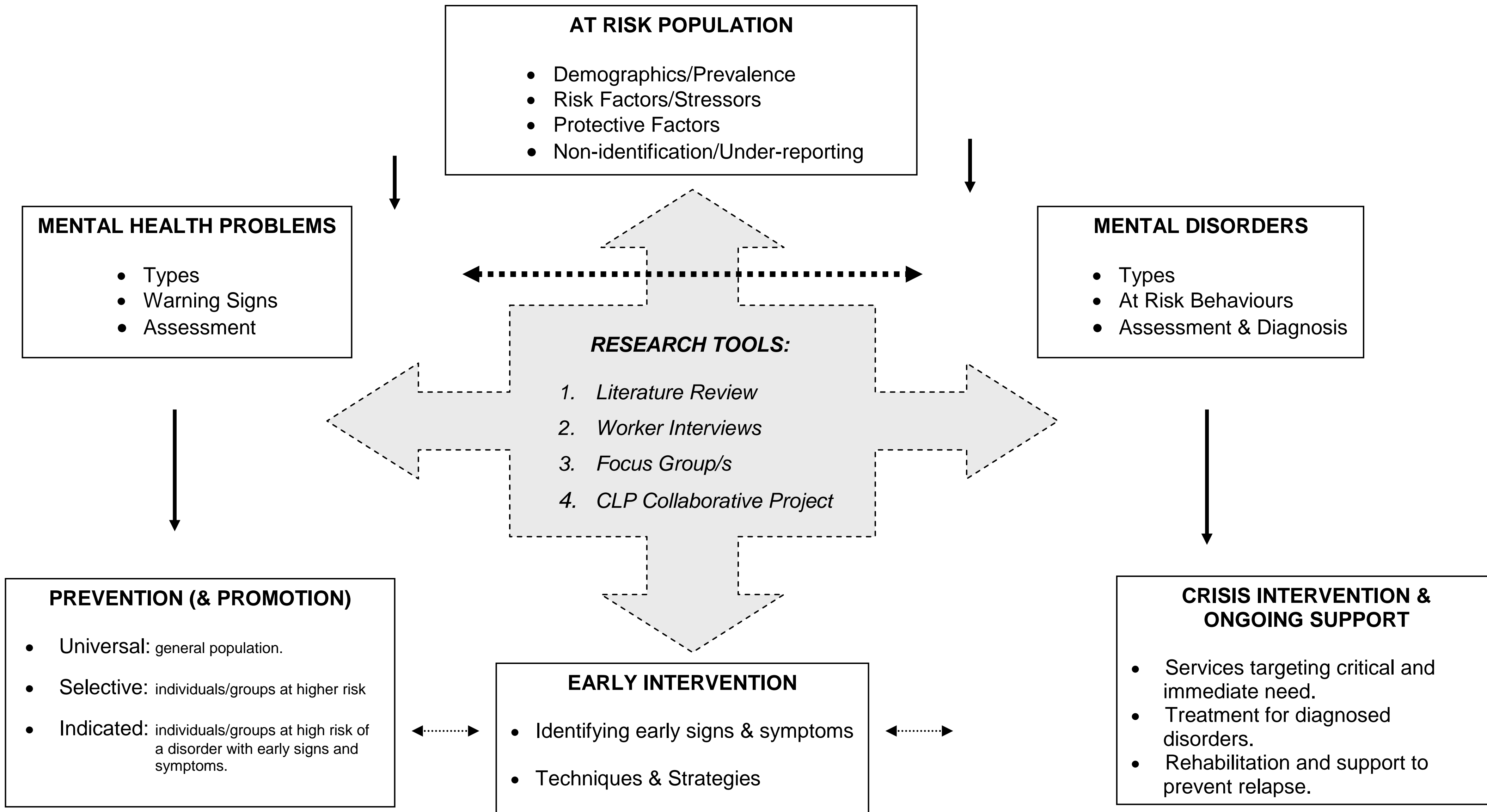
A 3-stage fictional case study relating the experiences of a young man with dual diagnosis issues was developed to facilitate discussion at the Focus Group.

4. CLP COLLABORATIVE PROJECT

A consultant psychologist was employed 2 days/week for 16 weeks to work with 9 CLP constituents who experience dual diagnosis issues. The psychologist worked in collaboration with CLP support workers. This work involved assessment of the mental health status of each participating constituent, followed by design, implementation, and evaluation of a 14-week treatment plan. The psychologist also provided training around dual diagnosis issues to CLP workers. This project gave CLP support workers direct experience and training in cognitive behaviour therapy, anxiety management, coping strategies, and supportive counselling. This provided a practical opportunity for CLP to identify some of the skills and techniques needed by workers to respond effectively to people with dual diagnosis issues. The project also furthered research and knowledge into the use and benefits of short-term psychological interventions for people with dual diagnosis issues.

Feedback (see Appendix C)

FRAMEWORK: CLP DUAL DIAGNOSIS PROJECT



3. Demographics and Prevalence

The Human Rights and Equal Opportunity Commission (1993) states that 2% of Australians have a learning difficulty (659). As a percentage of Australia's current estimated population of 19,430,964, this translates to 388,613 people (ABS Website 20/9/01). An overview of the key dual diagnosis literature consistently highlights the fact that people with learning difficulties are at increased risk of experiencing a range of mental health problems, compared with the general population. There is, however, some dispute as to the level of this increased risk. Holland and Koot (1998) attribute key methodological differences in the prevalence studies as the explanation for the wide-ranging prevalence rates (2). They discuss a review of 12 studies of children and adolescents with learning difficulties, which identified dual diagnosis prevalence rates from 14% to 80%, with a modal average of 45% (1). In real terms, this is between 69,950 and 310,890 people. Lennox et al (1997), in concurrence with Human Rights and Equal Opportunity Commission (1993) suggest the prevalence rate of psychiatric disorders in adults with learning difficulties/intellectual disability is between 30% and 50% (81). Using these percentages, between 116,583 and 194,306 Australians will have dual intellectual and psychiatric disabilities. Santosh and Baird (1999) discuss prevalence rates of between 10% and 60%, which translates to between 38,861 and 233,167 people (231).

Whilst a prevalence study was not within the scope of the Dual Diagnosis Project, the 27 workers who were interviewed in the course of the project were asked to estimate how many of the people with learning difficulties whom they work with, also deal with mental health issues. Whilst this question obviously calls on the perceptions and judgements of individual workers, the responses provide interesting and useful information nonetheless. Two central themes can be extrapolated from the responses workers gave to the question of prevalence. These are:

1. A significant number of the people workers support struggle with mental health issues.

Workers report a very high incidence of anxiety and depression amongst the people they work with. Workers told a rich collection of stories that resonated with the voices and experiences of people who deal with significant and ongoing stress, overwhelming worries, and negative feelings that interfere with their enjoyment of life. When questioned as to the incidence of dual diagnosis issues encountered in their work, workers made the following comments:

- Mental health issues are present in 50% of my caseload.
- I suspect that lots of the people I work with have mental health issues.
- 20% of my clients are suspected dual diagnosis.
- I suspect lots are undiagnosed (with dual diagnosis).
- Most clients experience mental health issues that interfere with their enjoyment of life.
- Anecdotally, dual diagnosis estimates are 40%.
- 20 clients have mental health issues (80% of caseload).
- Most women who use the service have mental health issues of some type.
- I would say a lot of people with intellectual disability could also be classed as having some type of psychiatric disability.
- 25% - 50% of caseload experience mental health issues.
- Everyone I work with deals with mental health issues.
- 100% of the people I work with experiences mental health issues of some kind.
- 75% of the people the service supports have some kind of mental health problem or disorder.

- Mental health issues are a factor for 80% of the people I have contact with.
- I'd say it's 50/50 (clients with mental health issues and clients without).

2. **Whilst mental health issues are a constant feature in their work, workers report that very few of the people they work with have a formal psychiatric diagnosis.**

Comments workers' made include:

- Not many people are clinically diagnosed.
- Only some clients are formally diagnosed.
- 10% are diagnosed.
- 2 are diagnosed.
- Some clients have a dual diagnosis.
- 1 or 2 diagnoses.
- There are less than 10 clients with dual diagnosis in the service currently.
- 5 (out of 40) clients with diagnosed dual intellectual disability and mental illness.
- 8 (out of 30) are formally diagnosed.
- 1 (out of 3) clients are diagnosed.
- 2-3 (out of 25) current service users have formal diagnoses.
- 1 (out of 5 clients) has a diagnosis.

With formal diagnoses rare amongst this population, it becomes important to establish other ways of recognising the mental health issues that people with learning difficulties experience. The voices and words of those people who experience dual diagnosis seems an obvious place to start. For the purposes of this report, the gatekeepers of this information were the workers who support clients and constituents with dual learning difficulties and mental health issues. Asked to reflect on the ways the people they work with describe their mental health issues, workers offered the following:

- "I need to get better"
- "I need to sort my head out"
- "I'm really stressed"
- "I'm sick up here (points to head) and I need a doctor"
- "Good day" or "Bad day"
- "I have depression"
- "I've got a lot on my mind, I have to sort things out"
- Things are getting too much "because of the thinking"
- "The voices are driving me crazy"
- "The voices are telling me what to do"
- "My head feels funny"
- "My head is telling me things"
- "The noises in my head are making me do it"
- "I keep getting pissed off"
- "I'm a mad schizophrenic"
- "I have panic attacks. I don't want to leave the room"
- "I'm getting sick"
- "I'm hearing voices"
- "Feeling weird"
- "Going off"
- "I'm mentally ill"
- "When I'm stressed I hear voices"
- "If I'm really stressed I can't think straight"
- "I talk to ghosts"
- "Life's just too hard. I just can't handle things"
- "I worry so much I make myself sick"

- “I do their voices to feel more powerful”
- “I’m sometimes another person on the day”
- “I’m sitting up in the tree and watching down at the house”
- “I’m another girl”
- “I wasn’t well”
- “I’m not happy today”, “I haven’t been happy all week”
- “I feel sad”
- “I was so stressed yesterday I had a nervous breakdown about it”
- “ I’m crazy”
- “Going a bit, you know, mental”
- “I’ve got to go and get my oil and grease change”
- “I’m trapped in a cage and I don’t know how to get out”.
- “I feel like I want to kill everyone”.
- “I loose my head. I feel better when I have the needle”.

4. Non-Identification and Under-Reporting

The first step in providing an appropriate, expedient, and effective response to people with dual diagnosis is the correct identification of the mental health issues that negatively impact on the lives of people with learning difficulties. However, despite the significant prevalence rates discussed in the previous section, non-identification and under-reporting of mental health issues in people with learning difficulties is widespread. Lennox et al (1997) note that psychiatric disorders in people with learning difficulties "often remain unrecognised", particularly in the case of major depression, other affective disorders, anxiety disorders, and abnormal grief reactions (81).

A survey of the literature posits a number of reasons for non-identification and under-reporting of mental health concerns in people who have learning difficulties. These include:

1. Communication difficulties

Identification and diagnosis of mental health issues relies on doctors and health professionals being able to obtain relevant information from the individual themselves. This includes the person communicating fluid and abstract ideas such as subjective descriptions of their feelings and thoughts. Often people with learning difficulties will have difficulty identifying and articulating this information (Holland and Koot 1998: 5; Stavrakaki 1999: 176).

2. Inappropriate diagnostic criteria and processes

Stavrakaki (1999) comments that the use of strict diagnostic criteria "leads to mental health issues in this population remaining unrecognised and under-diagnosed" (176). As mentioned above, current diagnostic processes rely heavily on the individual's ability to express abstract subjective concepts such as thoughts and feelings. If people are unable to clearly articulate their thoughts, assessment must rely solely on behavioural observations, which can be problematic in themselves (Santosh & Baird 1999). Holland and Koot (1998) discuss the difficulty clinicians face in distinguishing behaviours that are developmentally 'normal' for the individual, and behaviours that are new and should be viewed as 'abnormal', requiring further investigation and treatment (5). Some issues contributing to these difficulties are:

- High prevalence of some behaviours in people with learning difficulties, such as poor concentration.
- Behaviours provoked by limitations in cognitive and social competence, such as withdrawal.
- Behaviours that may indicate psychopathology in the general population, but not in people with learning difficulties, such as compulsions or obsessions (4).

3. Atypical presentation of psychiatric disorders

Lennox et al (1997) note that psychiatric disorders amongst people with learning difficulties may present in atypical ways, making accurate diagnosis difficult (81). It may also be difficult to differentiate psychiatric disorders from 'learned' problem behaviours - behaviours that people have developed to serve a specific purpose or function such as expressing need or resistance (Lennox 1997: 81). Stavrakaki (1999) notes that the higher an individual's intellectual ability, the more 'mainstream' their symptoms of depressive disorders will be. In the case of more severe learning difficulties, atypical symptoms will present more often (179).

4. Medication side-effects and withdrawal symptoms

Several authors comment on the widespread use of inappropriate and high dose psychotropic medications to control challenging behaviours in people with learning

difficulties (Lennox et al 1997: 84; HREOC 1993: 662). The side effects of these medications can themselves cause behaviours that can be difficult to differentiate from psychiatric disorders, thus impeding accurate diagnosis (Santosh and Baird 1999: 233; Tonge 1998: 2). If people are not consistent in their use of medications, or cease taking them abruptly, withdrawal symptoms can occur which can also be difficult to distinguish from the symptoms of mental illness (Santosh and Baird 1999: 239).

5. Diagnostic overshadowing

'Diagnostic overshadowing' refers to the process of attributing all abnormal or altered behaviours that an individual may experience, to their learning difficulty, rather than considering them symptomatic of a psychiatric condition (Santosh and Baird 1999: 231; Tonge 1998: 2). If psychiatric disorders are never even considered a possibility in people with learning difficulties, this leads, quite obviously, to them being missed and untreated. As Holland and Koot (1998) state, "unless the possibility of such problems is considered in the first place and an appropriate assessment undertaken to investigate the reasons for a change in behaviour, treatments and management strategies are unlikely to be effective (2).

6. Division between disability and psychiatric services

The gulf between disability and psychiatric services in their response to people with dual diagnosis is, in part, a systematic extension of the process of diagnostic overshadowing. The historical lack of collaboration between these two systems can be seen to be grounded in the belief that people with learning difficulties cannot experience mental illness, therefore, there can be no need for both systems to work together in the lives of one individual. Evidence of this situation was given at the National Inquiry into the Human Rights of People with Mental Illness, where it was noted that the needs of people with dual diagnosis,

> …are often ignored because they fall between two areas of service delivery: non-psychiatric services which cater specifically for people with disabilities, and services which provide expert psychiatric care but are unfamiliar with the needs of the intellectually disabled. This division of services leads to a further disadvantage because the client is treated as if the 'two conditions are mutually exclusive' (HREOC 1993: 660).

5. Risk Factors

The Australian National Mental Health Strategy identifies the following as risk factors increasing the likelihood that mental health problems and mental disorders will develop (CDHAC 2000: 15-16).

Individual Factors

- Prenatal brain damage
- Prematurity
- Birth injury
- Low birth weight, birth complications
- Physical and intellectual disability
- Poor health in infancy
- Insecure attachment in infant/child
- Low intelligence
- Difficult temperament
- Chronic illness
- Poor social skills
- Low self-esteem
- Alienation
- Impulsivity

Family/social factors

- Having a teenage mother
- Having a single parent
- Absence of father in childhood
- Large family size
- Antisocial role models (in childhood)
- Family violence and disharmony
- Marital discord in parents
- Poor supervision and monitoring of child
- Low parental involvement in child's activities
- Neglect in childhood
- Long-term parental unemployment
- Criminality in parent
- Parental substance misuse
- Parental mental disorder
- Harsh or inconsistent discipline style
- Social isolation
- Experiencing rejection
- Lack of warmth and affection

School context

- Bullying
- Peer rejection
- Poor attachment to school
- Inadequate behaviour management
- Deviant peer group
- School failure

Life events and situations

- Physical, sexual and emotional abuse
- School transitions
- Divorce and family break up

- Death of family member
- Physical illness/impairment
- Unemployment, homelessness
- Incarceration
- Poverty/economic insecurity
- Job insecurity
- Unsatisfactory workplace relationships
- Workplace accident/injury
- Caring for someone with an illness/disability
- Living in a nursing home or aged care hostel
- War or natural disasters

Community and cultural factors
- Socioeconomic disadvantage
- Social or cultural discrimination
- Isolation
- Neighbourhood violence and crime
- Population density and housing conditions
- Lack of support services including transport, shopping, recreational facilities.

Research indicates that people with learning difficulties are vulnerable to the same risk factors influencing the development of mental health problems and disorders as the general population (Holland and Koot 1998: 2; Stavrakaki 1999: 177). However, as we know, people with learning difficulties are at *increased risk* of experiencing a range of mental health problems, compared with the general population. This risk further increases proportionate to the severity of learning difficulty a person experiences - “the prevalence of psychiatric disorder is proportional to the severity of the mental handicap" (Lund 1985: 565). We can infer from this that people with learning difficulties experience an *increased vulnerability* to the risk factors that face the general population. An overview of the literature reveals a number of explanations for this increased vulnerability.

Santosh and Baird (1999) suggest the interaction between “brain damage or dysfunction …with social and family factors” (231). Key authors in the area of dual diagnosis literature expand on the elements of this interaction, identifying the following as particular risk factors to which people with learning difficulties are vulnerable (Holland and Koot 1998: 5-6; Stavrakaki 1999: 177, 179, 182; Lennox et al 1997: 81; HREOC 1993: 660; The Royal College of Psychiatrists: www.rcpsych.ac.uk).

Individual factors
- Biochemical and genetic factors
- Structural brain abnormalities
- Communication problems
- Atypical reward preferences
- Increased wariness of strange people and situations
- Negative reaction tendencies during interactions with other people
- Increased sensitivity to psychosocial stressors
- Poor self image
- Low self-esteem
- Low expectancy of success

Family/social factors
- Inadequate reinforcement, inappropriate punishment, reinforcement of deviant response sets

- Increased dependency on adults
- Lack of friends
- Personal and family history

Life events and situations
- Living with an intellectual disability
- Not having a job
- Not having a home
- Poor quality of life
- Experience of multiple traumas
- Rape/sexual assault
- Physical assault
- Verbal abuse
- Accidents
- Physical illness and health problems
- Move
- Loss
- Change in policy

Community and cultural factors
- Not having a valued social role
- Isolation

The Commonwealth Department of Health and Aged Care (2000) states that "single risk factors often have only a minimal effect on their own, but may combine to have a strong interactive effect, and exposure to multiple risk factors over time has a cumulative effect (14). This exposure to *multiple risk factors over time* is a significant feature of the life experiences of people with learning difficulties, and offers additional explanation for the increased vulnerability of this population to mental health problems.

The National Inquiry into the Human Rights of People with Mental Illness noted "social disadvantage inevitably means greater exposure to life's stress factors (stressors)" (HREOC 1993: 845). CLP have clearly identified through practice experience and research that people with learning difficulties are people who experience social disadvantage:

> Recent studies have documented the over-representation of people with learning difficulties in many areas of social disadvantage: homelessness, psychiatric disability, the criminal justice system, unemployment and health problems (O'Connor and Fowkes 2000: 10).

Professor Robert Sapolsky describes stressors as a challenge to our homeostatic balance - the ideal equilibrium of our body. According to Sapolsky, when we are challenged by a stressor our "stress response" kicks in, with the aim of re-establishing this equilibrium (Radio National 1999). However, we need resources to fuel our stress response. A significant feature of the lives of people who experience chronic social disadvantage – as many people with learning difficulties do - is a paucity of resources. As Stephen Moss (2000) states:

> Many people are not physically ill, but they do not have the intellect that allows them to naturally develop coping strategies. They have low esteem in society, they may have poor housing, they may have no autonomy, most don't have spouses or children, and many may not have much contact with their parents. So they are much more vulnerable.

If we are not able to respond and correct the imbalance, the result is perpetual disequilibrium, or "chronic, relentless stress". This chronic relentless stress has been described by Professor Stafford Lightman as "the dangerous stress, that's

what causes the problems…and that's what is causing us to have this great increased instance of depression" (Radio National 1999).

The direct service providers who participated in the Dual Diagnosis Project identified many risk factors drawn from their experience of working with dual diagnosis issues. The information workers provided matched perfectly with that put forward in the literature. It would seem, then, that despite a shared sense amongst workers that they often felt like they were 'ad libing' their way through their work when it came to dual diagnosis issues, workers have actually developed quite a sophisticated knowledge base on which to ground their practice. The key 'missing ingredients' are, perhaps, clear identification, acknowledgement and reflection on this knowledge. 21 broad risk factors are identified from the comments workers made. In an attempt to bring this information to life, some of the examples workers gave of the risk factors as they are experienced in people's lives are included below:

1. 'GENERAL' RISK FACTORS

- Same risk factors as for any person with a mental disorder.
- All the same triggers as for the general population
- Same risk factors as for the general community

2. ABUSE, EXPLOITATION AND TRAUMA

- Sexual abuse and exploitation
- Verbal abuse
- Physical abuse
- Experiencing trauma
- Child abuse
- Adolescent abuse
- Living the cycle of homelessness, with exploitation of and by others.
- Robbery

3. POVERTY AND DISADVANTAGE

- Poverty
- Poor socio-economic position
- Transience
- Dismal lives
- Limited decision-making power, and the insight to know this.

4. 'CARE' AND INSTITUTIONALISATION

- Institutionalisation
- Multiple adoptions
- Multiple foster homes across different states
- Taken into care
- Trauma of foster family system
- Having to live in institutions or group homes

5. SEPARATION FROM FAMILY

- Removal from family
- Not knowing biological family
- Isolation from siblings
- No family history
- Childhood deprivation. No attachment during early developmental years.

6. FAMILY DYSFUNCTION

- Huge desire to connect with family, and emotional upheaval when it doesn't work out.
- Poor home environment.
- Unstable family
- Rejection by family
- Lack of family interest
- Lack of family contact
- Abandonment by family
- Poor parenting skills (of the individual's parents)
- Breakdown in parents' relationship

7. LIVING WITH A LEARNING DIFFICULTY
- Living under really severe stress
- Constantly feeling judged and criticised.
- Being confused
- People not taking the time to communicate in a way that is comprehensible
- People with a learning difficulty are aware that they are different.
- Incredible pressure, both emotional and financial, to appear 'normal'.
- When people have a learning difficulty there is a tendency to push them into lots of activities, which can cause lots of stress.
- Being treated differently because they have a learning difficulty.
- Trauma experienced at the point when they discover they are different.
- Don't succeed as easily as others.

8. MEDICATION AND DRUG USE
- Drugs
- Smoking pot – 'he smoked himself psychotic'.
- Wrong medication bringing on mental health issues.
- Sudden cessation of medication and no appropriate substitute.
- Inconsistent with medication. Stop and start. Lack of continuity.

9. LACK OF PURPOSE AND MEANING IN LIFE
- Wanted a job
- Nothing meaningful to do.
- Boredom
- Lack of viable lifestyle

10. BIOLOGICAL
- People with some kind of brain injury are more likely to experience mental disorder.
- Organic function of intellectual disability increases vulnerability to stress
- Brain imbalances – organic, biological causes
- Genetics
- Chemical imbalance
- You can see family patterns around particular issues.
- Son of Vietnam Veteran (Agent Orange exposure)

11. PHYSICAL HEALTH
- Lack of exercise
- No role modelling of physical and emotional self care
- Poor physical health

12. SOCIAL DISLOCATION
- Extreme loneliness
- Living alone

13. POOR RELATIONSHIPS
- ‘Unhealthy’ relationships which often cause increased stress
- History of never feeling safe and secure in relationships
- Rejection
- Lack of connection to an important person
- No boundaries

14. UNRESOLVED GRIEF AND LOSS
- Grief and loss - parent dies, worker leaves
- Loss of significant relationship with people who’ve been an anchor.
- Realisation that certain goals may never be achieved.

15. EDUCATION
- Lack of schooling
- School being awful
- Harassment and bullying at school

16. INAPPROPRIATE CONTACT WITH MENTAL HEALTH SYSTEMS
- Inappropriate entry and treatment in psychiatric system

17. CONSTANT CHANGE
- Change in people’s lives is often not dealt with and leads to ‘breakdown’.
- No routine, no stability

18. LACK OF SELF-DETERMINATION
- Many people have influence on their life
- Incredible fear that their child will be taken by the Department causes high levels of distress.
- Having their children taken into the care of the Department.
- Being moved out of home with no say, no control, no choice.
- Lack of a sense of personal control and potency

19. SELF-HARM
- Suicide attempts

20. POOR SELF-ESTEEM
- Not feeling accepted and appreciated for who you are. Parents sometimes push too hard for ‘normalisation’.

21. LEARNED HOPELESSNESS
- Negative expectations
- So many things going wrong
- Hopes never realised. Goals and dreams never met.
- Negative experiences as an adolescent male – a danger period.
- Fear
- Moved through life without opportunities to problem solve, therefore haven’t developed these skills. Always protected or rescued.
- Continually not realising goals leads to difficulty determining what’s realistic.

6. Recognising Dual Diagnosis: Assessment Skills

Holland and Koot (1998) state "given the diversity of people with intellectual disability, mental health problems will present in varied ways" (2). One of the key variables is the difference in level of ability experienced by people with learning difficulties. The simple guideline Stavrakaki (1999) proposes is " the higher their intellectual ability, the closer their symptoms…are to those of the general population". People who experience more severe disabilities tend to present with more atypical symptoms (179).

An overview of the key dual diagnosis literature identifies the following potential signs and symptoms of mental health problems and mental disorders in people with learning difficulties (Stavrakaki 1999: 178; Lennox et al 1997: 80, 81; Santosh and Baird 1999: 232-236); The Royal College of Psychiatrists www.rcpsych.ac.uk):

Mood/Psychological

- Alterations in mood
- Irritability
- Depressed affect
- Tearfulness
- Loss of interest
- Low self-esteem
- Loss of confidence
- Seeking reassurance
- Unresolved grief
- Thinking life isn't worth living
- Panic attacks
- Excessive fearfulness
- Depersonalisation
- Derealization
- Delusional phenomena

Behavioural

- Increased behavioural problems
- Challenging behaviours
- Sudden or gradual changes in unusual behaviour
- Changes in routine or environment
- Psychomotor agitation
- Screaming
- Aggression
- Agitation
- Outbursts of anger and/or destructiveness
- Self-injurious behaviour
- Obsessive-compulsive phenomena
- Ritualistic behaviours
- Bizarre mannerisms
- Unusual patterns of speech or play
- Incongruous behaviour
- Inappropriate responses or behaviours
- Blunted or inappropriate affect
- Aberrant sexual behaviour
- Impulsivity
- Changes in level of activity
- Wandering or searching

- Inability to relax or restlessness
- Passivity
- A loss of adaptive behaviour
- Deterioration of living skills
- Increased dependency
- Loss of ability to communicate

Physical
- Eating too little or too much
- Sleep disorders
- Loss of energy
- Physical illness
- Complaining about aches and pains
- Loss of bowel or bladder control
- Sexual dysfunction
- Catatonic posturing

Social
- Social isolation
- Increasing withdrawal
- Self-preoccupation
- Agoraphobia

When asked to name the 'warning signs' that would alert them to consider the possibility that someone they were working with might be experiencing mental health issues, workers participating in the Dual Diagnosis Project identified the following. This information has been grouped into general indicators or warning signs, with some specific examples of each possible warning sign listed.

1. SUDDEN CHANGES IN BEHAVIOUR OR ROUTINE
- Any behaviours that are out of the ordinary for that person
- Any sudden changes in behaviour that may place the person at risk, either from themselves or others.
- Any significant changes in their lifestyle, routines, habits

2. ERRATIC BEHAVIOUR
- Agitation
- Talking fast, incoherent, jumping from one idea/topic/thought to another
- Unpredictable behaviour
- Over or under emotive
- Outbursts: of anger, moodiness, teariness
- Gross inconsistency in day to day responses
- Substantial swings in behaviour and mood

3. IRRATIONAL BEHAVIOUR
- Bizarre behaviour
- Irrational beliefs, unable to be dissuaded from despite evidence
- Disassociation
- Grandiose behaviour
- Unrealistic demands
- Desire for instant gratification
- Demanding behaviour
- Manipulative behaviour

4. ‘ACTING OUT’ BEHAVIOURS

- Aggressive behaviour
- Violent behaviour
- Irrational rage with no apparent trigger

5. ANTISOCIAL BEHAVIOURS

- Inappropriate sexual behaviour
- Inappropriate social behaviour
- Totally cut off from those around you, talk loud and push past others.

6. INTERNAL PREOCCUPATION

- Withdrawal
- Cessation in communication
- Isolation

7. DECLINE IN SELF CARE

- Poor personal hygiene

8. PHYSICAL COMPLAINTS

- Stomach hurts, head hurts
- Sleep difficulties
- Incontinence
- Eyes rolling
- Over-eating
- Under-eating
- Involuntary body movements – tremors and shakes

9. OBSESSIVE/COMPULSIVE BEHAVIOURS

- Repetitive behaviour over time, for example asking the same questions.

10. HALLUCINATIONS

- Talking to themselves
- Communicating with someone/thing who is not there.
- Talking to ghosts
- Hearing voices

11. OVERWHELMING WORRIES

- Not knowing where to start to address problems
- Feeling that problems will never be sorted out
- Feeling overwhelmed by thoughts

12. SCATTERED THOUGHTS AND BEHAVIOUR

- Disorganised thought
- Poor focussing on job at hand
- Inability to cope with work

13. DEPRESSION

- Apathy
- Bleak outlook
- Lack of initiative
- Lethargy
- Feeling down/flat
- Passivity
- Not feeling hopeful or motivated
- Feelings of having no control, no say

- Strong victim mentality
- Throwing up obstacles to new ideas
- Problem saturated stories

14. SADNESS
- Unhappiness
- Teariness
- Continual crying, upset, anger

15. STRESS SYMPTOMS
- Feeling uptight and tense
- Overloaded with stress
- Low tolerance for stress
- High anxiety
- Panic attacks
- Fear of other people and public places.

16. CHANGE IN LEVEL OF ACTIVITY
- Pointless activity (catching buses to nowhere)
- Start missing appointments with worker when usually regular
- Increased phone contact and use of after hours numbers.

17. LOSS OF SKILLS AND CAPABILITIES
- Change in motivation and social skills
- Changes in personal abilities: concentration, physical abilities
- Sudden money problems. Blowing money, having previously budgeted well.
- Inability to cope with simple, everyday tasks. Build up of small tasks to overwhelming proportions.

18. PRESENTING AS 'UP', 'HYPER', 'MANIC'
- Over vigilance
- High arousal
- Unfocussed
- 'All over the place', constantly changing the topic, unable to follow lines of thought through, talking about 50 different things in one meeting.

19. ADDICTIONS
- Commencement or increase in -use of alcohol, illicit drugs, fatty foods, spending sprees.
- Smoking more
- Increased dependence on TV. Stay up watching TV until early hours. Move bed into the lounge room in front of the TV.

20. SELF HARM AND SUICIDAL IDEATION
- Aggressive towards themselves.
- High levels of self-blame.

7. Diagnostic Tools And Processes

Historically, the recognition of mental health problems and the diagnosis of mental disorders amongst people with learning difficulties have been systematically denied. As outlined in the earlier discussion of non-identification and under-reporting, the strict use of inappropriate diagnostic criteria has helped perpetuate the myth that people with learning difficulties do not experience mental health problems and psychiatric disorders. However, as we now know, people with learning difficulties are in fact *more likely* that the general population to experience mental health problems and disorders. As the acknowledgement of this fact gains acceptance, the formal diagnosis of mental disorders amongst people with learning difficulties should increase, in turn leading to more accurate and effective treatment and interventions.

A. DIAGNOSES

Discussion with current practicing workers reveals that while diagnoses are generally few and far between, they do occur, and it is interesting to consider any trends in the types of diagnoses this population receive. To help develop this picture, workers who participated in the Dual Diagnosis Project were questioned as to the types of diagnoses they encounter in the course of their work.

The most common diagnoses workers reported were:
- Schizophrenia
- Bi-polar; Manic Depression; Bi-polar Affective Disorder
- Depression; Major Depression; Post Natal Depression

Following these, workers then mentioned:
- Anxiety Disorder
- Personality Disorder; Borderline Personality Disorder; Personality and Mood Disorder
- Post Traumatic Stress Disorder

Less common were:
- Obsessive Compulsive Disorder
- Psychosis; Major Psychosis

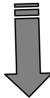
Least common were:
- Dementia
- Alzheimers
- Mania
- Eating Disorder

B. PATHWAYS AND PLAYERS

Workers participating in the Dual Diagnosis Project were questioned as to *how* the people they work with have obtained formal diagnoses. The diagram on the following page depicts the different contexts and means by which people obtain a diagnosis, as well as the people who are generally involved in the process. An explanation of the parts of the diagram follows, including some of examples given by workers.

DIAGNOSIS: PATHWAYS AND PLAYERS

A		***B***
DIAGNOSED PRIOR TO CONTACT WITH THE SUPPORT SERVICE	***and / or***	**DIAGNOSED WHILST IN CONTACT WITH THE SUPPORT SERVICE**



PROCESS INITIATED BY:

a	*b*	*c*
FAMILY/ SIGNIFICANT OTHERS	SERVICE PROVIDER	POLICE ARREST

DIAGNOSIS MADE BY:

1	2	*3*	*4*	*5*	*6*	*7*
GP	PRIVATE PSYCHIATRIST	HOSPITAL MENTAL HEALTH UNIT	CMH	DDU	DSQ	INSTITUTION

THE DIAGRAM EXPLAINED:

A. DIAGNOSED PRIOR TO CONTACT WITH SERVICE

- Diagnosis often stated in vague and bizarre medical records.
- Diagnosis may be 10-15 years old and irrelevant.
- Workers may contact doctors or hospital to get a verbal diagnosis in writing.
- People may have multiple diagnoses and not know what any of them mean.

B. DIAGNOSED WHILST IN CONTACT WITH THE SUPPORT SERVICE

PROCESS INITITATED BY:

a. FAMILY/SIGNIFICATION OTHERS

- Family or friends initiate and manage the process, arranging assessments and supporting interventions.
- Workers may provide support, advice, research, and appropriate referral.

b. SERVICE PROVIDER

- For example, support worker, GP, health worker.
- Service provider observes behaviours suggestive of mental health issues and supports the person they are working with to address these issues and participate in a process of assessment, diagnosis and treatment.

c. POLICE ARREST

- Person is picked up by the police, usually for antisocial or illegal behaviour, and transported to a public hospital mental health unit.

DIAGNOSIS MADE BY:

Workers discussed seven different ways they have seen people obtain psychiatric diagnoses. Outlined below each point are some comments illustrating how workers have experienced that particular process 'in action':

1. GP

- Mental health issues cause disruption in the person's life and they present to their GP seeking assistance. Often people are prompted and/or supported to do this by their family, friend, or worker. The GP manages the person's treatment, often with medication. Sometimes the GP will refer the person to a private psychiatrist who will manage assessment and treatment.

2. PRIVATE PSYCHIATRIST

- The person attends a private psychiatrist, following referral by a GP. Generally private psychiatric treatment is paid for by the person's family or through their funding package. On occasion services employ discretionary use of service funds to pay for private psychiatric assessments.

3. HOSPITAL MENTAL HEALTH UNIT

- A worker observes signs of a 'breakdown' and takes (or arranges transport of) the person to a hospital mental health unit where they are admitted and treated. In this scenario suicidal ideations or threats of harm to self and/or others are often involved. Worker experienced hospital as a useful crisis intervention because it has stopped the person killing themselves at that time.
- Police transport a person to hospital, often having been called to a situation where the person is engaging in violent or other antisocial behaviours. Workers' experience has generally been that the person is admitted overnight,

then released the next day. Once again, perhaps a useful crisis intervention, but with limited long term effect.

- The person presents to a hospital mental health unit in crisis. Workers commented that in this situation people are often viewed as a ‘problem’ to be moved quickly through the hospital system. Workers generally did not view this process as providing any useful or long term interventions, highlighting such issues as:

(a) Many people have had multiple admissions to hospital and multiple diagnoses by different doctors. Generally, people don’t understand any of the diagnoses they have received.
(b) Often there are limited, if any, hospital records of these multiple admissions kept.
(c) The person’s problems are generally seen as a by-product of their personality or learning difficulty, and not as a mental illness.

4. COMMUNITY MENTAL HEALTH (CMH)

- Workers outlined a range of ways contact with CMH might begin, including:

(a) Worker phones CMH with a referral. The CMH Access Team collects details over the phone. The person is asked to come in for an assessment if the CMH team discussion decides there are appropriate and sufficient indicators.
(b) The worker supports person to attend their local CMH clinic in person.
(c) The person telephones the After-hours Mental Health service for phone support.

- Workers saw the following factors as integral to the ultimate success or ‘usefulness’ of a CMH assessment and intervention plan:

(a) The worker has a good relationship with the local CMH. When this is in place an assessment is made and a treatment process initiated (often admission to hospital). Where such a relationship was absent, workers comments included:

> *“There are often discrepancies between what CMH say and what they will do. They often promise assessments, but they are rarely forthcoming”.*

(b) The worker supports the person to attend CMH appointments, or is kept informed of what took place. When workers were not involved it was difficult for them to follow-up with the person because they were not sure of the outcome of the CMH assessment, what interventions were initiated, and what support they should be providing. Without worker involvement and support treatment was generally ineffective, however, such involvement obviously requires the consent of the person involved.

- A number of workers commented on the difficulties they had experienced getting a service from CMH when the people they worked with did not meet what they perceived to be the CMH criteria of long- term or chronic Bi-Polar or Schizophrenia; or severe crisis. Workers’ felt this meant that CMH weren’t an effective resource in terms of prevention or early intervention work.

5. DEVELOPMENTAL DISABILITY UNIT (DDU)

- On suspecting mental health issues the worker, in consultation with the individual, arranges an appointment with the DDU for assessment by a psychiatrist. Where Disability Services Queensland (DSQ) has a role in the person’s life, workers have advocated that they arrange an assessment with the DDU.

6. DISABILITY SERVICES QUEENSLAND (DSQ)

- When Disability Services Queensland (DSQ) has a role in the person's life workers have advocated for an assessment by a DSQ psychologist.

7. INSITUTION

- Workers in the institution have a relationship with and easy access to psychiatrists and psychologists.
- As required, people living in the institution are attended by a psychiatrist and diagnosed.

C. KEY ISSUES AND CONCERNS

Workers participating in the Dual Diagnosis Project raised five significant concerns drawn from their experience of the diagnosis of mental health problems and disorders in people with learning difficulties. A number of the issues workers raised are reiterated in the key literature on dual diagnosis reviewed during the course of this project.

1. RELUCTANCE OF MENTAL HEALTH PROFESSIONALS TO DIAGNOSE MENTAL ILLNESS IN PEOPLE WITH LEARNING DISABILITIES

- Workers commented that whilst they suspect that lots of the people they work with have mental health problems, not many people are clinically diagnosed. Workers view undiagnosed depression and anxiety as a major issue for people with learning difficulties, an assertion that is supported in research discussed by Stavrakaki (1999) and Lennox et al (1997: 81).
- Workers feel that medical professionals and mental health workers are often reluctant to acknowledge psychiatric issues in people with learning difficulties. This harsh reality is supported in the discussions of a number of authors writing on the issue of dual diagnosis (Holland and Koot 1998: 5; Santosh and Baird 1999: 231; Tonge 1998).
- Workers' experience is that medical and mental health professionals often attribute problem or changed behaviours to the person's learning difficulty, denying the possibility of mental health issues. Fletcher (2001) and Tonge (1998) both discuss this situation, under the label of 'diagnostic overshadowing', and recognise the serious implications this has in terms of failure to recognise mental health issues amongst people with learning difficulties.
- Workers' advised that when seeking an assessment and diagnosis it is very important to choose the right psychiatrist, one who understands and accepts the existence of dual diagnosis.

2. MISDIAGNOSIS

Paradoxically, whilst many people with learning difficulties struggle to be recognised by the mental health system, others struggle to escape the burden of multiple and incorrect labels they have received from this same system. Workers comments included:

- People may carry with them multiple and conflicting diagnoses and labels. Often people will have diagnoses that are 10 to 15 years old, possibly irrelevant, but for which they are being treated with powerful medication.
- A significant number of people are inappropriately admitted to the mental health system. Some workers expressed their belief that the trauma of this experience could cause a person to experience mental health issues. Moss (2000) urges workers to exercise caution against viewing the world through dual diagnosis-coloured glasses, seeing all people's problems as mental health problems.
- Limited or poor verbal communication skills often play a role in misdiagnosis. Workers called for caution when conducting assessments and diagnosing

mental disorders, asserting that clinicians need to eliminate the possibility that the person may be using bizarre behaviours to attract attention, or express needs or frustrations. Santosh and Baird (1999) discuss the need to recognise that communication difficulties may be expressed as problem behaviours, and the inherent limitations of relying on behavioural observations to diagnose psychiatric disorders amongst this population (231, 235).

- Untreated physical health problems may lead a person to communicate pain through problem behaviours. Misdiagnosis occurs when the problem behaviours are labelled as mental health issues, referred to the mental health system, and treated inappropriately with sedation. Lennox et al (1997) discuss the importance of recognising and differentiating problem behaviours that are secondary to underlying medical disorders from problem behaviours that are symptomatic of a psychiatric disorder (81).

3. MISUSE OF LABELLING

- Some workers noted that people are sometimes labelled as they move through services and systems with diagnoses that have not been formally made. These can become permanent labels on people that transfer on paperwork between organisations.
- Assessment tools such as the PAS-ADD should not only be used as a means of giving a label to difficult clients. These tools are valuable only as long as they lead to more appropriate and effective interventions which help people with dual diagnosis. Moss (2000) discusses this issue of labelling, stating “we have to absolutely certain that we are not labelling people with more and more labels which makes them seem more and more different from us, or socially disadvantaged”.

4. LIMITATIONS OF DIAGNOSTIC PROCESSES

- Workers noted the difficulties of making a psychiatric diagnosis when people don’t have verbal skills. Holland and Koot (1998) discuss the importance of being able to obtain relevant information from a variety of sources in addition to the person themselves, including relatives and carers (5).
- The process of assessment and diagnosis can be confusing and intimidating for people with learning difficulties. One worker spoke of a person who visited CMH and “fed garbage” to the psychiatrist – “he thought he had to give the ‘right answer’, so he just made stuff up”. Stavrakaki (1999) discusses the limitations of using strict diagnostic criteria with people with developmental disabilities, and the probable risk that this will exclude potential cases and lead to the under-representation of the problem (178).

5. CONSTITUENTS’ UNDERSTANDING OF THEIR DIAGNOSES

- Workers stated that they often work with people who know they’ve been to hospital, but they can’t say exactly what for. They may have had multiple admissions and diagnoses at different hospitals by different people. Often people don’t understand what their diagnosis means.
- Workers also noted that people generally don’t talk about their diagnosis with any sense of control. They talk about it as a feature of themselves – ‘I have depression’. Moss (2000) warns against this dark and debilitating side of diagnosis, stating,

  > …the idea of illness, of illness that can never go away is not a dynamic liberating force. Illness creates victims…it is not unreasonable that many so called victims will lead limited, powerless and unfulfilled lives.

8. Interventions And Treatment Methods

It is clear from the responses of workers who participated in the Dual Diagnosis Project that they have at their disposal a variety of tools and strategies which they use to inform a wide range of interventions in response to dual diagnosis. What also became apparent, however, was that workers undertake this work with some trepidation, and a sense of trial and error.

Whilst workers spoke of a wide array of interventions, they repeatedly identified the belief that their work with dual diagnosis issues is primarily crisis intervention and ongoing support, and to a lesser extent early intervention. The explanation offered for this was that by the time a person comes in contact with a service they are already experiencing many risk factors for mental health problems, so the work is always 'at least' early intervention.

Presented below are nine intervention 'types' drawn from workers practice experience. Each intervention type is elaborated on by a series of practice principles identified workers in their discussion. The Prevention-Early Intervention-Crisis Intervention framework is used to structure this information. As noted earlier, these divisions are extremely artificial, but they do serve the purpose of illustrating that the weight of interventions workers utilise are at the crisis end of the spectrum.

A. PREVENTION AND PROMOTION

Most of the workers who participated in the Dual Diagnosis Project would argue that this part of their work is a form of early intervention. Technically, it can actually be viewed as *both* Prevention and Early Intervention. The Commonwealth Department of Health and Aged Care (2000) notes that 'indicated prevention' (which would include direct support work to people with learning difficulties) is encompassed under the mantles of both Prevention and Early Intervention (32).

1. General support work

- Take the time to talk with people about their life and their perceptions of how things are going and how they are feeling. Regular revisit this discussion as it provides you with information, helps you monitor changes, and helps to build a particular type of relationship that may encourage people to come to you when they are in crisis.
- Develop systems with people to help with organisation. If people feel their life is organised it can help them feel organised emotionally and reduce stress. Examples: Weekly calendar of events; Reminder notes around the house.
- Help people build structure into their lives. This can help people feel grounded and in control.
- Watch for the signs of mental health problems. Regular contact with clients means that workers will have a better chance of noticing when people's behaviour and mood deteriorates or changes.
- Identify with people potentially harmful or stressful situations, and their triggers, and plan ways to avoid or diffuse them.
- Help people to look ahead and identify what they can do now in preparation for possible crisis points in the future.
- Communicate with people to develop an understanding of their wants and needs, and any issues and concerns they have. Talk about ways they might meet their needs and address their concerns.
- Name strengths. Highlight people's competency and mastery. Acknowledge what people are doing well. Express your faith in their coping abilities.
- Be strategic and deliberate in how you have conversations with people about the hardships and struggles in their lives. Pick your moment.

- Challenging problem-saturated stories. Reframe and suggest another way of talking and thinking about their story.
- Introduce good themes. Help people plan to have good moments. Ask, "what things do you enjoy about your life?"; "what happened today that made you smile?".

B. EARLY INTERVENTION

2. Physical health promotion

- Promote and support physical health. This will have flow on benefits for improved mental health and well-being.
- Develop and support opportunities for people to participate in exercise and physical activity.

3. Relationship and belonging

- Loneliness is a major issue for people with learning difficulties. Isolation is a risk factor for the development of mental health problems.
- Relationships with key workers are important, but it is important that people have someone other than their worker who they can talk with and gain support from.
- Support the strength of people's links with others. Families, friends and neighbours.
- Support people to establish networks or friendship circles, people they can contact when they are not feeling well. People can feel supported and stresses eased just by knowing someone is there.
- Explore the idea of building relationships and sharing phone numbers with neighbours. Neighbours can have the service phone number or the worker's mobile phone number and can ring it if something is wrong.
- When considering options for interventions don't do things in isolation. Talk to the people who know the person to discuss what they like and dislike, and seek their input to help anticipate potential effects.
- It's important that significant others get support so they are able to maintain their relationship with the person with dual diagnosis. For example, workers have assisted in organising respite for carers.
- Groups promote relationships and create links between people. They can provide a safe and gentle therapeutic process. Groups can be social or organised around particular activities.

4. Skill development

- When people develop new skills their confidence and self-esteem is often increased.
- Encourage people to build on the skills and strengths they already have. Actively assist people to identify these.
- Support people to practice the skills they would like to have. For example, role-plays and video can provide safe opportunities for people to practice social skills and saying no.
- New skills can help reduce stress in people's lives, which has a positive impact on their mental health. For example, computing training responds to the stress of not being able to use a computer. Developing reading, writing, numeracy and financial skills can help reduce stress about not understanding and fear of being ripped off.
- People need multiple contexts in their lives. Learning new skills, going to groups and to work broadens peoples lives. They have more things to talk about with other people, and more opportunities of meeting people to talk to.
- People need more in their life than problems. Learning a new skill is like a job. Focussing on the job at hand gives people time away from their problems and

can break patterns of obsessing. Remind people this is work time now, not problem time.

- Develop skills in a safe, non-competitive environment. Give people opportunities to practice behaviours that make fitting into a group easier. For example, saying hello and goodbye, asking other's how they are doing, letting the facilitator know if your are sick and can't attend.
- Paid work develops skills, gives people money, and increases their confidence. When you pay people you have more leverage to challenge negative behaviours.

5. Stress and behaviour management

- Develop strategies to minimise practical stresses in people's lives. For example, automatic rent payment means people have one less bill to worry about, and their accommodation won't be jeopardised by their failure to remember to pay the rent.
- Support people to take action to deal with stresses. For example, a mother worrying about not communicating with her children can be supported to write a weekly letter.
- Focus on strengths and positives to counter negative and debilitating thoughts. For example, use strengths cards to challenge negative thinking; decorate a person's room with positive affirmations and photos which remind them of good times, people who care, and what a great person they are.
- Support people to plan and have good times, pleasurable experiences, and new opportunities.
- Help people identify activities that give them pleasure, and that they can engage in to reduce stress and anxiety and/or take their mind off their worries. There are many tools and strategies which can help:
  - *Aromatherapy*
  - *Relaxation*
  - *Deep breathing exercises*
  - *Keeping a diary, writing down thoughts to release feelings.*
  - *Art/Craft*
- Help people to identify their own mental health issues, including how they feel physically and emotionally when they are not well. This can help people recognise when they are becoming unwell.
- Support people to identify when they are becoming unwell by naming and talking about changes in behaviour or mood that you observe.
- Work with people to plan strategies for managing their mental health, things they can do when they recognise they are becoming unwell. For example:
  - *Tell someone*
  - *Exit the situation that is causing the problem*
  - *Seek out company*
  - *Take time out for yourself.*
  - *Calm yourself with a personal mantra/affirmation.*
- Help people identify what causes them to become unwell. Support people to identify triggers and anticipate future episodes.
- Develop a contingency plan in anticipation of future problems. Establish what your role and responsibilities as a worker will be, what response the person wants from you. Contingency plans are only effective if developed in collaboration with the person involved. Workers must clearly communicate the meaning and effect of any statutory and organisational guidelines that they are bound to follow.

C. <u>CRISIS INTERVENTION AND ONGOING SUPPORT</u>

6. Crisis response

- Directive and value laden practice, informed by analysis, is useful at this time.
- Recommend contact with medical/mental health professionals.
- Give people lots of hopeful and optimistic messages. Not to minimise their problems, but to create a larger story and a way forward.
- Increase the routine and structure around the person's life. Workers take up functional roles such as cooking and shopping.
- Encourage and support people to solve the particular stresses that they can. For example, obtaining money to pay the rent.
- Get the person out of the environment they are in if it is causing or exacerbating their stress.
- Warn against people making big decisions at times of crisis. For example, deciding to adopt a child out.
- Talk with people about how they are feeling. Regularly review this, watching for changes in mood or behaviour.
- Talk about things people can do to alleviate their stress and anxiety. Prompt relaxation skills and strategies. For example, go for a walk, listen to music, watch TV, phone a friend.
- Develop a safety plan. Especially when there are self-harm issues. For example, phone your worker, a family member, mental health after-hours number, an ambulance. Ask people to name what is going to help them.
- Initiate a previously developed contingency plan. Initiating a familiar plan can help people feel more in control when they are sick. When the person is well again the worker should review the contingency plan, discussing what worked and what could be done differently.
- Initiate a 24-hour on-call system and provide the person with a contact number with clear directions on its appropriate use.
- When someone becomes sick workers often need to reconstruct history and locate them if they have gone missing. When people are well workers need to identify who they can go to for information if that person gets sick. Individuals need to be in control of this as it is important when people are sick that they maintain/regain control of their lives.
- Take any appropriate and necessary steps to respond to threats of harm to self and others.
- Call the police as a last resort

7. Medical interventions

- Suggest and support people to obtain medical help when appropriate. Support them to make appointments and attend consultations with their GP, CMH, DDU, private psychiatrist. Sometimes financial support may be necessary.
- Medical interventions can give names and explanations for what people are experiencing, and this can be liberating. However, people need to understand them. Support people to understand their mental health issues and the interventions they are receiving.
- Support people to access prescribed medication. Some workers access discretionary funds.
- Support people to take prescribed medications properly. For example, take medication when the news is on.
- Know how to arrange an assessment and get a diagnosis (if appropriate). Know when and how to advocate for and obtain a proper response.
- Build relationships with doctors, psychiatrists, and mental health workers. This can assist appropriate and expedient interventions, and support their long-term success. Share information (with client consent) to promote a better response for the person. Seek advice on the best way to work with and manage particular mental health issues.

8. Therapy

- Therapy may involve group work or individual work.
- External therapists may have a degree of distance which enables them to express and discuss difficult issues.
- Talking about problems and finding practical ways of dealing with them are essential parts of treatment.
- Counselling can be very successful with people with learning difficulties as long as it is tailored to individual communication abilities and level of understanding.
- Creative strategies are often utilised that can help people to express and release emotions. For example:
  - *Music*
  - *Dance*
  - *Drawing/Painting*
  - *Pictures*
  - *Toys*
  - *Role plays*
- Therapy may be used for a variety of reasons, including:
  - *Teach people to self-express*
  - *Teach people relaxation skills.*
  - *Process grief and bereavement*
  - *Help people to identify, explore and communicate feelings.*
  - *Challenge negative beliefs and behaviours.*
- For workers to best support the aims and achievements of therapy they should attend sessions, or be informed of what work was done, and what support work they should be doing between sessions to promote therapeutic learnings.
- Workers need to be aware of the powerful emotions this type of work can bring up and develop strategies in advance to respond to these.

9. Appropriate referral

- Refer to specialist services when they are necessary. For example, sexual assault services; legal services; respite services.
- Work with families to help them link into support systems and resources.
- Understand available systems and resources so you can advocate for a service and challenge poor responses.
- Undertake joint work when appropriate. Be clear about your role and keep your promises.

9. Practice Skills For Dual Diagnosis Work

Evidence presented at the National Inquiry into the Human Rights of People with Mental Illness identified the lack of workers specifically trained to work with dual diagnosis issues as a "huge problem" (HREOC 1993: 663). The Inquiry highlighted "appropriate professional training" as an area of critical need that had to be addressed in order to provide quality service responses to people affected by dual diagnosis issues (663). This need is reiterated by a number of authors writing on the issue of dual diagnosis (Stavrakaki 1999: 184; Moss 2000).

Once we recognise the need for workers to be trained to respond to dual diagnosis issues, we must then ask what are the skills that workers need to develop to do this work. This question was asked of the 27 workers who participated in the Dual Diagnosis Project. Drawing from their practice experience, workers identified a wide range of skills that they believe are essential for effective work with people with dual diagnosis. These skills can be grouped into 3 main categories, namely:

1. **Theoretical Knowledge**
2. **General Practice Skills**
3. **Specific Dual Diagnosis Practice Skills**

The component skills that make up these three groupings are elaborated on below. In the individual interviews and the focus group, workers discussed in some detail *how and why* they use these skills. In an attempt to capture a sense of this information some of the elaborating comments and examples workers gave are also detailed below.

1. THEORETICAL KNOWLEDGE

a. Mental Health Knowledge

- General knowledge of particular disorders, including key signs and symptoms.

b. Knowledge of Learning Difficulties

- Understand how learning difficulties may affect individuals, and how individuals with learning difficulties may present.

c. Dual Diagnosis Knowledge

- To inform understanding of the relationship between mental health problems and disorders, learning difficulties, and drug and alcohol issues abuse, and how these may interact.
- To inform ability to distinguish between learning difficulties and mental health issues.
- Awareness of issues of diagnostic overshadowing, and the impact this can have on over or under recognition of mental health issues amongst people with learning difficulties.

2. GENERAL PRACTICE SKILLS

a. Relationship Building

★ *Between Worker and Constituent*

- You need to develop a relationship to provide meaningful support.
- You need time to allow for a slow process of relationship and trust building.
- Engage people as participants, rather than as problems.

- You need a relationship with people where you can name questionable behaviours.
- You need to work with the person, not a pathology.
- You need objectivity about your relationship with clients. When a person becomes ill and their behaviour changes it can be hard not to blame the person for behaving badly. You have to remember the person had a mental illness.
- You need to be comfortable to allow people to do what's ok for them. For example, you can't be sensitive about swearing.
- You need to work alongside people, explaining your what you are doing and why.
- Explain and encourage people to practice good manners and social skills. Things that make fitting into a group easier.

★ *Between Constituent and Others*

- Support the strength of people's links with others (families, neighbours).
- Support people to develop meaningful, intimate, non-exploitative relationships.

b. Communication Skills

- Use a range of communication skills.
- Recognise and respond to individual levels and styles of functioning and language.
- Listen and resist making assumptions.
- Go slow.
- Give clear explanations.
- Let the person know exactly what you're doing. Do a lot of processing 'what' and 'why'.
- Try to give simple, clear time frames.
- Negotiate when people become difficult to communicate with and motivate.

c. Counselling & Support

- Talk through anxieties.
- Grief and loss counselling.
- Debriefing and processing experiences of abuse.
- Supporting people to answer back to external contexts, to have some mastery over external forces.

d. Advocacy

- Workers need to be good advocates.
- Know how to work (and challenge) the networks and systems.
- Know the discourse of the systems, and use it to get results.
- Put forward your knowledge of the person to systems to facilitate an accurate and effective response.

e. Work with the individual

- See people as individuals, don't have one template for everyone.
- Work with people holistically.
- Make a time and place for problems. Liberate people from constant preoccupation.
- Be strategic. Pick your time and moment to address challenging issues.
- Have a long-term view. Remember there will always be some resistance to change.
- Give people hope that it won't always be like this.

f. Place the problem in a bigger picture.

- Recognise and respond to the broader social and political forces impacting on people's lives.

g. Creativity

- Be creative in your outlook.
- Use lateral thinking.
- Use creative tools such as art for the expression of emotions.
- Move beyond the concrete.
- Be resourceful.

h. Strengths based work practices

- Develop people's self esteem.
- Identify the person's strengths.
- People often have skewed notions of their abilities. Notice and point out the things people are doing to assist themselves.
- Introduce good themes into conversations with people about the hardships and struggles in their life.
- Challenge problem saturated stories.
- Reframe. Give people another way of talking and thinking about their story.
- Work with people's ability to influence their life in a way that they want. Work with the person's capacity to exert control.

i. Knowledge of systems and resources

- Know the right places and the right people to go to, to get help.
- Develop you knowledge of systems to inform advocacy work.
- Conduct community research to identify available services and supports for appropriate referral.
- Recognise when specialist services are needed and bring them in. For example, sexual assault services.

j. Collaborative work practices

- Utilise other workers' and services' advice, expertise, and personnel (for group work).
- Understand the culture and practices of other agencies, departments, systems.
- Need to work collaboratively with Mental Health and Disability Services Queensland.
- Develop contacts in the mental health and disability systems.
- Work with support workers, family and other carers.
- Be able to pull all stakeholders together to work together. No turf wars or client ownership.
- Build up personal connections and use these, rather than relying on policy to build a case for a response.
- Encourage a support person or family member to come into the counselling session who can go over/review/practice outside the session. This multiplies the capacity of the intervention to have an impact on the person's life.
- Clear communication between team members about current status of person's mental health, impact of interventions, and contingency plans.

k. Planning and analysis

- Identify the triggers of a person's mental ill health. Break down behaviours and look at causal links.
- Recognise what's happening and use this to plan appropriately for current and/or future interventions.
- Gather information from significant people – family, friends, workers.

- Learn from the past and plan ahead. Develop contingency plans with the person.
- Analytical skills.
- Problem solving skills
- Planning and program skills

3. SPECIFIC DUAL DIAGNOSIS PRACTICE SKILLS

a. Assessment
- Knowledge of types of mental health problems, and their signs and symptoms.
- Knowledge of and ability to identify a person's individual symptoms of becoming unwell.
- Ability to identify and compare a person's well and unwell behaviours.
- Try to be more accurate in your assessment. For example, use PAS-ADD Checklist.
- Monitor person's behaviour and state of mind. Predict relapses.

b. Early Intervention
- Know when to suggest to people that visiting a doctor could be helpful.
- Support people to plan to have good moments.
- Support people to recognise the good parts of their life, what they enjoy.

c. Support people to identify their mental well-being issues
- Help people to develop a language to communicate feelings, their sense of inner self, and their mental well-being.
- Help people to be aware of their own stress levels.
- Challenge people's normalisation of stress. Help people to recognise that it's not good to live with stress for a long time.
- Explore connections between what happened and how the person felt.
- Help people look ahead and prepare for the future, respond to their worries.

d. Support people to manage their mental well-being issues
- Skills for helping people to manage their stress.
- Relaxation. Support people to discover what works best for them.
- Plan strategies with the person for what they'll do when they feel unwell.
- Role playing feelings; acting out answers and solutions to problems

e. Knowledge and ability to use treatment strategies and models
- Support workers need lots of information about practical strategies.
- Managing challenging behaviours
- Challenge paranoia.
- Cognitive Behaviour Therapy
- Narrative Therapy
- Group work
- Intervention plans need to be manageable within the person's daily life.

f. Crisis Response Skills
- Flexibility.
- Ability to locate and develop after-hours options.

g. Threats of harm to self and/or others
- Be clear how you will respond to self-harm issues, and threats of harm to others.
- Explain organisational safety policies and procedures.
- Plan how to respond to suicide attempts and self-harming behaviours.

- Plan for your own personal safety.
- Follow your intuitive senses about threats, dangerous situations.
- Plan safety mechanisms for all your work. Individual and group.
- Know when it's not appropriate to work with someone. For example, when they are heavily medicated or in 'another place' psychologically. At these times workers just need to be with person and reassure them that they are safe with them.

h. Negotiating hospital and psychiatric systems

- Understand the hospital and mental health systems and help people negotiate them. Explain systems, processes, procedures.
- Liaise with people's psychiatrists and psychologists. Develop a relationship that will support the work they are doing with people.
- Know where to go and how to advocate for a current diagnosis.

i. Psychoeducation

- Help people with learning difficulties understand their mental health issues.
- Support families and workers to explain to the person their mental health issues.

j. Medication

- Understand the use of medications.
- Knowledge of medication and side effects.

10. Developing And Supporting Workers' Skills

Having identified the skills workers need in order to work effectively with dual diagnosis issues, it becomes appropriate to explore *how* workers might develop and maintain these skills. The workers who participated in the Dual Diagnosis Project identified seven key supports to developing their professional skills in this area. Workers gave many examples of each of these key supports and some of these are outlined below.

1. ACCESS TO 'EXPERTS'

- Having a relationship with psychiatrists and psychologists can facilitate the process of getting proper assessments.
- Talking with doctors. Get to know people's psychiatrists, who then feed back information.
- The DDU have been helpful in teasing out diagnoses.
- Specialist psychologists to whom the agency refers to deal with specific issues. For example, dementia and bi-polar.

2. COLLEAGUES AND PEER SUPPORT

- Colleagues provide advice, expertise, personnel resources to co-facilitate groups.
- Talking to colleagues and other experienced workers is an important source of information and support

3. AGENCY SUPPORT AND PROFESSIONAL SUPERVISION

- Help workers to maintain perspective. Workers can become frustrated when they don't recognise the role of mental illness in a person's challenging behaviours. Supervision helps workers look at their work more objectively.
- Residential support workers need to understand what is going on. Abuse occurs when support workers don't understand the nature of a person's disability, or believe the person has a disability. They take challenging behaviours personally. Support workers need lots of supervision

3. NETWORKS

- Other disability agencies.
- Participated in the Logan Mental Health group, a number of organisations and services who worked together to respond to difficult situations and people who fall between the cracks. We tried to look holistically at the person's life (school; home; work). Each agency asked what can we do, what resources can we offer. This process required lots of personal commitment by the workers involved.
- Served on the Mental Health Alliance. Discussions with other workers were very helpful.
- Get on mailing lists to find out what's out there to support residents and staff.

4. PROFESSIONAL DEVELOPMENT

- Read relevant books and literature.
- Attend courses, forums, seminars, training, conferences.

5. PRACTICE EXPERIENCE

- You pick most of it up along the way.
- Working at CLP provided an opportunity to develop an analysis around mental health issues.
- Being able to have heard people talk about their stories has taught me a lot.
- Experience means you know the right places to go to get help.

- Talking to professionals from an informed position means you can advocate. You know what can and should be happening, and when people are telling you incorrect information.

6. PERSONAL CHARACTERISTICS

Many workers also spoke of the particular personal characteristics that they felt might make someone more suited and successful in working with people with dual learning difficulties and mental health issues. These included,

- Being laid back or calm
- Ability to relate easily with a wide range of people
- Open minded
- Flexible and available
- Respectful
- No value judgements
- Empathetic
- Patience
- Personal commitment
- Having confidence in your skills

11. 'Gaps' Limiting Effective Responses to Dual Diagnosis

Workers participating in the Dual Diagnosis Project were questioned as to the gaps they encountered in the service responses available to people with learning difficulties, who also experience mental health problems and mental disorders. Workers identified 14 areas of concern.

1. PSYCHIATRISTS AND OTHER MEDICAL PROFESSIONALS

- Workers regularly deal with psychiatrists and other medical professionals who do not understand the relationship between learning difficulties and mental health issues. Many professionals in this field appear to practice under the misconception that people with a learning difficulty cannot experience mental health issues, and attribute all symptoms and problem behaviours to the person's learning difficulty.
- Workers often experience difficulty dealing with medical profession, and are regularly frustrated as they try to get information and explanations to help the people they work with.
- Workers argue that most people with learning difficulties don't get a great service out of most psychiatrists. Key issues are:
- Difficulties with communicating mean people can't express themselves well.
- Overzealous and inappropriate use of medication.
- Difficulties describing side effects and symptoms of medication leads to use of more old style medications. This means people tend to be more 'doped up' and then don't want to take the medication.

2. DUAL DIAGNOSIS KNOWLEDGE AND EXPERTISE

- Workers identified their need for specific information around the contribution psychological practices can offer people with learning difficulties. Workers want to better understand the nuts and bolts of some psychological practices, including the reason why certain therapies can't be used with people with learning difficulties.
- Workers want specific information on how mental illness may impact on people with learning difficulties, including:
  - Theoretical perspectives on mental illness and learning difficulties
  - Impact of mental illness on people with learning difficulties, compared with the experiences of the general population.
  - Triggers of mental health problems.
- Workers identified a lack of people with skills in dual diagnosis work.
- Workers need information on how managing the symptoms of dual diagnosis.

3. KNOWLEDGE AND UNDERSTANDING OF INTELLECTUAL DISABILITY

- Workers identified as a serious problem people with learning difficulties who are inappropriately admitted to the psychiatric system because of a lack of knowledge, skills and understanding of learning difficulties.
- Workers criticised a lack of acknowledgment that people with learning difficulties experience trauma. Normal responses to trauma are often treated as symptoms of mental illness. The person is then admitted to the psychiatric system and treated with inappropriate medication. The original trauma remains hidden underneath.
- Workers raised as an issue the lack of counsellors and therapists who acknowledge it is possible to engage in therapeutic work with people with learning difficulties.

4. FUNDING AND RESOURCES

- Workers noted the difficulties they face trying to obtain funding for people with undiagnosed mental health problems. Without a diagnosis it is very difficult to

secure funds. This in turn limits access to mainstream activities and services, as people can't pay.

- Workers identified a lack of adequate services available to people with learning difficulties who do not have a funding package.
- Workers commented that there are never enough human resources in the disability sector. Never enough money to pay qualified staff. One-on-one staff would be ideal for some clients with dual diagnosis.

5. MENTAL HEALTH SYSTEM: CRITERIA AND ATTITUDES

- People with learning difficulties don't get useful help from Mental Health clinics. Workers are often knocked back because person has a learning difficulty.
- Workers identified huge problems getting Mental Health to acknowledge a psychiatric illness in a person with a learning difficulty. Mental Health's response is "it's not our responsibility".
- The perception is that Mental Health staff are scared of dual diagnosis and they don't want these clients.
- The Mental Health system appears to only provide a response to people at the extreme end of the mental health spectrum. Workers face difficulties accessing mental health services with people who are not in as severe a state.

6. COLLABORATION BETWEEN DISABILITY AND MENTAL HEALTH SERVICES

- Workers identified a lack of ability of disability and mental health services to work together. There is significant segregation between the two sectors, with constant battles over who is responsible for people with dual diagnosis issues.

7. FLEXIBLE COMMUNITY BASED SUPPORT

- Workers identified a lack of community based psychiatric support for people with dual diagnosis.

8. CRISIS AND AFTER HOURS RESPONSE

- There are limited options for crisis intervention out of hours if a person's mental health problems aren't recognised by Mental Health. If you go to Casualty to try and get a psychiatric admission you may wait there for 6 hours then be told to go home. The other option is to call the police. This is not a great option.

9. ACCOMMODATION

- Workers identified a dearth of suitable accommodation for people with dual diagnosis issues. Hostels are often unsafe and unsuitable, whilst living alone in a unit often doesn't work.

10. MEDICATION

- Workers noted their need for information and education around medication issues affecting people with dual diagnosis.
- Problems resulted from the fact that services are not legally allowed to dispense medication.

11. HOSPITAL SYSTEMS

- Workers raised concerns about poor hospital processes with respect to responding to people with dual diagnosis, including
  - Lack of records/poor records
  - Lack of consistency with doctors
  - Often people are taken there by police in an out of control state, and then they calm down and are told to go home.

12. TREATMENT AND MANAGEMENT STRATEGIES

- Stress management that's meaningful. 'Relaxation' needs to be grounded for people. What do they do to relax?
- Workers need to understand how people use substances. What comes first, stress or drug use?

13. TRAINING AND SUPPORT FOR SERVICE PROVIDERS

- Workers at activity centres have limited time, skills, and awareness to respond helpfully to a person with challenging behaviours. People end up getting banned.
- Residential Service Officers have minimal training. Lack of understanding can lead to abuse.

14. GOVERNMENT AND POLICY RESPONSE

- Workers identified limited support of dual diagnosis issues at higher levels of government.
- Advocacy groups are not individualised. They are not interested in individual stories, they are more interested in systems. They want to look at responses to either the mental health system or the disability system, they do not understand the interconnected nature of these for people with dual diagnosis.