Models of Service Provision to Adults with an Intellectual Disability with Co-existing Mental Illness (Dual Diagnosis)

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Developmental Disability Unit, School of Population Health, The University of Queensland

Contents

Appendices

Executive Summary

Introduction

This report is a component of a project called *Improved Services for People with a Dual Diagnosis of Mental Illness and Intellectual Disability* that is being conducted jointly by Queensland Health, Disability Services Queensland and Housing Queensland. The objective of the project is to enhance the quality of life of adults with a dual diagnosis within the community through improved access to appropriate services, and better coordination of services to these clients across government agencies and between government and non-government services. This project is overseen by the Queensland Government's Chief Executive Officers' Human Services Committee.

The Developmental Disability Unit, (School of Population Health, The University of Queensland), developed the report on behalf of an across government working group with representatives of the three Departments. The aim of the report is to provide a review of the available evidence about suitable models for providing services to individuals with a dual diagnosis, who require the services of more than one Department. It contains an examination of published literature, and examination of approaches used in a number of other selected jurisdictions, via material available on the internet and through personal communication with researchers and service providers in a number of western nations.

The review will inform Queensland Government departments about appropriate models of care, and assist Queensland service providers to develop best practice models of care for these very disadvantaged clients, which are consistent with international best practice.

Target Group

The mental health needs of adults with an intellectual disability can require multiple services and supports from a range of government and non-government agencies. Needs tend to cut across agency boundaries and rarely can be met by one service provider. This report specifically targets adults with an intellectual disability whose mental health needs are intensive and often challenging.

The target group includes adults with an intellectual disability who have a diagnosed mental illness (dual diagnosis) and those who require assessment because their behaviour suggests they may have a dual diagnosis. Although this group will tend to present with low support needs, adults with a dual diagnosis or a suspected dual diagnosis may have one or more of the following characteristics:

- A range of support needs ranging from low (mild intellectual disability) through to moderate levels of intellectual disability (higher support needs);
- Challenging behaviour and or dangerous behaviour;
- Involvement or a history of involvement with the criminal justice system.

Background

Adults with an intellectual disability are at increased risk of mental health problems when compared to the general population. There is general agreement within the literature regarding a higher lifetime prevalence of mental disorders in adults with an intellectual disability although there are differing opinions regarding the prevalence rate (Turner & Moss, 1996). The prevalence of mental disorders in adults with an intellectual disability is likely to be lie between 30-40%. Estimates of the prevalence of dual diagnosis will vary according to the age and location of the populations studied, definitions of intellectual disability and mental disorders, diagnostic criteria; exclusion or inclusion of challenging behaviour; and the instruments used (Borthwick-Duffy, 1994).

In 1993, the ABS Survey of Disability, Ageing and Carers reported that approximately 1.86% of the Australian population had an intellectual disability. Prevalence rates are problematic because of methodological issues already identified but generally the international literature suggests that between 1-3% of the general population will have an intellectual disability. This population is growing in numbers and will continue to make significant demands upon human, health and disability services across Australia.

Adults with dual diagnosis are not a homogenous population and when considered together form a very diverse group, inclusive of those with low support needs or mild disability through to those people who have high and often complex support needs eg severe disability. Their diverse characteristics means that their needs vary considerably from individual to individual. For example, some adults with a dual diagnosis have self-injurious behaviour and yet others will live independently with minimal supports. The differing presentations and associated needs is very confusing to some professionals and consequently means there is no standard response when working with an adult who has an intellectual disability and co-existing mental health problems.

This population is isolated in terms of services or support and knowledge of where to go for help. Families and carers are often desperate for assistance and yet cannot break into the system to access much needed mental health services or advice. They can be exhausted by the need for constant and vigilant advocacy to obtain services. Many families and carers feel that only when problems get to crisis point or where they can no longer manage, is there some chance of a service response.

Accurate assessment, diagnosis and analysis of the presenting mental health problems are fundamental prerequisites for the treatment and management of dual diagnosis (Emerson, 1996). Psychiatrists, general practitioners, mental health and disability service providers are not trained to identify and analyse how psychopathology is masked or distorted by the presence of an intellectual disability. A range of specialist services, through community outreach may be required, including:

- Assessment of the relationship between challenging behaviour, mental illness, intellectual disability and cognitive function;
- Consultation on medication;

- Psychological consultation and assistance with the management of behavioural disturbances;
- Access to appropriate treatments and interventions eg psychotherapy or cognitive behaviour therapy etc;
- Development and monitoring of behavioural programmes to be implemented by caregivers in the place of residence of the client;
- Liaison, consultation and case conferences with the primary carers, including the general practitioner and other professionals;
- Support for the maintenance of sustained recovery through psychiatric case reviews.

The complex needs of this group translates into difficulties in supporting and sustaining community placements. They provide significant challenges in regard to meeting their clinical needs within the context of community based accommodation options. The impact of challenging behaviour or mental health problems in adults with an intellectual disability is one of the leading reasons why this group of people is returned to restrictive residential arrangements (Davidson et al, 1999). Dual diagnosis can be a direct threat to successful community placements. An important component of any specialist service for adults with an intellectual disability needs to incorporate access to short term acute admission and treatment within a mental health inpatient treatment and assessment facility. Discharge into appropriate supported accommodation that maintains recovery will also be important. Where discharge into independent living is not appropriate in the short term, access to extended treatment and rehabilitation will be required.

Despite strong public policy support for a range of community care, few residential options that suit the needs of people with a dual diagnosis have emerged and institutionalised service responses remain the only option for many people with an intellectual disability who have complex behaviours. Until viable alternate options are developed that suit their multi-faceted needs, change is likely to be slow. Consequently, adults with a dual diagnosis often appear to fall into the "too hard basket" because there are no clear solutions or responses to problems being experienced. Complex needs can therefore remain unmet by both mental health and disability professionals. People with an intellectual disability can become lost in the gaps in service responses. Ideally, both mental health and disability services should feel well equipped to provide their relative contribution (Day, 1994).

Effective Support within Community Settings

Deinstitutionalisation and community care has not automatically resulted in guaranteed quality of life for all people with an intellectual disability. In particular, people with a dual diagnosis have suffered because their mental health needs cannot be met by one agency and required services cross professional and agency boundaries (King & Barnett, 2001). Most western nations believed that community care would "solve" problems associated with institutional care, particularly challenging behaviour. However, these are false assumptions and service providers are now faced with questions regarding appropriate models of service provision for people with complex needs living in community settings (Day, 1994).

Consequences to deinstitutionalisation and community care include:

- *Loss of staff professionally trained in intellectual disability* eg registered and psychiatric nurses were replaced by residential care officers and on-site (institutional) medical clinics were closed as people with an intellectual disability who moved to the community were expected to access primary health care services including general practitioners who were untrained in the management of the health and well-being needs of adults with an intellectual disability;
- *Loss of awareness of the health and mental health needs of adults with an intellectual disability* eg formal and informal opportunities for education and training were scarce, ad hoc and unplanned for a range of professionals and carers including medical practitioners, allied health and disability professionals, unpaid carers and family members.
- *Expectation that health needs would be fully met within the generic health care system* eg specialist or tertiary health services were not planned;
- *Extremely few health professionals working full time with adults with an intellectual disability* eg deinstitutionalisation embrace a social construct of disability and explicated rejected the medical model therefore health interventions were considered inappropriate;
- *Insufficient understanding of special health care needs across service sectors* eg lack of awareness of health and mental health problems in this population has given rise to decreased equity of access, poor health care and crisis; and
- *Existing service unable to meet demand and respond appropriately* eg people with a dual diagnosis fall through the gaps in existing service provision despite the existence of real and unmet mental health needs.

It is important to stress that concerns relate to the provision of the "right mix" of services that are available in the community. For example, when adults with an intellectual disability present with challenging behaviour, assessment needs to rule mental health problems either "in" or "out". Problems associated with community care are not about re-institutionalisation but about the need to establish responsive services from a range of agencies that can meet the needs of adults with a dual diagnosis within community settings.

Housing configurations and supported accommodation options can pose particular barriers to adults with a dual diagnosis living a reasonable quality of life within the community. For example some adults with a dual diagnosis may benefit from quiet, organised and routinised lifestyles, either alone or perhaps with a carefully chosen housemate. This approach can be compared to lack of choice of housing locations or the need to share with numbers of other people who live in noisy or chaotic settings, perhaps aggravated by busy arterial roads or dense neighbourhoods. Resource constraints and planning problems have resulted in groups of adults with an intellectual disability living together who are incompatible. There is little capacity for choice in regard to share arrangements and the end result is that housing arrangements tend to ignore individual needs.

Challenging behaviour and other psychiatric morbidity can be exacerbated by inappropriate decisions regarding shared households. Housing models can compromise not only individual mental health and well-being but also community integration. Carers and professionals become stressed and unable to cope. Some adults with a dual diagnosis would benefit from slowed re-entry into community life. A range of supported housing options need to be developed where an adults with a dual diagnosis can have the opportunity to learn life skills in a

supervised environment that is community based. Highly skilled staff with expertise in dual diagnosis are required to support such approaches.

Queensland Perspective

During the 1970s and into the 1980s state government responsibility for people with an intellectual disability transferred from Queensland Health through to the department now known as Disability Services Queensland. This shift reflected changing social values that resulted in the downsizing of institutions and emergence of supported accommodation options within community settings.

The complex needs of people with disabilities are increasingly visible within contemporary Australian society. Institutions continue to close and different community accommodation options are emerging in suburbs of every type and location. Deinstitutionalisation and community care underpins both mental health and disability policy implementation across Australia. However, for adults with an intellectual disability, a reasonable quality of life within the community relies upon:

- Community acceptance, support and tolerance of adults with a dual diagnosis;
- Recognition that adults with an intellectual disability are vulnerable to mental health problems;
- Provision of appropriate, accessible services by generic services eg mental health services and disability services;
- Access to generic services that employ highly skilled and expert professional staff who can assess, diagnose and provide appropriate treatments or interventions; and
- Generation and maintenance of services infrastructure that sustains adults with a dual diagnosis within community settings eg innovative housing or accommodation configurations.

Unfortunately one of the negative consequences of deinstitutionalisation was the loss of psychiatric expertise and involvement in the health care of this population. There is a growing body of evidence that demonstrates the vulnerability of adults with an intellectual disability to mental health problems. People with an intellectual disability frequently fall through the gaps in current service configurations. Their physical and mental health has suffered considerably as a direct result.

A number of obstacles can be identified which have contributed to neglect of the mental health needs of people with an intellectual disability living in Queensland. There has always been confusion regarding clinical and diagnostic distinctions between intellectual disability and mental disorders. Secondly, difficulty has been experienced differentiating between the primary and secondary disabilities (Bouras & Syzmanski, 1997). Other obstacles include:

- The nature of intellectual disability eg this group has compromised communication therefore reporting of signs and symptoms of mental disorder is difficult;
- Invisibility ie lack of professional awareness and sensitivity that people with an intellectual disability are at risk of mental health problems;
- Diagnostic overshadowing ie where psychopathology is attributed to intellectual disability;
- Assumptions that behaviour problems were a product of institutions;

- Linked assumptions that community living would eradicate behaviour problems eg "fix" the problem; and
- Belief that generic, community based health, mental health and disability services would cope with the needs of people with an intellectual disability.

In 2001 the Developmental Disability Unit released the report "Not on the Same Page". This report identified key issues in service provision to adults with a dual diagnosis across Queensland. The following synopsis briefly identifies some of the key issues relevant to the contemporary Queensland setting:

Inter-organisational conflicts

The relationship between mental health services and disability service providers across Queensland (government and non-government) has been characterised by conflict and disagreement. Issues of concern between the sectors relates to:

- Inappropriate admissions to mental health units;
- Delays in returning to community based living options;
- Blocked beds and no throughput means mental health services are reticent to accept further referrals of adults with a dual diagnosis;
- Mental health services fear abandonment by disability service providers;
- Disputes and disagreements result in discontinuity and fragmentation of care or clients fall through the gaps and get lost in the system;
- Inadequate communication flows through and results in poor coordination between services;
- Eligibility barriers feature in disagreements due to poor "fit" into criteria for services;
- Lack of dual diagnosis service options
- Mental health doesn't know what disability service providers do and vice versa;
- One size fits all approach by service providers eg there is no acknowledgment that the mental health needs of adults with an intellectual disability require specialist skills;
- Service responses are always crisis response driven and there are rarely preventative or quality of life maintenance functions;
- Negative attitudes and sometimes fear projected towards working with people with an intellectual disability who have co-existing mental health problems;
- Minimal acknowledgment that people with an intellectual disability experience vulnerability to mental health problems;
- Poor dual diagnosis knowledge, skills and expertise with virtually no awareness of the growing evidence base in this field.

Competence and Capacity

Mental health and disability service providers (government and non-government) across Queensland have voiced concerns regarding the capacity of both organisations to respond effectively to the mental health needs of adults with an intellectual disability. Although these concerns appear to be related to lack of knowledge and skills, strained relationships between the service systems has a compounding impact. An organisational and cultural chasm appears to exist between the service systems that had resulted in warfare in some areas of

Queensland. Although both service sectors understand that clients would be better served through collaborative efforts, the sectors experience major difficulties when communicating and interacting.

Attitudes

Attitudes are more complex than simple fear of people with an intellectual disability or fears of those who have a mental illness. Beliefs, values and attitudes can influence professional behaviour of and may act as a barrier to effective clinical relationships. Negative attitudes and stereotypes can be major barriers. For example, if Queensland service providers are "stuck" on the intellectual disability (diagnostic overshadowing), logically mental health problems may fail to be considered or understood. There is widespread and general failure by Queensland psychiatrists, mental health and disability professionals to acknowledge adults with an intellectual disability are vulnerable to mental health problems. Similarly, other human service providers including teachers and guidance officers. Accordingly, within Queensland there is considerable professional reticence from mental health services to provide a service response.

Training and Education

Queensland service providers from mental health, disability and other community sectors are untrained in specific issues that impact the mental health and well-being of adults with an intellectual disability. Mental health and disability professionals often appear unsure if they have the necessary expertise and skills to work with adults with a dual diagnosis who have complex needs. They lack confidence and therefore their professional efficacy is compromised when working with this group of people.

Professionals from the mental health and disability sectors come from different organisational cultures therefore they do not talk the same language. Dual diagnosis education and training would have to address the need for a shared professional language and framework of understanding when working with adults with a dual diagnosis.

Collaboration and Interagency Interaction

Queensland service providers need to be taught how to collaborate. Interaction and communication between the sectors doesn't occur naturally therefore situations and contexts need to be engineered. Queensland Health and Disability Services Queensland have had some success in recent months in trialling the implementation of guidelines between integrated mental health services and disability services Queensland across four Queensland locations. The guidelines focussed upon the joint management of adults with a dual diagnosis or suspected dual diagnosis. Other collaborative interagency initiatives are required.

Access to Expertise

Academic research and an evidence-based approach to services provided to adults with a dual diagnosis who have complex needs is also lacking across Queensland. Service providers desire access to expert advice and information when working with complex clients but they don't appear to know where to go to obtain such quickly. There are few experts out there across Queensland to refer to or to seek advice from.

Models

Critical review of the literature and contemporary service responses to adults with an intellectual disability and cc-existing mental illness across OECD nations reveals an array of different models of service provision. Consideration of both the national and international perspectives reveals little consensus regarding the ideal model of service provision that address the needs of adults with an intellectual disability who have complex problems. A number of service models and configurations are evolving and few approaches have been systematically or objectively evaluated.

There is sparse empirical evidence that demonstrates the most effective approach to meeting the needs of this vulnerable group. However, there is some anecdotal agreement across the OECD nations that demarcation and disputation between agencies is having serious consequences upon the health and well-being of adults of an intellectual disability. Cross agency collaboration and partnerships are required. The United Kingdom has gone so far as to introduce legislation, the Health and Social Care Act 2001, to ensure government and non-government agencies work together in partnership to meet the needs of adults with a dual diagnosis.

Most nations generally concur that the majority of people with an intellectual disability can and do live satisfactory lives within a range of community based living options. There is also widespread agreement that some of this group will require inpatient assessment and treatment within a mental health facility sometime during their lifetime. However, there is no broad consensus within the literature or the field as to whether generic or specialist mental health service provision is warranted (Chaplin & Flynn, 2000).

The uncertainty regarding the most appropriate model of service provision for adults with a dual diagnosis is reflected within the available literature (Trower et al, 1998). Although elements of service provision can be identified, how they are combined remains the subject of considerable debate (Day, 1994). Three approaches can be identified although there is considerable overlap:

- *Residential service provision* eg inpatient and outpatient or outreach services where treatment, assessment and support services tends to take place within (or from) hospital settings although some residential based services options may be community based;
- *Non-residential community based service provision* eg outpatient or outreach services where treatment, assessment and support services only take place within community settings – these services tend to operate without access to inpatient services although generic services may be used; and
- *Partnerships and interrelationships* eg formal and informal arrangements where government and non-government agencies provide a range of services including inpatient, outpatient or outreach services ranging from primary care, secondary care through to tertiary care and support.

Generic Services

Adults with a dual diagnosis have the same needs as the general population, in addition to special needs for assistance and support to overcome and manage problems presented by their psychiatric morbidity. Service responses will need to consider the individual characteristics of each person presenting but in general adults with a dual diagnosis require access to mental

health services that can provide community based and inpatient assessment and diagnosis; therapeutic interventions and treatment including psychopharmacology and non-medical interventions; review and followup. Case management will need to link with government and non-government service providers that may already be involved with the person or alternatively need to be involved.

The generic approach to the provision of mental health and disability services is based upon the assumption that services and treatment programmes are most appropriately provided within the wider community as opposed to institutions. For example, generic mental health services are inclusive of both primary and secondary health care provision.

This approach assumes that adults with an intellectual disability can and should be supported by ordinary mental health services within the broader community (Day, 1994). Specialised services are refuted on the basis that these services result in stigma, labelling and negative professional attitudes (Newman & Emerson, 1994). Regardless, many professionals, including psychiatrists argue that generic service provision to adults with a dual diagnosis (for example within Sweden, Denmark and the USA) has not been successful. Reasons have included negative attitudes, inappropriate settings, and poor staff knowledge about the mental health needs of adults with an intellectual disability lack of psychiatric input.

Specialised or Tertiary Services

The literature suggests that adults with an intellectual disability who have mental health needs cannot be effectively served by generic services because their complex needs are beyond the capacity of mental health service provision (Day, 1994). Problems relate to deficiencies in availability, accessibility and adequacy. Generic service provision only tends to occur because there are no alternatives eg specialist service responses are simply not available.

In response, some nations such as Canada and the USA have responded to the need for a specialised response and developed tertiary services. Tertiary services can be defined as specialised interventions that are delivered by highly trained professionals (Wasylenki et al, 2000). These interventions can be provided when adults with an intellectual disability have a dual diagnosis, mental health problems or challenging behaviours that are complex and refractory to primary and secondary care. Often the mental health sector, the disability sector and other community sectors struggle to provide appropriate service responses. Reasons for referral revolve around the need for higher levels of specialised assessment and then guidance in regard to ongoing support or management.

Tertiary services can be provided flexibly and do not need to be tied to particular settings, time frames or even inpatient assessment and treatment (Wasylenki et al, 2000). For example, a mobile or portable tertiary care model such as assertive community treatment means the location is irrelevant. The level of care is linked to the person in need rather than being dependent upon a particular setting. Services can be provided for contracted timeframes or specific purposes, ie negotiated between the providers and the client or their carers.

Tertiary services may be delivered through clinics that exercise mobile outreach, assertive community treatment and/or specialised outreach teams, community based residential programmes eg day services, or inpatient assessment and treatment services. This approach

is an important strategy for maintaining community placement options. Other advantages include the ability of tertiary services to develop high levels of dual diagnosis expertise, to train and educate a range of professionals including medical practitioners, and finally to expand the capacity of primary care and secondary care systems to respond to the needs of adults with an intellectual disability who have co-existing mental illness.

2 Elements of Successful Service Responses

The needs of adults with a dual diagnosis involve multiple agency responses. A successful service response to this vulnerable group of people requires *cross-agency responses where government and non-government agencies must work together in partnership.*

. Disability service provision that meets the needs of adults with an intellectual disability across Queensland has tended to be occur across two streams: residential support options provided through government and non-government sectors; and ambulant multiprofessional support teams that have been community-based and focussed. Historically these teams have typically involved different versions of behaviour support with some specialist teams emerging. These developments reflect international trends where community based teams have adopted behavioural approaches although many are eclectic with multiple orientations (Allen & Felce, 1999).

Team interventions whether from the mental health or disability sectors, have been expected to compensate for deficient resources and inadequate systemic supports. This response fails to meet the needs of adults with a dual diagnosis and is inappropriate in the 21st century, particularly in light of the international evidence.

Adults with a dual diagnosis who have complex needs require services that cannot be provided through one solo agency. Treatment and support challenges require distinct responses by a number of services (Patterson et al, 1995). The needs of adults with a dual diagnosis are multifaceted and can change over time. Services required need a cohesive and cooperative response from a range of agencies and professionals. A network or continuum of care is needed. Elements of a successful service system that responds to the mental health needs of adults with an intellectual disability include:

- Cross-boundary teams with experience in addressing both the mental health and primary needs of adults with an intellectual disability;
- Dedicated inpatient assessment and treatment beds within the continuum of community to inpatient services to ensure access to a therapeutic environments;
- A community-based habilitative support system with the capacity to provide varying degrees of support over lifetimes in recognition of fluctuating needs, relapsing and/or recurrent mental health problems or disorders;
- Enhanced communication networks between not only mental health and disability services, but all other service providers including housing and education;
- Linkages between the academic, research and community sectors to improve practice by accessing and contributing to the growing evidence based about the mental health needs of adults with an intellectual disability;

- Multiprofessional and cross agency approach to dual diagnosis education and training of professionals and direct service delivery staff that come into contact with adults with a dual diagnosis.

3

4 Conclusion

There is no ideal model of service provision that redresses the complex mental health needs of adults with an intellectual disability who live within community settings. However, it is clear that the mental health needs of people with an intellectual disability who live within Queensland *cannot* be met satisfactorily within mainstream mental health services or disability service provision. Specialised service responses are required.

The development of appropriate service responses that meet the complex mental health needs of adults with an intellectual disability should aim to develop and enhance the capacity of current community services to respond. This response capacity should not be restricted to the mental health and disability sectors, but needs to involve other stakeholders such as housing and education. The international experience suggests that specialist services are required to support and guide mainstream service providers. Additionally, specialist service responses are often required to support those people with dual diagnosis with the most challenging needs (Mansell, 1993).

Collaborative partnerships that draw upon existing developments and encourage emerging expertise and interest should be encouraged and enhanced. Priorities for service improvement appear to cluster around:

- Highly skilled assessment and diagnosis that draws upon evidence-based practice;
- Access to short term inpatient treatment and assessment that specifically caters to the mental health needs of adults with an intellectual disability;
- Access to longer term rehabilitation and treatment that specifically caters to the mental health needs of adults with an intellectual disability;
- Development of a range of supported accommodation options that enable adults with a dual diagnosis to live within community settings;
- Better co-ordination and integration of care for adults with a dual diagnosis;
- Comprehensive case management by a single individual or agency who is responsible for the client & assists with cross-agency collaboration;
- Improved information systems and sharing between stakeholder agencies;
- Holistic approach to needs and care planning that integrates the interface between community-based teams and inpatient care;
- Offering seamless specialist services with a single point of access;
- ?Improved partnership working between agencies and professions (cross agency, cross boundary approaches that address relationships between professionals as well as agencies); and
- Improved training about management of the complex needs of adults with an intellectual disability, for staff at the coalface across all involved sectors.

To guarantee appropriate service response that meet the mental health needs of adults with an intellectual disability, government must identify models that work outside of the traditional

mental health/disability dichotomy. Services must have access to highly skilled teams consisting of clinicians and professionals who can competently cross the mental health/disability service divide. Clinicians and professionals within these teams must have expertise in working with both systems so that the needs of adults with a dual diagnosis can be met holistically. There is a range of options available that hold potential for the Queensland setting. The main challenge is to engage all the relevant stakeholders in genuine endeavour to meet the mental health needs of adults with an intellectual disability.

Queensland needs to develop cross sector specialised services for adults with a dual diagnosis who have complex needs. The model of service provision should ensure that there are coordinated responses to adults with a dual diagnosis that draws upon mental health and disability services expertise. The preferred model must ensure that adults with an intellectual disability have access to:

- The full range of mental health services including generic and specialist services such as inpatient and forensic;
- A system that is person focussed rather than organisation focussed eg flexible and able to respond to adults with a dual diagnosis whose needs cross boundaries;
- Appropriate admissions and discharges including required follow-up and support (reduce inappropriate admissions and discharges);
- Appropriate community support and services that maintain both physical and mental health and well-being.

Key program components should include:

- Community based consultation and outreach through a multidisciplinary team of senior clinicians (psychiatrist, clinical psychologist, social worker and OT at minimum) to individuals living at home with their families, in contact with either disability services or mental health services. This team would work across agency boundaries and would work with all professionals and service providers, including carers and family members.

- Consultation with mental health services and disability services – consultation, assessment, diagnosis, program recommendations, triage and liaison including system facilitation, crisis planning, education and training.

- Triage and access to inpatient treatment and assessment beds staffed by psychiatric nurses and residential care staff for short term, time limited assessment and treatment development. Access to these beds should be only available through the community based consultation and outreach service multidisciplinary team.

- Education, training and research opportunities that are university based (undergraduates and graduates) cross-agency and multiprofessional in nature. Formal and information initiatives would target medical practitioners (consultants and trainees), health, mental health (including nurses) and disability professionals, managers, direct care staff, families, carers etc These events and programmes would aim to provide opportunities for networking, collaboration and interaction between all dual diagnosis stakeholders.

- Interagency communication mechanisms that provide formal and informal opportunities to network, develop continuity of service provision across sectors and promote best practice and evidence based approaches to clinical excellence. These mechanisms should also be used prevent, manage and resolve interagency issues and conflicts.

Future Directions

Services developed to meet the needs of adults with a dual diagnosis need to reflect Queensland history and culture, values, the existing knowledge base, resources and priorities. There are a range of possible responses that emerge from this report. Individualised approaches to mental health care is required but it is equally important that mental health services, disability services and community agencies work closely together so that expertise, skills and resources can be shared in the interests of adults with a dual diagnosis. The problem is very complex and simple solutions can be elusive.

It is highly likely that there will be increasing need for specialised mental health services as people with a dual diagnosis who have complex and longer term needs live within community settings. Not only will inpatient and outpatient treatment and assessment be required but a range of supported accommodation housing options will also emerge as critical to successful life within the community.

These options need to be carefully considered by the Queensland agencies that are involved in the provision of services to adults with a dual diagnosis. There are a range of options that should be carefully considered in the search for models of service provision relevant to Queensland. Eleven models of service provision have been identified as operating across the OECD nations. An outline of these models is attached. These models have been identified as Option 1, Option 2 etc through to Option 11. Examples of some international service responses are also included within the Appendices.

Generic mental health services lack the necessary commitment, expertise and support to provide dual diagnosis services. Disability services struggle to meet the complex needs of this group. A unique specialist model of service provision that compliments existing services may need to be specifically developed in Queensland. The most practical approach would involve assimilation and modification of aspects of dual diagnosis service delivery that are currently in operation across OECD nations.

Chapter One: Overview & Context

1.   Background

There is increased awareness across the western world that adults with an intellectual disability are vulnerable to mental health problems. There is also growing international recognition that community care has resulted in the mental health needs of adults with an intellectual disability being neglected.   When compared to the general population, this group have higher rates of psychiatric disorder (Lund, 1985) and can also present with problem behaviours that require intensive service interventions (Mansell, 1993). Where adults with an intellectual disability have a dual diagnosis, ie co-existing with a mental disorder, their complex needs will often require sophisticated responses from a number of service providers.

This group is particularly challenging to clinicians and professionals because of the range of developmental, behavioural, emotional and family support issues that often must be addressed simultaneously. Obviously there are service implications associated with these multiple demands that cross agency boundaries and can confound eligibility criteria. For example, people with an intellectual disability can have mental health problems that masquerade as challenging behaviour. Assessment, diagnosis, treatment and long-term management may require a comprehensive array of services that is simply unavailable from one agency.

Historical responses to people with an intellectual disability who displayed challenging behaviour or mental health problems relied upon institutionalisation and segregation. Community care was expected to "right the wrongs" of institutionalisation as it was anticipated that this approach would extinguish challenging behaviour. In fact, challenging behaviour, mental health problems and physical health problems are often misdiagnosed, inappropriately treated and poorly managed in community settings.

Mental health problems can be a major factor limiting not only quality of life but also successful community interaction and adaptation (Reiss, 1994). It has also been suggested that people with intellectual disability who also have challenging behaviour are at risk of re-institutionalisation (Bouras & Holt, 2001). The availability and accessibility of a range of support services is critical if community placements are to be successfully maintained.

Theoretically and ideally the mental health needs of this population should be accommodated within generic service provision by human services, including mental health and disability service sectors. However, this group seems to fall uncomfortably between the gaps in mainstream service provision (Moss et al, 2000). Successful community living opportunities for people with a dual diagnosis require a comprehensive and collaborative service structure, including appropriate accommodation and activities of daily living. Unfortunately these service developments remain "under construction" within Australia.

1.2　　　Aims & Objectives

This brief report explores service responses and where available, models of service provision that meets the mental health needs of adults with an intellectual disability. The spectrum of services considered are drawn from both the Australian and international experiences. There is great variability of service models in this area, making comparisons and conclusions difficult (Moss et al, 2000). There is little empirical evidence about the efficacy of models or approaches to service provision; therefore the report is primarily descriptive although anecdotal information is included.

Throughout the report a number or common themes are evident, including the limited number of "dual diagnosis" services that are operational within Queensland or the wider Australian setting and problems experienced by adults with a dual diagnosis when attempting to utilise mental health services. Barriers to effective services in the Australian setting relate partially to the interface between both mental health services and human services, particularly disability services. Other barriers and obstacles to service provision are identified in the report.

1.3　　　Methodology

The report has been developed using a logical problem solving process that involved literature review and consideration of anecdotal experiences of service providers. To complete the report using this process articles, reports and references were considered. This material was obtained through:

- Thorough review of the literature on service provision to adults with an intellectual disability, adults with a dual diagnosis and adults with challenging behaviour – literature addressing the health care of this population was also considered;

- Medline, PsycInfo, Swetsnet, Infosearch, Sciencedirect and Proquest were searched for peer-reviewed articles on the physical and mental health needs of the population in addition to health care service provision and accessibility

- Publications and reports were obtained from national and international agencies providing services relevant to adults with an intellectual disability including government departments were also obtained through the internet (refer to references)

- Email requests for relevant reports, reference material and anecdotal comments were forwarded to a range of senior academics, researchers and clinicians from the UK (Wales, Scotland, England & Ireland); Northern Ireland; the Netherlands, Belgium; Germany; Greece; Sweden; Norway; Canada, the USA, Spain; France and Italy.

o   Terms of Reference

5   The report was developed on behalf of a reference group. This reference group was a cross-government working party comprised of senior government officers from Queensland Health, Disability Services Queensland and Housing Queensland. The Developmental Disability Unit, The School of Population Health, The University of Queensland completed the report on behalf of the reference group.

6

o   Target Group

The target group includes adults with an intellectual disability who have a diagnosed mental illness (dual diagnosis) and those who require assessment because their behaviour suggests they may have a dual diagnosis. Although this group will tend to present with low support needs, adults with a dual diagnosis or a suspected dual diagnosis may have one or more of the following characteristics:

- A range of support needs ranging from low (mild intellectual disability) through to moderate levels of intellectual disability (higher support needs);
- Challenging behaviour and or dangerous behaviour;
- Involvement or a history of involvement with the criminal justice system.

Whilst there are major problems with definitions and classifications eg different approaches are used in different nations, the report attempts to prioritise the needs of adults with mild intellectual disability although some people with moderate levels of intellectual disability will benefit from the models discussed later in the report.

Whilst the needs of "young" people or youth with an intellectual disability will briefly mentioned, those under 18 years of age are outside the ambit of this report and it's recommendations. However, the unmet needs of youth with an intellectual disability, particularly those transitioning between children/ adolescent services through to adult services must be acknowledged and targeted for further consideration at another stage by the report's stakeholders.

This report is concerned with adults with an intellectual disability whose needs are the most challenging, often intensive and usually complex. These problems often lead to a range of negative responses that in addition to causing injury to the person and others, can result in social exclusion, isolation, neglect, abuse, seclusion or restraint, increased stress and costs to service providers (Emerson et al, 2000).

1.6   Terms and Concepts

There is much confusion regarding terms and concepts within the health and human services sectors and also more generally, the social sciences. Key terms are therefore briefly defined.

1.6.1   Intellectual Disability

The term intellectual disability is used widely in Australia and New Zealand. The equivalent term used in the United States and Canada is mental retardation. Although this term is considered somewhat derogatory by Australian standards, the term is used with no such intention within North America. The United Kingdom tends to prefer the term learning disability. Other terms including intellectually handicapped, cognitive impairment or mentally handicapped are also used on occasions. There is increasing tendency within the literature for the term intellectual disability to be used. This trend is having some influence upon service delivery in the western nations. For ease readability, this report, wherever possible, attempts to consistently use the term intellectual disability.

Intellectual disability is formally conceptualised in most modern definitions with regard to deficits in adaptive behaviours, cognitive ability and the appearance of these problems during the developmental period (Sturmey, 1999). People with an intellectual disability may have abnormalities of brain development and function, and associated difficulties in communication and other skills needed to develop socially. The severity of the disability determines how many people need life-long ongoing support and assistance with basic tasks of everyday life including eating and sleeping.

1.6.2 <u>Dual Diagnosis</u>

Dual diagnosis is a term that was first utilized in the USA during the 1970s to describe mental health problems in adults with an intellectual disability. A conceptualisation of co-morbidity, dual diagnosis refers to adults with an intellectual disability who have a concurrent mental illness or mental disorder. Adults with dual diagnosis are not a homogenous population and when considered together form a very diverse group, inclusive of those with low support needs or mild disability through to those people who have high and often complex support needs eg severe disability. This population is growing in numbers and will continue to make significant demands upon human, health and disability services across Australia. Their diverse characteristics means that their needs vary considerably from individual to individual. For example, some adults with a dual diagnosis have self-injurious behaviour and yet others will live independently with minimal supports.

Because adults with an intellectual disability are vulnerable to mental health problems, it is important that carers, service providers, professionals and psychiatrists recognise that it is possible to have both an intellectual disability and a mental disorder. There are a number of biomedical reasons why adults with an intellectual disability are more likely to experience an episode of mental illness during their lifetime eg:

- A number of syndromes of genetic origin that result in intellectual disability are associated with mental disorders; and
- Brain trauma or insults can result in mental health problems.

Adults with an intellectual disability are also much more likely to experience stressful and adverse life events that result in trauma and increased vulnerability to mental health problems. Factors that trigger or enhance the development of mental health problems cluster in the lives of adults with an intellectual disability eg genetic, biochemical, early experiences, psychosocial stressors and cognitive/behavioural problems (Bouras et al, 2000). In combination, these factors can make assessment and diagnosis complex. The clinician must tease out whether

presenting signs or symptoms are biologically driven, an environmental response, or a mental health problem or mental disorder. Case recognition must also consider the possibility of multiple causation.

There is general agreement within the literature regarding a higher lifetime prevalence of mental disorders in adults with an intellectual disability when compared to the general population. However, there are differing opinions regarding the prevalence rate (Turner & Moss, 1996). Estimates of prevalence of dual diagnosis will vary according to the age and location of the populations studied, definitions of intellectual disability and mental disorders, diagnostic criteria; exclusion or inclusion of challenging behaviour; and the instruments used (Borthwick-Duffy, 1994).

Research suggests that at minimum, 10% of people with an intellectual disability have a dual diagnosis (Reiss, 1990) although one study suggested 87% (Philips & Williams, 1975). Prevalence rates in other studies varied from 14.3% through to 67.3% (Campbell & Malone, 1991). Another review of twelve epidemiological studies showed that prevalence rates ranged from 14% to 80% (Borthwick-Duffy, 1994). The prevalence is much more likely to lie within the range of 30-40% of adults with an intellectual disability.

Results from an ongoing Australian study of young people aged 4-18 years have shown the prevalence of clinically significant emotional and behavioural problems is approximately 40% (Einfeld & Tonge, 1996). The classic prevalence study of psychopathology in children living on the Isle of Wight in the UK (Rutter et al, 1970) found similar rates. Psychopathology in those with intellectual disability, using these prevalence rates, is therefore a more serious community problem than schizophrenia that has a lifetime prevalence of approximately 1% (Einfeld & Tonge, 1996).

Accurate assessment, diagnosis and analysis of the presenting mental disorders are fundamental prerequisites for the treatment and management of adults with a dual diagnosis (Emerson, 1996). Psychiatrists and general practitioners are not trained to identify and analyse how psychopathology is masked or distorted by the presence of an intellectual disability. There can be major difficulties in establishing a diagnosis of a mental disorder in people with an intellectual disability, particularly when the capacity to participate in the clinical assessment is compromised. Many adults with an intellectual disability will be able to describe complicated, internal feelings but those with more severe disabilities will have difficulty describing such phenomena (Deb et al, 2001). When an individual is unable to verbalise or describe psychiatric symptoms, there is increased reliance upon the observations of carers and substitute decision makers. Diagnosis and assessment must therefore adopt a practical approach. The clinician must draw upon different sources of information including carer reports, direct observations of behaviour and careful consideration of history.

Despite such barriers there is broad consensus within the literature that the entire range of mental disorders can be diagnosed within this population (Arnold, 1993). Signs and symptoms of mental health problems are fundamentally similar to the general population. However, clinicians and professionals should adopt a thorough approach to assessment, try to understand individual psychopathology, and carefully choose a formal diagnostic label (Syzmanski & Crocker, 1989).

1.6.3 <u>Challenging Behaviour</u>

There is considerable overlap between dual diagnosis and challenging behaviour (Allen & Kerr, 1994) therefore thorough mental health assessment is necessary. The term covers a wide spectrum of behavioural disturbances, some of which may reflect covert neuropsychiatric disorders (Verhoeven & Tuinier, 1999). Challenging behaviour is really a broad social construction rather than a formal psychiatric diagnosis (Moss, 2000).

There is general consensus that there is a high rate of behaviour disorders amongst people with an intellectual disability (Deb et al, 2001). Research repeatedly stresses the importance and value of involving mental health professionals in the multidisciplinary assessment, treatment and management of adults with an intellectual disability (King et al, 1994; Moss et al, 2000). Importantly, many mental disorders may present or masquerade as challenging behaviour. Between 30% and 50% of people with learning disabilities may show a variety of behaviours, particularly challenging behaviour, that are precipitated by problems such as communication disabilities and physical and mental illness (Emerson, 1995). Regardless, the existence of a challenging behaviour should never be construed as automatically meaning that the person has a dual diagnosis. The existence of a mental illness is only one possible explanation for challenging behaviour (Emerson et al, 1999).

1.7 Queensland Perspective

This population is isolated in terms of services or support and knowledge of where to go for help. Families and carers are often desperate for assistance and yet cannot break into the system to access much needed mental health services or advice. They can be exhausted by the need for constant and vigilant advocacy to obtain services. Many families and carers feel that only when problems get to crisis point or where they can no longer manage, is there some chance of a service response.

Consequently, adults with a dual diagnosis often appear to fall into the "too hard basket" because there are no clear solutions or responses to problems being experienced. Complex needs can therefore remain unmet by both mental health and disability professionals. People with an intellectual disability can become lost in the gaps in service responses. Ideally, both mental health and disability services should feel well equipped to provide their relative contribution (Day, 1994).

1.7.1 <u>History</u>

In Australia, the emergence of community based care policies during the late 1970s marks the beginning of psychiatry's "schism" with services provided to people with an intellectual disability. Towards the end of the 1970s and into the 1980s state government responsibility for people with an intellectual disability transferred from Queensland Health through to the department now known as Disability Services Queensland. This shift reflected changing social values that resulted in the downsizing of institutions and emergence of supported accommodation options within community settings.

Mental health services provided to adults with an intellectual disability during the 1990s in Queensland were often inappropriate and less comprehensive when compared to others

without intellectual disability using that service. Fragmentation and lack of treatment coordination contributed. Services accessed by people with a dual diagnosis were of questionable standard and there was little choice. The more severe the level of intellectual disability, the less likely generic mental health services were accessed.

1.7.2 21st Century

The complex needs of people with disabilities are increasingly visible within contemporary Australian society. Institutions continue to close and different community accommodation options are emerging in suburbs of every type and location. Deinstitutionalisation and community care underpins both mental health and disability policy implementation across Australia. However, for adults with an intellectual disability, a reasonable quality of life within the community relies upon:

- Community acceptance, support and tolerance of adults with a dual diagnosis;
- Recognition that adults with an intellectual disability are vulnerable to mental health problems;
- Provision of appropriate, accessible services by generic services eg mental health services and disability services;
- Access to generic services that employ highly skilled and expert professional staff who can assess, diagnose and provide appropriate treatments or interventions; and
- Generation and maintenance of services infrastructure that sustains adults with a dual diagnosis within community settings eg innovative housing or accommodation configurations.

Unfortunately one of the negative consequences of deinstitutionalisation was the loss of psychiatric expertise and involvement in the health care of this population. There is a growing body of evidence that demonstrates the vulnerability of adults with an intellectual disability to mental health problems. People with an intellectual disability frequently fall through the gaps in current service configurations. Their physical and mental health has suffered considerably as a direct result.

1.7.3 Barriers and Obstacles

A number of obstacles can be identified which have contributed to neglect of the mental health needs of people with an intellectual disability living in Queensland. There has always been confusion regarding clinical and diagnostic distinctions between intellectual disability and mental disorders. Secondly, difficulty has been experienced differentiating between the primary handicap and the secondary handicaps (Bouras & Syzmanski, 1997). Other obstacles include:

- The nature of intellectual disability eg this group has compromised communication therefore reporting of signs and symptoms of mental disorder is difficult;
- Invisibility ie lack of professional awareness and sensitivity that people with an intellectual disability are at risk of mental health problems;
- Diagnostic overshadowing ie where psychopathology is attributed to intellectual disability;
- Assumptions that behaviour problems were a product of institutions;

- Linked assumptions that community living would eradicate behaviour problems eg "fix" the problem; and
- Belief that generic, community based health, mental health and disability services would cope with the needs of people with an intellectual disability.

In 2001 the Developmental Disability Unit released the report "Not on the Same Page". This report identified key issues in service provision to adults with a dual diagnosis across Queensland. The following synopsis briefly identifies some of the key issues relevant to the contemporary Queensland setting:

Interorganisational conflicts

The relationship between mental health services and disability service providers across Queensland (government and non-government) has been characterised by conflict and disagreement. Issues of concern between the sectors relates to:

- Inappropriate admissions to mental health units;
- Delays in returning to community based living options;
- Blocked beds and no throughput means mental health services are reticent to accept further referrals of adults with a dual diagnosis;
- Mental health services fear abandonment by disability service providers;
- Disputes and disagreements result in discontinuity and fragmentation of care or clients fall through the gaps and get lost in the system;
- Inadequate communication flows through and results in poor coordination between services;
- Eligibility barriers feature in disagreements due to poor "fit" into criteria for services;
- Lack of dual diagnosis service options
- Mental health doesn't know what disability service providers do and vice versa;
- One size fits all approach by service providers eg there is no acknowledgment that the mental health needs of adults with an intellectual disability require specialist skills;
- Service responses are always crisis response driven and there are rarely preventative or quality of life maintenance functions;
- Negative attitudes and sometimes fear projected towards working with people with an intellectual disability who have co-existing mental health problems;
- Minimal acknowledgment that people with an intellectual disability experience vulnerability to mental health problems;
- Poor dual diagnosis knowledge, skills and expertise with virtually no awareness of the growing evidence base in this field.

Competence and Capacity

Mental health and disability service providers (government and non-government) across Queensland have voiced concerns regarding the capacity of both organisations to respond effectively to the mental health needs of adults with an intellectual disability. Although these concerns appear to be related to lack of knowledge and skills, strained relationships between the service systems has a compounding impact. An organisational and cultural chasm appears to exist between the service systems that had resulted in warfare. Although both service

sectors understand that clients would be better served through collaborative efforts, the sectors experience major difficulties when communicating and interacting.

Attitudes

Attitudes are more complex than simple fear of people with an intellectual disability or fears of those who have a mental illness. Beliefs, values and attitudes can influence professional behaviour of and may act as a barrier to effective clinical relationships. Negative attitudes and stereotypes can be major barriers. For example, if Queensland service providers are "stuck" on the intellectual disability (diagnostic overshadowing), logically mental health problems may fail to be considered or understood. There is widespread and general failure by Queensland psychiatrists, mental health and disability professionals to acknowledge adults with an intellectual disability are vulnerable to mental health problems. Similarly, other human service providers including teachers and guidance officers. Accordingly, within Queensland there is considerable professional reticence from mental health services to provide a service response.

Training and Education

Queensland service providers from mental health, disability and other community sectors are untrained in specific issues that impact the mental health and well-being of adults with an intellectual disability. Mental health and disability professionals often appear unsure if they have the necessary expertise and skills to work with adults with a dual diagnosis who have complex needs. They lack confidence and therefore their professional efficacy is compromised when working with this group of people.

Professionals from the mental health and disability sectors come from different organisational cultures therefore they do not talk the same language. Dual diagnosis education and training would have to address the need for a shared professional language and framework of understanding when working with adults with a dual diagnosis.

Collaboration and Interagency Interaction

Queensland service providers need to be taught how to collaborate. Interaction and communication between the sectors doesn't occur naturally therefore situations and contexts need to be engineered. Queensland Health and Disability Services Queensland have had some success in recent months in trialling the implementation of guidelines between integrated mental health services and disability services Queensland across four Queensland locations. The guidelines focussed upon the joint management of adults with a dual diagnosis or suspected dual diagnosis. Other collaborative interagency initiatives are required.

Access to Expertise

Academic research and an evidence-based approach to services provided to adults with a dual diagnosis who have complex needs is also lacking across Queensland. Service providers desire access to expert advice and information when working with complex clients but they don't appear to know where to go to obtain such quickly. There are few experts out there across Queensland to refer to or to seek advice from.

As institutional settings within Queensland continue to downsize, adults with a dual diagnosis who have complex needs have been the last to move into community based living options. Although not initially placed, Disability Services Queensland and various non-government disability service providers are now assisting these individuals to enter alternate accommodation and community environments that may be less tolerant of challenging behaviours when compared to the institutional setting. Maintaining them in the community is a difficult task for community service providers, be it health, mental health and disability services.

1.7.4   Dual Diagnosis Services in Queensland

Access to mental health care is problematic for adults with an intellectual disability and is only usually available through general practitioners who have minimal knowledge of the health care problems of this group of people. The people who have close relationship with people with an intellectual disability – family, friends, carers etc are often ill equipped to identify and relay to the appropriate professional symptoms and signs of psychiatric disability. They find it difficult to

"get past the gate." Frequently mental health needs remain undetected, poorly managed or misdiagnosed. Many fall through the cracks in the system.

Queensland Health provides nine specialist inpatient programs for people with a dual diagnosis. Two of these cater for people with a dual diagnosis only. Seven others combine extended treatment and rehabilitation services with dual diagnosis services in the one setting. The Park, West Moreton Health Service District and Baillie Henderson Hospital, Toowoomba Health Service District provide exclusive tertiary programs for their catchment districts. The Park services four districts and Baillie Henderson Hospital fourteen. These services target those adults with intellectual disability and a concomitant mental disorder who exhibit aggressive or violent behaviour that cannot be managed within the local integrated mental health service. These units provide specialist assessment, extended inpatient services on a medium to long-term basis that enables people with a dual diagnosis to receive treatment and rehabilitation. The referring service retains responsibility for ongoing care and support subsequent to successful treatment and rehabilitation.

Specialist dual diagnosis inpatient services are provided in Community Care Units across the state in seven health service districts. These are combined with the extended treatment and rehabilitation inpatient service and are not exclusive to people with a dual diagnosis. The sites are located in the following health service districts: Townsville, Charters Towers, Sunshine Coast, Redcliffe/Caboolture, The Prince Charles Hospital, The Royal Brisbane Hospital and Gold Coast.

Guidelines developed by Queensland Health, Mental Health Unit with Disability Services Queensland to manage clients with a dual diagnosis are also working towards addressing some of the problems. The guidelines encourage a collaborative service response, between Queensland Health Integrated Mental Health Services and Disability Services Queensland, when a consumer has an intellectual disability and diagnosed or suspected mental health problems.

Other services do operate to meet the needs of adults with a dual diagnosis. None of these services holistically address whole of lifespan issues for adults with a dual diagnosis. Two of these, ARROS (non-government) and the Developmental Disability Unit Clinic (University of Queensland) operate with large waiting lists due to limited resources. A Dual Diagnosis Project Worker has recently been appointed in Cairns (located within Integrated Mental Health Services) and a Dual Diagnosis Project Worker has been appointed within the Community Living Programme, Nundah, Brisbane. Both these positions are short term funded through Disability Services Queensland and are not involved in the provision of clinical or outreach services.

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

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

- *St Vincent's Community Services Ipswich* – operate an outreach and support service for adults with a dual diagnosis in a discrete geographical area

Contact with professionals employed within the above services suggests that some generic mental health services accept people with an intellectual disability who have mild levels of intellectual disability – many of these clients may not identify with intellectual disability services eg they may have attended special school and live independently in the community. These agencies also suggest that some generic mental health services refuse to provide services to people with an intellectual disability citing this client groups it he responsibility of disability services. These experiences suggest that the diagnostic overshadowing phenomena is alive and well within Queensland, eg where challenging behaviour or psychopathology is attributed to the existing of the intellectual disability rather than assessing the presenting signs or symptoms (Reiss, 1994).

1.7.5   Views of Service Providers

Few community based service providers would argue that disability services (both government and non-government agencies) struggle to provide physical and mental health and well-being support to the population. Research conducted by the Developmental Disability Unit (Edwards & Lennox, yet to be published) reveals that many Queensland services feel unable to cope with the complex needs and challenging behaviours that adults with an intellectual disability can display.

Many agencies and services providers are unsure of how to proceed in supporting the needs of those with intellectual disability. Co-existing mental health problems exacerbated pre-existing lack of confidence. Key informant interviews and consultations with dual diagnosis stakeholders (paid and unpaid carers as well as service providers) revealed the following "shared" experiences when working with adults with an intellectual disability with a diagnosed mental disorder or suspected mental disorder:

- Inadequate skills and knowledge in understanding dual diagnosis;
- Under-funding and resource constraints;
- Lack of collaboration between agencies or service providers;
- Negative stereotypes of the consumers/clients;
- Conflicting professional language/discourse;
- Difficulty in identifying mental health problems;
- Restricted cross service system entry eg eligibility problems;
- Limited treatment and interventions;
- Isolation and remoteness; and
- Need for expert dual diagnosis support and expertise transfer.

When mental health problems have been identified or assessment is required, disputation between professionals and agencies often follows. These issues have also emerged in regard to responsibility for adults with an intellectual disability with mental health problems or challenging behaviour. This group has proved difficult not only to find community placements for but also to sustain successful community placements. This report examines the experiences of these agencies and addresses many aspects of the problematic interface between mental health and human services.

1.7.6   View of Psychiatrists

Psychiatrists and general practitioners should play a crucial role in meeting the mental health needs of adults with an intellectual disability in Queensland. They are important gatekeepers to mental health and physical health and well-being because of their assessment and diagnostic responsibilities, therapeutic interventions and treatment recommendations. Negative beliefs, values and attitudes about people with an intellectual disability and their needs for mental health services can influence the behaviour of these medical practitioners. Psychiatrists and GPs can act as a barrier to effective clinical relationships.

The Developmental Disability Unit (Edwards & Lennox) surveyed Queensland Psychiatrists during 2001 and explored their perceptions about adults with an intellectual disability. The survey also addressed training and education needs that relate to the mental health of adults with an intellectual disability. Research outcomes are included within the 2002 Report, "Not on the Same Page". 140 Psychiatrists responded to the survey that was twice mailed through the Queensland Division of the Royal Australian New Zealand College of Psychiatry (RANZCP). Of particular relevance to the terms of reference of this report are the responses of Psychiatrists when questioned about the management of adults with concurrent intellectual disability and mental disorder (dual diagnosis).

The majority of Psychiatrists believe that adults with an intellectual disability receive a poor standard of mental health care with 68% (n=121) responding affirmatively to the survey question and only 23% disagreeing (n=41). When prompted about their approach to assessment and diagnosis, most Psychiatrists (70% n=124) believe that their approach to adults with an intellectual disability reflected symptom management rather than diagnosis-based treatment. Only 23% (n=41) disagreed. The majority of Psychiatrics did not support the treatment of adults with an intellectual disability within the acute ward setting. Approximately 20% (n=35) believed that the acute admission ward was suitable whereas approximately 73% (n=130) of respondents did not. This finding may suggest that an alternative mental health setting is required when treating adults with an intellectual disability who have acute needs.

The study suggests that negative perceptions that dominate contemporary society also penetrate the professional realm of psychiatry. The scope of current education and training opportunities for Psychiatrists in Queensland needs to be widened to address the mental health needs of this neglected and vulnerable group. The key finding was that that approximately three quarters of survey respondents consistently expressed concerns about the psychiatric management and treatment of adults with an intellectual disability.

1.7.7   Prevalence

The same research by the Developmental Disability Unit (Edwards & Lennox, yet to be published) demonstrated that across Queensland, there is a sizeable group of adults with a dual diagnosis. A Queensland-wide survey of organisations/agencies that provided services to adults with an intellectual disability (n=395) was conducted during 2001 by the Developmental Disability Unit with 40% (n=156) completing the survey. Consultations and focus groups also collected information from a range of dual diagnosis stakeholders.

Contact with 156 Queensland agencies providing services to adults with an intellectual disability estimated that out of approximately 7,000 adults with an intellectual disability that were served by these agencies, (upper limits of prevalence) that more than 20% had a "dual diagnosis". Managers, staff and professionals associated with these services, clients and their families and carers, described unmet need for adults with a dual diagnosis. Although the numbers of adults with an intellectual disability are estimates and more likely an underestimation, there is little doubt that this minority of Queenslanders consume vast resources and place enormous pressure upon government and non-government services.

1.8   Contextual Issues

The following issues are provided as contextual factors that need to be considered when involved in strategic planning and service development for adults with an intellectual disability who have complex needs. The variety and breadth of issues below serves to illustrate the statement that this is a diverse population with diverse needs that cuts across and within sectors and service providers within those sectors. Issues are not presented in any particular order or priority.

1.8.1   Deinstitutionalisation & Community Care

Deinstitutionalisation

Deinstitutionalisation and community care has brought the needs of people with complex needs to the attention of the public (Mansell, 1993). Existing services experience major problems in meeting the complex needs of this group. Service responses within Queensland are patchy, ad hoc and lack strategic direction.

While it is very difficult to provide estimations of the number of individuals falling within this group, they are comparatively small in number although the resources they require are substantial. Adults with an intellectual disability who have concurrent mental health problems or challenging behaviour present significant challenges for services in regard to individualized responses, accommodation requirements, community inclusion and social integration

There are often disputes and disagreements between services in regard to responsibility for this group and associated problems in regards to the availability of specialist support, problems within services with staffing levels and the availability of appropriate skills. Comprehensive responses to the needs of a small, but demanding population are required but demographic diversity will make responses complex. Diverse clinical needs and ad hoc patterns in service delivery will add to the problems.

Numerous factors underpin the failure of current services to provide appropriate levels of support including organisational inefficiencies, lack of commitment, leadership and management problems, conflict between service ideologies, lack of knowledge, insufficient resources and services. (Emerson et al, 2000).

Fragmented Service Responses

The establishment of multidisciplinary community based teams that have attempted to manage a wide range of physical and mental health need has generally accompanied closure of institutions. The development of these team approaches to community care failed to appropriately factor in the reality that the health care needs of this population are more complex and more numerous than the general population (Hassiotis et al, 2000). Research suggests that the health care problems, including psychiatric morbidity is so numerous that the population characteristics are in fact a disincentive to community based service providers (Ziring et al, 1988).

Awareness of the mental health needs of adults with an intellectual disability who have complex needs is a relatively recent phenomenon originating in the second half of the 20th century. Prior to the early 1990s, it is difficult to identify UK or USA based literature that discusses the susceptibility of people with an intellectual disability to psychiatric morbidity, and there was virtual silence regarding treatment (Jacobsen, 1999). At this time interest associated with the psychiatry of intellectual disability began to emerge in the UK and parts of the USA but discussion tended to focus upon decisions regarding admission to hospital facilities or institutions.

Across Australian there have been major changes in service systems accessed by people with an intellectual disability in recent years in response to the closure of institutions. As deinstitutionalisation and community care continues, the provision of services for people with an intellectual disability has slowly devolved through to generic community based government and non-government service providers. Whilst there exists general agreement that community care has benefits, there is less success in developing services to meet the complex needs of people with an intellectual disability (Bailey & Cooper, 1997) and service confusion remains a characteristic problem or feature (Bouras et al, 1995).

Within the UK, Psychiatrists believe that they are the ideally located professional/medical specialty to manage the needs of this group of people (Sellar, 2000). However, there is little consensus of opinion within the literature in regard to the ideal model of service delivery that best manages physical health, mental health and the related complex needs of this population.

General Practitioners may better manage this group rather than Psychiatrists if a medical model approach needs to modified to fit the Australian perspective. Australian research (Lennox & Kerr, 1997) suggests that GPs may be unprepared to manage the complex needs of this group and there is research that reports that carers often find it difficult to locate general practitioners who will take on adults with an intellectual disability (Lakhani & Bates, 1999). The specialist GP model has emerged with the Netherlands where medical practitioners can train for four years in intellectual disability to emerge as specialist consultants who work closely with multi-professional teams in community care outreach activities.

Other research highlights the range and differences between services provided across the UK (Bailey & Cooper, 1997) and this experience appears similar in North America and Australia. Although closure of large scale institutions is generally associated with positive outcomes for people with an intellectual disability the research suggests community care services are unable to meet both routine and complex needs of the population. Special needs and characteristics of the group require distinctive clinical skills in diagnosis and treatment of both physical and mental health needs of this population (Criscione et al, 1993).

Regardless of the best of intentions, the barriers to effective community based service delivery are so pervasive that service delivery in Australian setting is fragmented and ad hoc. Additionally, there is considerable disparity between the quality of community based services and support options (Emerson, 1999).

At the very heart of community care is the need for a range of services to be both local and accessible to those in need. Historically generic community services were protected from adults with an intellectual disability with complex behaviours because this group of vulnerable people had been institutionalised. Community services can no longer rely on institutions to contain and segregate people with complex behaviour problems. Deficiencies in the service sectors have been exposed and exacerbated by the very nature of community care (Bouras & Holt, 2001).

Consideration of community-based models of care appropriate to the needs of adults with an intellectual disability have been flawed by a number of serious and erroneous assumptions. Most models were based upon the belief that:

- Support options and services available in the community would be cheaper than institutional care and contain escalating resource allocations;
- Generic services would have the capacity (skills, knowledge etc) and the willingness to provide services to adults with an intellectual disability;
- Community care would "solve" challenging behaviour eg institutionalisation caused and sustained challenging behaviour.

The community appears to have been ill prepared to respond to the complex needs of the population. Advocates of community care inappropriately failed and continue to fail to acknowledge the many barriers to health and wellbeing in this vulnerable group. Consequently there has been scant progress within Queensland for service development strategies that ensure appropriate services are both community based and accessible as the debate has polarised around institutional versus community models of service delivery. Unfortunately, theory and reality have not translated well and we know more about the problems resulting from community care rather than the solutions (Browne et al, 1995)

1.8.2   <u>Physical Health and Mental Health</u>

There is broad agreement within the literature that services for people with an intellectual disability who have challenging behaviour can be provided within community settings (Allen and Felce, 1999). There is also evidence that psychological benefits are associated with community care, but impact on the health status in not similarly available (Rimmer et al, 19995) and in fact their health care needs are in danger of being ignored (Rodgers, 1993)

There is a high prevalence of unmet mental health needs within the community, specifically undiagnosed or misdiagnosed mental disorders in people with intellectual disability (Roy et al, 1997). Referrals to mental health services will depend upon a wide range of variable factors including availability of mental health services, awareness of general practitioners in regard to the mental health needs of adults with an intellectual disability, skills and knowledge, and attitudes of carers and families (Roy et al, 1997).

The behavioural presentation may not be considered to be typical or indicative of a mental disorder but considered as typical of challenging behaviour seen in someone with "intellectual disability". Behaviour of people with an intellectual disability has historically attributed to their "disability" and this form of diagnostic overshadowing adds to the complexity of assessment, diagnosis and treatment. (Ryan & Sunada, 1997).

The diagnosis or failure to diagnose a mental disorder can result in:

- Inadequate case management;
- Increased hospitalisation;
- Inappropriate medication regimes; and
- An associated diminished quality of life (Sturmey, 1995).

General practitioners usually prescribe psychotropic medication with little experience in intellectual disability and dual diagnosis (Webb, 1996). Literature suggests the need for research, which pays attention to the role of general practitioners in relation to the mental health needs of this population (Moss et al, 1997).

Where the complex problems experienced by the adults with an intellectual disability, psychopathology came become chronic. The burden of care falls heavily upon carers, both paid and unpaid, including families and relatives. Recent reviews of training programs suggested knowledge and skills of physicians, nurses and medical students improved after education (Moss et al, 1997). The need for specialised expertise when responding to the complex mental health needs of this population is a theme within the literature.

1.8.3 <u>Challenging Behaviour in the Community</u>

There is also some cause for concern in relation to the management of challenging behaviour in community settings. However research demonstrates that there is a clear relationship between challenging behaviour and institutionalisation. Further, there is clear evidence that challenging behaviour is associated with placement breakdown following community placement (Allen, 1999). Consequently if accommodation or housing arrangements are far from optimal, chances of placement breakdown may be significantly higher (Allan, 1999)

A range of service characteristics have been associated with re-institutionalisation including:

- The size of the service (smaller less able to cope with challenging behaviour);
- Whether or not adequate specialist support is available (eg mental health services);
- Client access to an advocate;
- The degree of restrictiveness within the residential setting;
- Communication within the organisation and service; and
- Resource deployment.

However, whilst this is persuasive, the evidence is largely anecdotal (Allen, 1999).

Community care has been associated with positive outcomes such as a more active and normalised lifestyle including increased satisfaction an choices, improved skills and adaptive behaviours, increased community activity and interaction, increased engagement in domestic

and personal activities, increased support from care staff (Emerson & Hatton, 1994; Hatton & Emerson, 1996). Preliminary data for 32 people with an intellectual disability relocating from Challinor Centre to community living have similar results (Young et al, 2000). However, in regard to the severity of challenging behaviour, there appears to be little difference between the institution and the community (Emerson, 1999). The Queensland results suggest that while maladaptive behaviour did not decrease when measured using the ABS, results from direct observations did show decreased challenging behaviour and increased appropriate behaviour in the community (Young et al, 2000). The authors also conclude that the development of comprehensive behaviour support services is imperative.

There appears to be little difference between institutional or community life in regard to the severity of challenging behaviour (Emerson, 1999) The existing level of residential support available in the community does not meet demand and there is little evidence of rationality in the allocation of resources in residential service provision (Emerson, 1999). So the generic versus specialist debate has been borne of the normalization and social role valorisation principles that underpin the community care movement. While the debate has unfolded, adults with an intellectual disability who have complex needs have remained somewhat invisible or those who have requested services have often fallen through the cracks of current service providers.

1.8.4   Identification and Recognition

The recognition of mental disorders in people with an intellectual disability is particularly difficult, due partly to communication limitations that often make it difficult for the individual to describe mental symptoms. A second influential problem is that of diagnostic overshadowing where all presenting problems, signs and symptoms of psychopathology are ascribed to the person's intellectual disability (Levitan & Reiss, 1983).

The people who are usually first to notice significant signs and symptoms are the carers, who are often the least qualified to undertake this important task. As a result, failure to meet needs often occurs at a fundamental level because the problem is never recognised (Moss & Patel, 1993). Difficulties associated with detection and diagnosis mean that trained and experienced staff are required to meet the range of health care problems experienced by this population (Bailey & Cooper, 1997). Service provision is heavily reliant upon carers initiating the referral process (Hastings, 1997) therefore education may lead to improved health advocacy. Referrals also need to be a more interactive and dynamic process eg looking for more than "general labelling" plus a reason for the referral (Hastings, 1997).

Despite these diagnostic difficulties and ambiguities, higher rates of mental health impairments have been found among individuals with an intellectual disability than in the general population (Zigler and Burack, 1989; Dosen, 1993; Moss, 1994; Moss et al., 1997; Embregts, 2000; Reiss, 1990). The awareness and understanding of staff and other carers about a wide range of issues relating to the detection, management and treatment of mental illness in people with an intellectual disability may greatly assist identification and treatment of complex needs (Bouras and Holt, 1997; Holt and Bouras, 1997; Moss et al., 1998; Prosser et al., 1998).

1.8.5   Safety and Harm Minimisation

Service providers are required to consider the balance that exists between, on the one hand, duty of care to individual patients and their civil liberties, versus the expectations of the wider public to be protected from harm. Apart from these generic issues, however, there are a number of specific issues relating to the mental health of people with an intellectual disability. These specific issues include a broad range of aspects including: risk factors, case identification, assessment and diagnosis, treatment, long-term management in the community, and monitoring of outcomes. The issues have major implications for the organisation of services (Moss et al, 2000).

1.8.6   <u>Homelessness</u>

Homelessness can be defined in different ways and levels of homelessness do vary considerably across different parts of Australia.   Needs of individuals also varies considerably. Many homeless people may not discern the need for the involvement of mental health or disability service professionals but they may welcome assistance with shelter, food and basic life fundamentals. Levels of mental health problems vary considerably depending upon locations, methodologies and definitional issues. Another confounding factor is comorbidity, particularly alcohol and drug misuse problems. Intellectual disability can also be a risk factor for homelessness (Davis et a, 2002). Anecdotal experience suggests that adults with an intellectual disability who have mental health problems (dual diagnosis) and other complex needs may also be more highly prevalent in the homeless population. Research is required to clarify this hypothesis.

The movement of people from institutions into community care may have meant that some adults with learning disability have disappeared into the community with little structured follow-up (Martin, 2001). One study described the experiences of people with an intellectual disability in Bristol who were not in contact with specialist services. This research showed that two-thirds of the 28 people interviewed described a history of one or more of transience, shared or temporary accommodation, and homelessness (Simons, 2002). The lack of access to employment, low income, difficulty in managing money, and limited social networks, may be significant factors that contribute to homelessness within this group of people.

However, there is limited research that exposes homelessness in this population (Davis et al, 2002). In official United Kingdom homelessness statistics, people with an intellectual disability are relatively 'invisible' (Simons, 2002). Research completed in Sydney, Australia also concludes that people with an intellectual disability are over-represented in homeless populations (Hill, 1998).

1.8.7   <u>Housing & Accommodation Support Options</u>

There has, over the past two decades, been a substantial investment in research and development in the UK into the quality and costs of housing and support services for adults with an intellectual disability. Australian research findings (Young et al, 2000) are generally consistent with the international literature from North America (Kim et al, 2001) and Scandinavia (Mansell & Ericsson,1996).

Recent UK research suggests that domestic sized housing options provide higher quality support and better outcomes for people with learning disabilities than institutional and congregate forms of accommodation options (Emerson et al, 2000). Small community-based housing was associated with increased choice, more individualized support, greater social inclusion and wider social networks. NHS residential campuses, when compared with supported living schemes and residential care homes supporting six or fewer people, were shown to offer poorer quality support and poorer outcomes for people with an intellectual disability (Emerson et al, 2000).

This research suggested that while hostels and larger residential care homes supporting 10 or more people have some advantages over long-stay institutions, they have a number of disadvantages (and no areas of clear advantage) when compared to domestic-scale housing and support. An exception to this general trend is provided by village or intentional communities that are run through the voluntary sector for people with low support needs eg mild levels of intellectual disability. The literature suggests that village communities, when compared with supported community-based living options and residential care homes supporting six or fewer people, may offer a number of benefits. Such benefits include:

- Better internal planning procedures and less rigid routines;
- Greater access to a variety of comprehensive health checks;
- Greater access to structured day activity;
- Less exposure to crime,
- Exploitation or verbal harassment reported by staff

However, the research also identified some disadvantages including:

- Supported accommodation was provided in larger, less homely more institutional settings;
- Lower staff ratios and fewer qualified senior staff;
- Less access to independent advocacy;
- Less social integration;
- Fewer recreational/community-based activities.

There is extensive evidence of considerable variation in the quality of support and quality of outcomes in community-based housing and support services. There is some anecdotal evidence that government and non-government service provision of supported accommodation has been based upon the presumption that a reasonable quality of life would flow from reasonable living standards. It is clear that the UK research shows that an acceptable level of quality cannot be assumed to exist within any approach to providing housing and support. As a result, any housing and support strategy will need to pay careful attention to monitoring and enhancing the quality of services.

The research demonstrates that robust relationships between measures of resource input and either the quality of support or outcomes for people with an intellectual disability do not exist (Emerson et al, 2000). Quality outcomes appear to be influenced by how resources are chosen and utilised. The implications of this evidence are that:

- Resources are required to provide quality services and support but the level of resources may not be a good indicator of quality
- The method of resource allocation suggests that inefficiencies exist within housing and support services
- Provision and monitoring of housing and support services should pay increased attention to the use of systematic individualised approaches and procedures.

Compatibility

Anecdotal evidence suggests that there are clearly two factors identified where housing and accommodation options in the community breakdown:

- Problems in the environment; and
- Incompatibility with other residents.

For many people with an intellectual disability who have complex problems, particularly challenging behaviour, the environment is of particular significance. It seems extraordinary how often services, when faced with someone who has a low tolerance for noise or chaos or who finds it difficult to interact with large groups of people, then places that individual in a house full of similarly noisy people. Other people cannot tolerate cramped or built up environments, others have difficulty with cars and traffic. For example, it is well acknowledged within the literature that adults with autistic spectrum disorder have poor tolerance for noise and enjoy structure and routine in their lives. Unfortunately they are often placed in living environments where these particular requirement are not respected

Very few people an intellectual disability, let alone those with more complex needs, are able to make choices in regard to where they live, who they live with and the location of their "home". When their accommodation breaks down, despite problems with changes in routine, they are often moved between accommodation options, which further exacerbates their challenging behaviour. Even when clinicians and staff are aware of their particular needs, lack of choice in accommodation options restricts choices and ultimately where the person lives and whom they share with.

It is clear from the experiences of many services, that the person centred planning process needs to pay genuine and particular account of both environmental issues and compatibility issues that are relevant to that person It is essential to know someone very well if there is a chance of getting the environment and who someone lives with right. There is also strong evidence to suggest that using supported living as the approach rather than traditional placements in residential care homes or nursing homes is more likely to increase the chances of a successful placement.

Supported living ideally involves each individual choosing a place to live (in a community) that most people might like, with people they choose (and no-one else if that is their choice), with the support they need, under their control, from people who are committed to them. This would enable the issue of the environment to be looked at individually. Compatibility is at the heart of supported accommodation. Although supported accommodation can involve twenty four hour support, choices are critical and often linked to success or sustainability.

However, given the hidden costs of repeated placement breakdown, and the very expensive alternatives in special hospital units or even prisons, in the long term it could still be the most cost-effective option. More research is required to examine the benefits of supported living and the comparable costs

Housing is central to effective community mental health care therefore a range of housing options needs to be available for adults with an intellectual disability within Australia. A range of innovative housing/accommodation options needs to be established, trialled and evaluated within Queensland. It is essential that housing, disability, human services and health/mental

health services are actively involved in joint planning exercises that meet the needs of this vulnerable population.

All Australian States/Territories from the 1960s have embarked on programmes that have resulted in the closure or downscaling of institutions. Deinstitutionalisation plans by Australian state governments have never been centrally monitored or reported. Consequently, there is no readily available Australia-wide picture of the proposed changes in the numbers of people living in institutions for people with intellectual disabilities (Bostock et al, 2001)

The first national snapshot of the projected numbers of people moving from institutions to community-based housing aimed to predict the effect of deinstitutionalisation on housing markets and to assess how effectively and appropriately the housing needs of people with an intellectual disability were being met in the community. The research outcomes may provide assistance to better understand the increasingly complex and challenging links between deinstitutionalisation, community care and housing for people with disabilities.

Key findings (Bostock et al, 2001) show that:

- There are approximately 6,000 people with an intellectual disability living in institutions in Australia, although this figure should be treated with caution as definitions of institutions vary between States and Territories.
- Deinstitutionalisation appears to be slowing across most jurisdictions in Australia, with notable exceptions, such as New South Wales and Victoria.
- The separate evolution of Commonwealth funding agreements for housing, and for people with disabilities, poses a policy coordination barrier and may work against achieving stable accommodation for people with complex needs.
- A tension exists between the policy aim to be more responsive to diverse client needs, and funding constraints.
- Group homes, which enable support services for several clients to be pooled, provide economies of scale in operation, and are often preferred over other (more expensive) models which cater more explicitly to individual needs
- There is an emerging need to ensure that the housing built for intellectually disabled people today is appropriate for future generations of users.
- Many younger people prefer individual or share housing, and service providers are aiming to better cater to individual needs.

This research suggests that new funding frameworks that 'tie' funding to individuals and are portable between service providers could improve individual client control and choice in housing and support. It is also stated that greater use of the private rental market may ease cost pressures on public and community housing agencies in providing suitable accommodation to this group of people. (Bostock et al, 2001)

The research emphasises the need to tailor support services to individuals, rather than providing services that are based upon "one-size-fits-all" models. Decision makers need to recognize the need to move beyond the group home model. It should be noted that for other client groups using housing agencies there is no suggestion that, for reasons of economies of scale or financial imperatives, people in housing need should be asked to share rooms, or to

live in collectives or group homes or in clusters. This is despite the equally significant funding constraints on providing secure, affordable housing for people in housing need.

The research (Bostock et al, 2001) had originally anticipated that people moving from institutions had a diverse range of housing options available. Information from this study suggests, however, that the housing experiences and choices of people with an intellectual disability remains highly constrained. The study also reveals that the client relocation process tends to be closely managed in disability services and that the group home remains the major community housing model. In fact, people with disabilities often cannot meet their needs for secure, affordable and appropriate housing within the private market.

If genuine housing solutions for people with complex support needs depend on the development of working relationships between the range of government and non-government agencies, then there is a need for greater dialogue and information sharing between key State/Territory and Commonwealth agencies. The need exists for the Australian governments at all levels to adopt a more co-ordinated approach.

1.8.8 <u>Forensic Issues</u>

Historically, there has been minimal attention paid to the situation of adults with an intellectual disability who have offended or are at risk of offending. Recent research confirms that people with an intellectual disability are over-represented in the criminal justice system in many western jurisdictions (Hayes, 2000; Petersilia, 2000). The area poses particular difficulties because of discrimination and opposition within the wider community. Strategic responses will require not only the provision of appropriate services, but innovative responses to negative community attitudes (Hayes, 2000).

The relationship between challenging behaviour and forensic problems in people with intellectual disability may be blurred. Many behaviour problems in people with an intellectual disability may well be considered to be offences in those without disability. One of the determining characteristics of an "offence" is that the perpetrator is aware of behaviour that is socially sanctioned or censured. Even when someone with mild intellectual disability may understand the nature of the offence, the criminal justice response and the response of carers is diverse across cases and situations (Clare & Murphy, 1998).

Challenging behaviour has been reported in the literature between 10-30% dependent upon the level of intellectual disability. However, this behaviour does not automatically result in involvement of the criminal justice system although it may place the individual at significant risk of such. The presence of intellectual disability increases the probability of offending behaviour (Hidgins, 1992). Offending behaviour is likely to be conceptualized as challenging behaviour although the reverse may not be appropriate (Lyall et al, 1995). It is highly likely that services for adults with challenging behaviour will also be required to assist the needs of those whose behaviour has resulted in involvement with the criminal justice system therefore there are support, training and expertise ramifications for staff (Mansell, 1993).

A survey completed in UK demonstrated that 16% of patients in 3 secure hospitals had an intellectual disability but only one in five had a dual diagnosis (Taylor et al, 1998). Most of this group had entered these hospitals when a child and only eight were new to treatment upon

admission. These results are consistent with Australian evidence where the prevalence of intellectual disability was determined to be 20% of the prison population. Such evidence may suggest the need for proactive early intervention programmes in Australia (Hayes, 2000).

The prevalence rates for offenders with an intellectual disability are generally considered to be higher than those in the general population. This is especially true for sexual offences and arson Hayes, 1991 (Hayes, 1991) some studies do however suggests that this group is not over-represented in the sex offender population (Hayes, 2002). Although adults with an intellectual disability comprise a minority within the group convicted of sex offences, nearly half have been convicted of sex offences and recidivism is high (Quinn & Smith, 2000).

1.8.9 <u>Transition Issues: Young People with an Intellectual Disability and Complex Needs</u>

In response to changing community values and supported by legislation, young people with problem behaviours can no longer be placed into care and protection of the state solely because of challenging behaviour. Some of these young people have now joined the growing ranks of the homeless (Bath, 1998). There is a strong preference in youth work for community-based options and institutional service provision is considered totally inappropriate.

In NSW, the 'Usher' report (Ministerial Review Committee, 1992) led to the closure of several older institutions and the establishment of 6-bed units for young people with high needs and challenging behaviours (Bath, 1998). The movement away from the residential model to individualised case management and supported living in a range of environments has virtually closed their units.

There is another form of residential care that is emerging with Queensland media often reporting how may children at risk, are placed on a one to one basis in hotel accommodation funded by the state government. This model is difficult to describe. One-to-one arrangements are generally established for young people with particularly high needs and challenging behaviours who cannot be placed in foster care or in the few remaining group care options. Usually this approach is utilised when all others have failed. Many social workers and youth workers would argue that these approaches are conceptually unsound and certainly not a preferred approach (Bath, 1998).

Ad hoc responses to this difficult group are typically expensive. The utilisation of this model is crisis driven and definitely does not adopt a therapeutic, let alone preventative approach. The only other major developmental approach to this difficult to serve group of young people been movement towards the brokerage models for at-risk young people where the primary service is case management and options such as shelter and board are purchased from other providers (Bath, 1998). Again, these options are expensive and resource intensive. Services that provide support operate at their very best but are marked by chaos and stress for all involved. Services and staff involved are asked to do a job that they were never designed for.   This report is unable to address the needs of young people with an intellectual disability who have complex problems, but models of service provision must take their account and their potential impact into careful strategic consideration.

1.9   Concluding Comments

Deinstitutionalisation within the Queensland setting has over-focussed upon social needs of adults with an intellectual disability to the detriment of their physical health and mental health needs. Adults with an intellectual disability with complex needs have therefore been underserved or inappropriately treated because of a range of inter-organisational barriers (Patterson et al, 1995). Contemporary service delivery strategies to this group of people have been described by Disability Services Queensland (2001) as being inadequate and characterised by:

- Limited and informal interagency, multidisciplinary responses;
- High cost service arrangements that are not sustainable long-term;
- Social isolation and maintenance of behaviour with no real long term therapeutic progress
- Minimal inclusion and or/continuance of natural support for the individual demonstrating dangerous, complex behaviour;
- Human resource management issues including workplace, health and safety concerns and duty of care responsibilities
- Documented lack of appropriate accommodation options for short term assistance; and
- Inadequate long term and short term accommodation arrangements.

Defining the target group is problematic given the reality that this population does not fit readily into one agency's criteria for service provision and the needs cut across multiple agencies. In response, service provision has been lagged, unplanned and ad hoc with consequence that relate to expensive and lack of clarity between agencies about levels of responsibility. Decision makers must also consider the capacity and willingness of the community to meet the needs of all adults with an intellectual disability, regardless of the severity or complexity of their requirements (Bouras & Szymanski, 1997) who have complex needs.

The responses of most service providers to people with challenging behaviour highlight the critical barriers. Eligibility policies and criteria are used to exclude people with complex problems from services rather than being used to provided the needed services. There are many reasons, but the artificial demarcation between disability services and mental health services must major responsibility.

Community care has had paradoxically both sweet and bitter outcomes. Idealistically considered to be the panacea for al problems, and some anticipated that both mental health problems and challenging behaviour would disappear when moved from institutions (Bouras & Szymanski, 1997). A with an intellectual disability have a range of unique needs that require special consideration, energy remains focussed upon challenges associated with the achievement of community acceptance, valued social roles and a reasonable quality of life.

Despite increasing emphasis being placed upon the importance of mental health in the conceptualisation of health and quality of life, governments have historically failed to recognise the complexity of needs faced by people with disabilities. In particular, the mental health needs of adults with an intellectual disability have not received due attention. These emergent needs have highlighted the lack of collaboration between health and human services and the need for these relationships and approaches to problem solving to be strengthened.

Research considering the impact of twenty years of deinstitutionalisation and community care policy across the western world has brought the needs of people with an intellectual disability who have complex needs into sharper focus. Although this group of people is small in number, adults with an intellectual disability are a significant minority who consume large amounts of resources. Despite great improvements in the philosophy of care and associated service developments, this significant minority poses great challenges in regard to care and support (Bouras & Szymanski, 1997)

Problems have become exacerbated by eligibility confusion, unclear service provision and disagreements about who should be responsible for providing care (Bouras et al, 2000). Anecdotal experience suggests a similar situation in Australia. Generic, mainstream services experience major difficulties when attempting to respond to the complex needs of adults with an intellectual disability. The needs of this group are frequently multi-dimensional with many service systems being involved.

Despite a number of different models and approaches to providing services, an "ideal" or a preferred model is yet to be identified. This report considers a range of service configurations currently being utilised within Australia and internationally. Considerations of these models of service delivery will assist Queensland government and non-government service providers to make decisions regarding the range of service responses required to meet the needs of adults with an intellectual disability who have complex needs.

Chapter Two: Models & Service Responses

2.   Introduction

Although there has been a radical developments in service delivery over the last two decades, the complex needs of adults with an intellectual disability, including mental health problems and or challenging behaviour, have not been well addressed in most western nations. A common problem for most western nations is conflict between and within organisations in regard to the management of adults with an intellectual disability between system and agency service cracks (Woodward, 1993).

The most advanced service development appears to have taken place in the United Kingdom although there remains a significant gap in service provision in most countries (Chaplin & Flynn, 2000). Each country has been uniquely shaped and constrained by demography and history, with legislation and policy developing accordingly. This chapter explores trends in service responses and configurations to adults with a dual diagnosis. A brief description and where available, synopsis of service models is provided. The appendices in Chapter Three provide more detail of service responses. Consideration of models can be helpful in strategic planning exercises where service development and implementation is being contemplated (Thornicroft & Tansella, 1996). Where available, evaluation outcomes of models are also provided but where unavailable anecdotal commentary is provided which was gathered from senior clinicians and academics that were contacted during the project duration.

The challenge for legislators and governments has been to provide an appropriate spectrum of services to adults with complex needs within the community setting. This appears to be a global challenge – whether a western or eastern nation. Services may be required by adults

with an intellectual disability who have concurrent mental health problems, have challenging behaviour, or who have offended or are at risk of offending.

The prevailing philosophy of service provision in most western nations requires that adults with an intellectual disability access and utilise generic services within the mainstream setting. However, regardless of availability, access is often compromised by the nature of the intellectual disability and additional specialist services are often required (Bouras & Holt, 2001). In most of the nations services to people with an intellectual disability are now underpinned by a normalisation and social role valorisation with ongoing deinstitutionalisation, closure of large scale institutions and the establishment of community based accommodation options. The advocacy movement has assisted these developments with the voices of consumers, their family members and carers being instrumental drivers of change. Despite some apparent similarities, movement and change has varied considerably between and within the nations.

○ Australian Perspective

State governments within Australia have made minimal responses to the needs of adults with a dual diagnosis. Initiatives across Australia have tended to develop on a state-by-state basis that has resulted in isolated and uncoordinated service development. Australian agencies or organisations involved in service provision to adults with a dual diagnosis are generally not aware of dual diagnosis developments or activities in other states. There are no formal or informal mechanisms set in place for networking or sharing of expertise or resources across the states. Protocols and interagency agreements are beginning to emerge between stakeholder agencies across the states.

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

Adults with an intellectual disability who have complex mental health needs often require "care" throughout their entire lifespan. They may require additional support and assistance to access appropriate services and then maintain lifestyles that maximize mental health and well-being as well as physical health and well-being. Few carers, whether paid or unpaid, would disagree that care is a complex, inter-professional process that is undertaken by a variety of staff, both clinical and non-clinical (Sharp & Kilvington, 1993).

Victoria

A range of innovative developments have been established within Victoria. In addition to the development of a collaborative document entitled, "Protocol between Intellectual Disability Services and Psychiatric Services'" that guides service responses to adults with a dual

diagnosis, the Victorian Government's Department of Human Services has developed a number of projects.

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

The *Northern Region Dual Diagnosis Project* is also in operation within Victoria. Although there were no Psychiatrists employed, two mental health professionals are involved in assessment in the northern metropolitan region (Disability Branch).

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

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

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

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

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

The CDDHV has also completed a training package for these professionals in the use of GAP MAP. The GAP MAP (Global Assessment of Psychopathology - Managing the Assessment

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

- Mental health for adults with an intellectual disability;
- How to write behavioural descriptions;
- Addressing carer concerns and safety issues;
- Medical review;
- Maximising information reliability in assessment using checklists and rating scales; and
- A guide to diagnosis and treatment of the most common psychiatric disorders.

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

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

New South Wales

The Centre for Developmental Disability Studies (CDDS) began operating in 1997. This Centre operates through the University of Sydney where a Foundation Chair of Developmental Disabilities was created. The CDDS creates and disseminates knowledge that can improve the lives of people with developmental disabilities. In addition to research activities, the CDDS operates a general health clinic for adults with intellectual disability, many of whom present with a dual diagnosis. However, this is a primary focus at the present time (McVilly, 2002, in private communication).

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

Other local dual diagnosis initiatives are also developing within New South Wales. For example, the South Western Sydney Area Health Service, Area Mental Health team has a Clinical Nurse Consultant working in the dual diagnosis area (developmental disability and mental illness). Difficulties in making contact or networking with clinicians and project workers are a significant barrier to dual diagnosis service development and enhancement across Australia.

One Psychiatrist in New South Wales does work extensively with adults with an intellectual disability. Dr Peter Wurth who runs his private practice from suburban Sydney but also operates a "fly in clinic" for Tasmania on a regular basis (McVilly, 2002, in private communication).

South Australia

The South Australian government has been proactive in responding to the needs of adults with a dual diagnosis through the Intellectual Disability Services Council (IDSC). The IDSC is the lead agency for people with an intellectual disability in South Australia.

The Dual Disability Programme is provided by the Specialist Intervention Support Service, part of the IDSC Community Services Division. The Dual Disability Program aims to improve the way in which IDSC and mental health services work together to assist of people with dual disability.

This Programme forms part of a number of services designed to assist families/clients who are experiencing extreme distress/difficulties. The Specialist Intervention and Support Service is staffed by a team with a wide range of skills and experience. It includes psychologists, social workers, speech pathologist, family workers and behaviour support workers.

The Specialist Intervention and Support Service is structured as four programs. In addition to the Dual Disability Program, there are:

- **The Developmental Services Team**

  This team undertakes research and training in the provision of developmental services for individuals or groups. The team works closely with regional services to meet the needs of individuals for assistance with skills development.

- **Adolescent and Adult Intensive Intervention Team**

  This team provides intensive interventions to adolescents and adults with intellectual disability who, due to their behaviour, are at risk of losing their accommodation, day placement or access to the community.

- **Intensive Family Intervention Team**

  This team provides intensive intervention for children with intellectual disability whose families are at high risk of family breakdown or where the child may be placed out of the home.

All programs provide an advisory service to case managers and service providers as well as assisting with training and education initiatives. Research and evaluation are also a major focus of the Specialist Intervention and Support Service.

The momentum for the establishment of the Dual Disability Programme can be traced back to the mid 1990s. In 1995 recurrent commonwealth funds of approximately $70,000 were made available through the Commonwealth State Disability Agreement to address dual diagnosis within South Australia. These funds were used to establish a steering committee and appoint a project officer in 1996. Initially this committee was involved in the allocation of brokerage funds to support service provision to individual adults with a dual diagnosis. The committee was also involved in collaboration with agencies in policy development relevant to adults with a dual diagnosis, as well as cross-agency dual diagnosis training.

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

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

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

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

Tasmania

In Tasmania, OPTIA INC, a non-government agency supporting adults with an intellectual disability has developed a "Dual Diagnosis Outreach Program". OPTIA INC has negotiated with a Sydney based Psychiatrist, Dr Peter Wurth, to run a dual diagnosis clinic. OPTIA pays for Dr Wurth to fly from Sydney to Hobart to complete the dual diagnosis clinic on an "as

required" basis. Dr Wurth consults with staff and adults with a dual diagnosis, when funding is available. This Consultant Psychiatrist has a private practice in Sydney. Dr Wurth has an interest in the area but the bulk of his practice is within general adult psychiatry.

Additionally there are two registered nurses employed by the Department of Community Health Services in Hobart. These nurses were conducting a small-scale study into models of care and models of nursing for adults with a dual diagnosis. Outcomes of this project however, were unable to be identified.

Western Australia

In Western Australia, the Disability Services Commission (DSC) and the Mental Health Services of the Department of Health have formally responded to the needs of adults with an intellectual disability who require access to services provided by both departments through the development of a protocol. The "Protocol Between the Disability Services Commission and the Department of Health: People with Intellectual Disabilities and Mental Health Disorders: Guidelines for Service Providers" was established in February 2002. The Protocol is modelled on the Victorian government's document, "Protocol between Intellectual Disability Services and Psychiatric Services", Human Services, Victoria, June 1994. The purpose of this protocol is to enable the departments to meet the needs of these consumers and ensure that they receive the services most appropriate to their needs in as smooth and coordinated a manner as possible. Additionally, the Disability Services Commission (DSC) and the Metropolitan Mental Health Services (Department of Health) established a high level interagency committee in April 2001. This committee specifically meets to address the needs of adults with an intellectual disability who have concurrent mental health problems. Both government and non-government agencies representing disability and mental health service provision are involved at a senior level.

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

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

- Assessment and intervention for adults with an intellectual disability who are considered to have a mental illness. This service would be involved in the provision of early interventions to prevent the breakdown of the person's place of work or home;
- Consultancy and training to families, carers and service providers to enhance functional and adaptive skills and to support the individuals with mental health disorders in their own homes, communities and places of work; and

- A multi disciplinary service that will involve collaboration with DSC Local Area Coordinators, social workers, medical officers, clinical psychologists, medical specialists and other agencies including non-government organisations.

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

o International Perspectives

There is no centralised system of collection or comparison that analyses information on the policy, planning and delivery of services for people with an intellectual disability and mental health needs on an international basis (Moss et al, 2001). Direct comparison of the size and structure of populations of adults with intellectual disability is however possible although it is restricted due to problematic data collection practice.

A recent study (Moss et al, 2001) developed a snapshot of the approach of some European nations. The table below, extracted from this study, provides an approximate picture and therefore some limited comparison. The research suggests that the needs of adults with an intellectual disability who have coexisting mental health problems are not well addressed by these nations. The authors do suggest that England may be an exception although they caution that there are gaps in service delivery to this population apparent.

This research shows that the countries considered are fairly even in terms of the number of adults with intellectual disability and the estimated co-morbidity with psychiatric disorders. Initiatives have focused on the need to integrate individuals with intellectual disability intellectual disability into community care. In general, this has resulted in less reliance upon hospital-based provision, an increased emphasis on community-based care, and an avoidance of institutional care. With the widespread acceptance of deinstitutionalisation, debate has focused around whom should provide services for people with an intellectual disability and precisely how they should be delivered. Australia appears to have have had a parallel experience.

Estimates of Prevalence of Intellectual Disability & Comorbidity (Dual Diagnosis)

Country	Intellectual Disability Population	Dual Diagnosis
Austria	45, 000	28.9%
England (UK figures)	(1% of general population)	40%
Greece	150,000	36%
Ireland	26,964	22.2-56%

	(7.57 per 1000)	
Spain	152,548	32.3%

2.2.1 <u>England</u>

During the last 20 years there has been a radical reshaping of service provision for people with intellectual disability in England. The main characteristics of this have been de-institutionalisation (resettlement) and the development of community care. The decade from 1980 to 1990 saw some closure of institutions and a few innovative service developments. Pressure groups, networks of professionals, parents and consumers all tried to influence the model of services to people with intellectual disability based mainly on the principle of Normalisation (Wolfensberger, 1969, 1991).

In England, debate has focused more fiercely around whether individuals with an intellectual disability ought to receive 'ordinary' or specialist, segregated health services. Policy guidance has been broad and open to wide interpretation. The Department of Health (1989) noted that specialist facilities and services might be required for those who were also mentally ill, had behaviour problems or offend. At a later stage the Department of Health (1992) recommended that people with intellectual disability should use ordinary health services whenever possible. However, it was recognised that sometimes support would be needed for a person to access these, and that additionally sometimes specialist services would be needed. The Reed Report (Department of Health, 1994) highlighted the relative lack of facilities for mentally disordered offenders with intellectual disability and recommended that a range of services should be available with the appropriate level of security.

The publication of the Mansell Report in England "Services for People with Intellectual disability and Challenging Behaviour or Mental Health Needs" (1993) offered impetus for the development of specialist services for people with severe intellectual disability and severe challenging behaviours. Emphasis was given to community and locally based services to support good mainstream practice.

The Royal College of Psychiatrists Council Report "Meeting the Mental Health Needs of People with Intellectual disability" (1996) addressed the issues of people with mild intellectual disability and mental health needs (dual diagnosis). It recommended the development of specialist mental health teams to ensure co-ordinated services, and effective liaison and integration with other agencies. These teams should have expertise in both intellectual disability and mental health and provide direct services to patients and carers, and training and advice to other agencies.

They should be based locally and provide inpatient care as well as outpatient and community based interventions. The Signposts for Success (DoH1998) recommended that multidisciplinary services should be available to provide skilled assessments and intensive input to people with intellectual disability and mental health needs. Where emphasis has been on treatment in the community, there is a growing recognition that individuals with intellectual disability require not only additional services and support, but also help to access services.

The UK has a Faculty of Learning Disability of the Royal College of Psychiatrists, which has existed for one hundred and fifty years. This has promoted the needs of those with dual diagnosis. It has been very active in developing and monitoring training programmes, organising conferences, contributing to research and influencing national policy. In England people with intellectual disability and mental health needs often have local specialist services, although these may not be comprehensive (Bailey and Cooper, 1998). Different districts have developed different service models depending on their local situation (Gravestock and Bouras, 1997).

Some services centre around residential, usually hospital, provision perhaps with out-reach work, whilst others are more community-based sometimes with access to in-patient facilities (Bouras and Holt, in press). Approximately two-thirds of the NHS Trusts who have completed resettlement have retained some long-stay beds (some for people with enduring mental illness or challenging behaviour) and the majority provide assessment and treatment beds either in specialist units or general psychiatric units (Bailey and Cooper, 1998). Overall, 60.7% of NHS Trusts no longer have institutional beds and 20% have no long stay provision at all for people with intellectual disability (Bailey & Cooper, 1998).

Across England as a whole, however, the average NHS Trust manages 10.3 long stay beds per 100,000 of the population with intellectual disability. Indeed most NHS Trusts continue to provide long-stay beds for a minority of individuals with additional needs such as mental health problems, challenging behaviours and complex physical disabilities. In recent years in many NHS Trusts, the emphasis has been upon providing specialist assessment and treatment beds within generic and specialist services. In keeping with the principles of normalisation, individuals ordinarily resident in the community use these specialist services at times of greatest need. In a review of NHS bed provision in England and Wales, Bailey and Cooper (1998) report an average of 1.8 assessment and treatment beds per 100,000 of the mentally retarded population.

2.2.2   Greece

In the past decade mental health care in Greece has undergone major transformation. The outcry over poor conditions in Greek mental health hospitals, especially in the Leros institution, began in the early 1980s. Soon afterwards, the European parliament passed the 815/84 Regulation, under which extensive financial support was dispensed for reforming psychiatric care over five years (Tsiantis et al., 1995).

In 1992 legislation aimed to fulfil the principles of "deinstitutionalisation, sectorisation, preventive and outpatient services and development of new social and community oriented services" in Greece (Yfantopoulos, 1994). This resulted in the construction and adaptation of buildings for psychiatric and psychological services, legislation for work opportunities, increased awareness of residents rights, decrease in the number of beds in large public and private psychiatric hospitals, development of in-patient psychiatric units in some district general hospitals, and the setting up of some community-based services (Madianos et al, 1994; Tsiantis et al, 1995).

Inevitably, these reforms of mental health services affected the quality of care offered to adults with intellectual disability, as many of them were -and still are- in psychiatric institutions. There is a view that the intermediary structures have not brought the change envisaged in the 1983 legislation (Madianos, 1995; Tsiantis et al., 1995) and the predominance of the asylum mentality in the mental health system continues to characterise the image of Greek psychiatry (Strutti & Rauber 1994). With some exceptions, new services have been developed side by side with old ones, without replacing the old services. Also the majority of the Community Psychiatric Services projects funded by EU were developed in the two largest Greek cities of Athens and Thessaloniki, in spite the fact that most existing services were already concentrated in these areas (Liakos, 1996).

The Greek government now recognises the importance of assisting people with an intellectual disability to access community-based services. The government is planning the development of Centres for Social Support & Rehabilitation for Individuals with Special Needs, some of which are already under construction (Law 2646/98) (Greek Government Gazette, October 1998). These will provide diagnostic services and systematic evaluation that will aid the placement of the individual into the appropriate rehabilitation program. They will also offer counselling services (i.e. prognosis, psychological support for the whole family), occupational therapy, speech therapy, physiotherapy and psychotherapeutic intervention, training programs in independent living, referral to specialised services for therapy and rehabilitation, and recreational programs. In addition, the Greek Ministry of Health and Welfare is planning the creation of other special centres for individuals with autism. The current legislation also refers to home-based social help for individuals with special needs and the elderly.

In Greece, where the emphasis of services is rehabilitation, 37.3% have no input from a psychiatrist, 22.5% none from a psychologist and 23.5% no access to a social worker. Services to these with dual diagnosis are unevenly spread. There are fifty-one institutions for individuals with special needs that offer services to individuals with mental, physical, motor and social handicaps (Madianos & Stefanis, 1997). These institutions operate under the social welfare system of the Greek Ministry of Health and Welfare. Twenty-two of these institutions are located in the Greater Athens Area, five are located in the city of Thessaloniki and twenty-

four are located in the rest of Greece. Three out of the thirteen geographical health sectors lack such institutions.

The great majority of these institutions (64.7%) accept both children and adults. The majority are both day centres and residential units with some offering outpatient care as well. Other mental health services also serve individuals with intellectual disability. These vary from 'traditional' residential care (e.g. Psychiatric Hospitals, Private Psychiatric Residential Facilities) or 'alternative' forms of residential care (e.g. Hostels/Boarding Houses) to outpatient services offering diagnostic and/or counselling facilities (e.g. Psychiatric Sectors in General Hospitals, Mobile Mental Health Units) or day centres (e.g. Mental Health Centres, Vocational Training Units).

2.2.3   <u>Ireland</u>

In Ireland services (Robins, 1986) have developed over the last century although many adults with an intellectual disability were found in workhouses and psychiatric hospitals. Gradually specialist institutions were established by private philanthropists or by religious orders continuing as service providers until our time. In the late 1950's 'parents and friends' groups were set up by relatives unwilling to see their family members go into institutions. Having started with schools for a young population these have now evolved into full services providing a range of residential and day services.

In 1965 the Report of the Commission of Inquiry on Mental Handicap supported the development of community care stressing however that an appropriate mix of facilities should be available. 'Voluntary Bodies' provide most services with some involvement by health boards. Though some people with intellectual disability remain in psychiatric hospitals or designated units, public opinion is pressing for continued change in this area and hopefully legislative commitment will follow (Ryan, 1999).

Where the special needs of this group has been recognised at a legislative level, precisely how services will be provided to them remains unclear. For example, in Ireland the White Paper on Mental Health (1995) covers many areas and options while making few recommendations. Follow up documents have not been forthcoming and pilot projects have not been initiated. Beyond knowing that there is awareness at government level of the special needs of this population and the probability of funding for "special units" for people with intellectual disability and severe behaviour problems, it is uncertain as to what Department of Health policy is going to be in the area of Mental Health and Intellectual disability. Resulting policy and legislation are therefore awaited.

In Ireland provision for people with dual diagnosis varies across the country with the concentration of services being in the Eastern Region that is also the most highly populated. Psychiatrists who work with people with dual diagnosis are usually employed by a voluntary body and do not provide services to people with mild intellectual disability unless they already attend the services of the employing body.

People with mild intellectual disability are reliant on the generic service for mental health service provision. Research (Parton et al 1984, Kennedy et al, 1988) suggests that this leaves their needs undeserved. A recently established psychiatric service in the Eastern Health Board

Region which was set up to serve people with dual diagnosis in a rural area is attempting to remedy this deficit in the catchment area it serves by not attaching itself to a particular intellectual disability service but basing itself in the generic services. Whether this will start a trend of service provision to all with intellectual disability and mental health needs as opposed to just those attending services remains to be seen. Irish psychiatrists in this sub-speciality also have commitments to generic services either as adult psychiatrists or as child psychiatrists depending on their training and the way in which the post was set up.

They have access to a multi-disciplinary team but the other members of this team will not be solely involved in mental health work. There is currently little formal provision for people with dual diagnosis who need inpatient treatment. People with dual diagnosis do not have access to the continuum of services that people without intellectual disability have and this needs to be rectified.

2.2.4 <u>Spain</u>

Since the late 1970s the mental health service in Spain has undergone deinstitutionalisation. This followed the recommendation of the European Council and was based upon the report of the National Commission for Psychiatric Reform (1985). The goals set by the Commission included: integration of the mental health service in the general health system, development of a community-oriented model based upon geographical area, development of intermediate services and rehabilitation programs, a progressive shift to psychiatric services within general hospitals, and priority to programs in specific areas such as child psychiatry. The implementation of these recommendations varies between regions.

Spain is divided into 17 autonomous regions called "Autonomous Communities" (AC), plus two Autonomous Cities (Ceuta and Melilla). During the last 20 years, three parallel processes have taken place: decentralisation from national to regional agencies, different for each AC, a health reform and a mental health reform. The combination of these has produced a complex situation. For instance Andalusia and Asturias opted for the complete closure of psychiatric hospitals, whilst the Basque Country and Catalonia remodelled and included them in their strategies.

In Spain, appropriate policy and legislation in relation to people with intellectual disability and additional mental health needs is not yet in place. There is no national framework for the care of people with intellectual disability and psychiatric disorders. Neither the National report for the Mental Health Reform nor the regional mental health plans provide information on this issue, except for the special report on Psychiatric Hospitals in the Basque Country (San Martin et al, 1992). This report includes a brief comment on diagnostic overshadowing and the prevalence of people with intellectual disability living in psychiatric hospitals. However, no mention is made of this population in the section on health planning. The Basque Country has not implemented any care strategy in the last ten years.

In Spain generic mental health services are responsible for those with dual diagnosis. As elsewhere, staff in these services do not have the necessary skills or resources to meet this need. The lack of special settings is particularly relevant in a period characterised by deinstitutionalisation, since other health services are not prepared to cope with those with dual diagnosis. On the other hand social services have not been designed to provide adequate care

for this group. Little attention has been paid to those with dual diagnosis in the Navarre organisational structure. On the other hand, specific programs have been developed in Galicia such as respite units, time-limited stay units and mental health liaison services. A limited number of projects for people with dual diagnosis have been developed in Spain. For example, Catalonia and Andalusia had developed special residential services, and various non-governmental organisations have implemented imaginative services such as INTRAS and PROMI. This latter has developed 14 centres in Andalusia and elsewhere. It provides vocational and social support for 1200 people with intellectual disability. It works in close association with mental health professionals at the University of Cadiz who provide clinical, training and research expertise.

2.2.5 <u>Austria</u>

In Austria people with intellectual disability have access to generic mental health services in theory, but in practice this is often not guaranteed. This is the result of lack planning and training. Despite this fact mental health services for people with intellectual disability can be identified throughout Austria. For instance, a special psychiatric service for adults with intellectual disabilities was set up three years ago on the site of the Neurological Hospital of the City of Vienna, Rosenhügel, within the Department of Neuropsychiatry for Children and Adolescents with an associated Centre for People with Disabilities.

This hospital is mainly for children and young adolescents, offering services ranging from neurorehabilitation to child and adolescent psychiatry within a generic model (Berger, 1999). The service also offers psychiatric and psychotherapeutic services for older adolescents and young adults with disabilities, most of them with intellectual disability. It offers both in-patient and out-patient services, including a six weeks psychiatric rehabilitation program, set up to facilitate the deinstitutionalisation program of the Psychiatric Hospital of the City of Vienna. Additionally, a liaison service for social work (casework) is offered in co-operation with the Department for Adolescent Psychiatry and Disability Psychiatry of the Psychosocial Centres of the City of Vienna.

2.2.6 <u>USA</u>

The history of service provision to adults with an intellectual disability and mental health problems is somewhat piecemeal across the USA. This approach probably reflects the fact that health and human services reflect a categorically segregated service system. This history has some parallels with the development of the health and human service systems in Australia.

Similar to Australia, separate service structures exist within the US for disability services (known as intellectual disability services) and mental health services. US federal and state governments also provide separate or complimentary services. These separate systems have contributed to diffusion of responsibility and jurisdictional disputes (Fletcher et al, 1999). Conflicts occur between these two service systems. When compared to the UK, the USA lacks a federal specialised dual diagnosis services although interesting integrated models of service delivery can be identified in various states. However, when compared to Australia, the US has more developed and well-resourced service infrastructure on both federal and state levels.

During the 19th and 20th centuries the US human service system at both the federal and state levels developed into organised categories of what were thought to be discrete, specialised problems. Service agencies became even more specialized and categorically segregated during the 1970's and 1980's. Through this period human services became increasingly specialized not only by problem type but also by such eligibility issues as client age, gender, and even ethnicity. Not only did the number of agencies increase but also their size. Integrated service delivery was not even considered.

During the 1980s the complex needs of multiple problem clients emerged and helping these individuals and their families became a major responsibility of many agencies across the US. This client group did not seek assistance from one agency but was found in mental health and addiction treatment agencies, schools, family counselling agencies, child welfare agencies, youth service bureaus, welfare reform initiatives, criminal justice programs and public health clinics. These clients/ families presented with a great number and diversity of problems, problems of great complexity and chronicity, and problems that often had powerful intergenerational momentum.

This change in the characteristics of clients reflected the diminishment of natural safety nets: changes in nuclear family structure, decreased contact with extended family and kinship networks, the loss of value-homogenous neighbourhoods, and sustained isolation from major social institutions (church, school, workplace). Equally troubling was the fact that multiple problem clients often brought long service careers marked by:

- Service extrusion;
- Premature service disengagement;
- Multiple relapses and episodes of service re-engagement;
- Iatrogenic insults resulting from inappropriate service interventions.

Whilst a comprehensive array of specialist dual diagnosis services does not consistently exist in every US state, University Affiliated Programs (UAP) were initially established under the auspices of the Developmental Disability Assistance and Bill of Rights Act. In 1999, President Clinton signed the re-authorization of the Developmental Disabilities Assistance and Bill of Rights Act. This bill reinvigorated the former University Affiliated Programs into a National Network of University Centres for Excellence in Developmental Disabilities, Education, Research and Service (UCEs).

These Centres of Excellence in Developmental Disabilities Education, Research and Services, are located in major cities and can be found in every state and territory in the USA. The Centres provide interdisciplinary academic, professional and community training. Staff of these centres are also involved in diagnosis, evaluation and treatment. Specialist inpatient mental health treatment and assessment units also operate on an ad hoc basis across the USA. These programs link clinicians, professionals and academics. They focus upon providing clinical services and are involved in teaching and education activities at the undergraduate and postgraduate levels.

Overall, mental health services provided to people with an intellectual disability in the United States tend to be provided (Bouras & Szymanski, 1997):

- By visiting consultants rather than full time professionals (Menolascino, 1994);
- As part of outpatient clinic services, usually part of a University Affiliated Programme, via a multiprofessional team (Menolascino, 1994); or
- In a special inpatient/outpatient service as part of an integrated generic mental health and developmental disabilities service (Rochester model).

Most USA professionals would argue that any workable model of service provision for adults with an intellectual disability must involve some access to inpatient assessment/treatment units. For those with mild intellectual disability, the evidence seems to be that behavioural techniques and most psychoactive medications work just as well as for non-disabled persons.

With moderate to severe intellectual disability, however, the need for specialised units becomes clearer, both because of the diagnostic confusion that ensues when one cannot use all of the regular criteria (e.g. how does one assess depression in a person who is non-verbal) but special programming aims and issues (Baker, 2002 in personal communication). One very (anecdotally) successful program is the Lindens, at Bancroft Neurohealth in New Jersey (USA). The living units (called neural-behavioral stabilisation units) each have five or six patients, the stay is typically measured in days and weeks, and the staff is intensively trained in behavioural methods. The clients of these units can often be children with an intellectual disability and severe emotional problems, but also individuals with brain injury and complicating psychiatric difficulties.

In the USA, and other countries where there is an overall lack of specialist services for people with intellectual disabilities, there is evidence of adverse consequences (Davidson et al, 1998; Jacobson, 1998). A prevailing view is that people with intellectual disabilities and concomitant psychiatric disorders have often been under-served or inappropriately treated because of inter-organisational barriers, leading to unnecessary hospitalisation and lengthy delays in community placement.

2.2.7 <u>Canada</u>

The Ontario Government adopted a policy of deinstitutionalisation in 1973, and in 1974 the Developmental Services Act moved the responsibility for individuals with developmental disabilities from the jurisdiction of Health to Community and Social Services. The last 15 years has seen particularly significant change in services and supports provided to individuals with developmental disabilities and dual diagnosis.

In 1987 the closure of all 16 Ministry of Community and Social Service (now called the Ministry of Community, Family and Children Service) facilities for the developmentally disabled by 2012 was announced. Ten years short of that timeline and three facilities remain open. The Table below captures the most significant government decisions, policies and directions over the last 15 years.

1987-2002 Time Line of Government Policy Related to Dual Diagnosis

1987 Challenges and Opportunities, Ministry of Community and Social Services (MCSS). 25 year plan to close 16 facilities for the developmentally disabled

1988 Building Community Support for People: A Plan for Mental Health Reform, Ministry of Health (MOH). Dual Diagnosis included as part of the target group for mental health service development.

1990 Ontario Interministerial Initiative on Dual Diagnosis - Funding to 5 time limited projects across the province to bridge the mental health and developmental sectors

1993 Putting People First - Mental Health Reform - Focused on a shift from institution to community. Included Dual Diagnosis in Definition of Seriously
Mentally Ill, the priority population for service.

1996 Mental Health System Design Process to guide implementation of Mental Health Reform – lead by District Health Councils

1997 Making Services Work For People Policy guidelines and reinvestment strategy for developmental Services. Focus on proactive, coordinated and streamlined system. No mention of Dual Diagnosis or mental health needs.

1997 Joint Policy Guidelines For the Provision of Services for Persons With A Dual Diagnosis, MOH and MCSS. Purpose was to ensure access to service in either or both the developmental or mental health sectors. Identified
collaborative cross sector approaches that support access. Defined the role of components of the health and social services sectors in meeting needs of individuals with a dual diagnosis.

1998 Dual Diagnosis Joint Policy Guidelines Implementation Work Plan, MOH and MCSS - established expected outcomes at a provincial, regional and local level, including cross sector committees. Health Services Restructuring Commission (HSRC) Review of all general and psychiatric hospital bed based services across the province.

1999 Making It Happen Implementation Plan for Mental Health Reform and Operational Framework for the Delivery of Mental Health Services and Supports, MOH. Focus on proactive, coordinated, streamlined system similar to Making Services Work For People.

1999 Reports from DHCs/MCSS Regional Offices to Corporate MCSS and MOH re progress on Dual Diagnosis Implementation Work Plans

2000 Planned closure of designated developmental service facilities completed.

2001 Mental Health Implementation Task Forces established in all regions of the province to develop recommendations for Ministry of Health on Provincial Psychiatric Hospital restructuring (from HSRC), community reinvestments and implementation of mental health reform. Dual Diagnosis included in the planning process 4 Year plan to move 978 individuals from MCSS Facilities to communities.

The Dual Diagnosis Guidelines and Implementation Work Plan of 1997 and 1998 appears to have significantly influenced local and regional responses to dual diagnosis in a number of ways. New committees were initiated with links to local planning and funding bodies, best practice approaches to enhance local community response were utilized through cross sector co-chairing and membership, and there was a focus within the committees on training and cross sector protocols.

In Ontario today there is certainly greater understanding that best practice service approaches include cross sector, integrated and comprehensive assessment of individuals, their environment and natural supports, and individualized services that are flexible, creative and seamless that bridge across professional and service boundaries. (Dart, Gapin & Morris, 2002) There are also excellent examples in pockets across the province of successfully implemented services that are responding to the specialized needs of individuals with developmental disabilities. For example:

- **Griffin Community Support Network** - crisis and safe bed resources and supports linked to Mental Health, with access to time limited day, case management and specialized services
- **Dual Diagnosis Resource Service, CAMH** (Specialized ACT Team) - telephone consultation, multidisciplinary assessment, diagnosis, crisis planning, time limited treatment services
- **Dual Diagnosis Day Treatment and Inpatient Unit**, CAMH
- **COTA Specialized Dual Diagnosis Case Management** - Medium and Long Term
- **Dual Diagnosis Program, Whitby Mental Health Centre -** Inpatient Unit, Day Program (transitionary), Outreach and Consultation

However those services are unevenly distributed and difficult to access across the province.

In 1998,The Public Policy Committee of the CMHA, Ontario Division identified mental illness in persons with developmental disability as a mental health issue that is often unrecognized, undiagnosed and untreated. The Committee formed a Task Force on Dual Diagnosis that examined ways of addressing the needs of this population.

CMHA Ontario Division defines a person with dual diagnosis, as "an individual with a developmental disability and mental health needs". Approximately 1 % of the population has moderate or severe developmental disability, totaling roughly 80,000 individuals in Ontario. Conservative estimates indicate that 30% of these, approximately 24,000 individuals in Ontario, also have mental illness.

Jurisdictional entanglements and inadequate identification of this special population has meant that the needs of persons with dual diagnosis have, more often than not, "fallen between the systems. In 1974, responsibility for funding of services for person with developmental disabilities was transferred from the Ministry of Health (MoH) to the Ministry of Community and Social Services (MCSS). However the MCSS had no specific mandate for the mental health needs of this population.

There are a number of governmental initiatives currently underway which will affect services for persons with dual diagnosis. In 1990, the MCSS embarked on a plan to develop a wide range of community services and living arrangements for persons with developmental delay, in a move to deinstitutionalise those living in MCSS facilities. Recently, additional funds have been announced for supports to developmentally delayed persons living with aging parents, for at-home programming for affected children and for infant development programs. Over the next few years, MCSS local offices will be working with other ministries and local communities to provide a range of supports, more integrated services and consistent core services to children and adults with developmental delays.

The Ministry of Health, in mental health planning documents issued in 1988 and again in 1993, identified persons with "intellectual disability" as a special population needing attention in its plans to develop more comprehensive community based mental health services. Many individuals who have dual diagnosis have been cared for in the Ministry of Health's Provincial Psychiatric Hospitals, the majority of which were slated to close under hospital restructuring.

The Ministries of Community and Social Services and of Health have different approaches and are each separately undergoing extensive restructuring. In 1997, these Ministries recognized the need to work jointly on programming for persons with developmental delays and mental illness with the release of joint policy guidelines for the provision of services for persons with a dual diagnosis. Joint responsibilities for the dually diagnosed remain a priority and there is much effort being expended in developing linkages among service systems. The desire is for joint initiatives be maintained and not become "lost" in the process. At the same time, the government has undertaken the Human Services and Justice Coordination Project, involving health, social services and justice ministries, to plan services for people with clinical needs (including people who are dually diagnosed, mentally ill or have contact with the criminal justice system.

Major barriers to effective services to this population that have been identified within Canada include (Dual Diagnosis Task Force, 1998):

- Stigma and misunderstanding;
- Prevention of mental illness and mental health promotion;
- Philosophical differences between the mental health and social services system have prevented coordinated care of this shared client population;
- Integration of the service delivery systems is necessary but interagency communication is not well-established and collaboration across systems is limited'
- Very few staff working in the two systems have contact with such clients and may not have the specialized training to deal with a person whose needs cross both domains;
- Deinstitutionalisation may affect individuals with dual diagnosis since they were often cared for in institutional settings and community support systems to help them with their special mental health concerns have not yet been developed;
- Generic community services have not received additional resources nor are they designed or staffed to absorb the level of behaviours and requirements of these high-need clients once relocated into the community;
- Staff training and special support services are needed for staff and carers supporting people with complex needs in the community;
- Poverty is a way of life for persons with mental illness, adults with intellectual disability and persons with a dual diagnosis;
- Organizational exclusionary criteria, misconceptions and lack of expertise underlie this situation and will need to be addressed if dual diagnosis clients are to receive equitable care;
- Most programs have criteria which limit the types of clients they are mandated, funded and equipped to serve eg most mental health programs do not accept persons with developmental delay and the reverse is also true the disability sector;
- Identification, assessment, misdiagnosis are also barriers and there few unique criteria for diagnosing mental illness in a person with a developmental delay;
- Clients will also need to be able to access specialized care from fields such as psychology, speech-language, occupational therapy etc;
- Aging Parents – many parents whose offspring have dual diagnosis have kept their sons or daughters in their homes, often simply because there was nowhere else for them to go;

- Persons with disabilities are four times more likely to experience abuse, neglect or exploitation than other adults.

The Canadian government concludes that better coordination of, and collaboration on services for individuals with dual diagnosis is needed within and between the mental health and developmental services sectors. Barriers to equitable services must be eliminated between the mental health and developmental services sectors. People with dual diagnosis need a continuum of supports, built on effective use of inter-sectoral resources.

2.2.8 <u>New Zealand</u>

New Zealand has a population of 3.9 million (Statistics New Zealand, July 2002) with the four million mark expected to be reached within the next two years. The Queensland government Office of Economic and Statistical Research (OESR), using 2001 census data estimated the Queensland population to be 3.7 million. Similarities are self-evident in regard to population size. New Zealand shared similar problems to Australia in regard to the provision of services to adults with an intellectual disability. In recent briefing paper to the incoming minister, the disability services portfolio identified the following problems:

- Need to develop linkages across the disability and health sectors and across
- Need government departments to improve integration and co-ordination of planning,
- Need improved levels of funding and delivery of services to people with disabilities
- Need to redress service gaps particularly in habilitation and rehabilitation, support for informal caregivers of people with high/complex needs, and for people who require an ongoing mix of DSS and personal health or mental health services

The first point of contact is usually through a primary health care provider such as a GP, accident and medical centre, midwife, independent nurse practitioner, Family Planning clinic, pharmacist (chemist), optometrist (eye care), dentist or complementary therapist.

Dual diagnosis is an area that has not been well developed in the current service configuration. The emergence of two Dual Diagnosis inpatient/outpatient units was initially associated with deinstitutionalisation in Dunedin and Christchurch. These units developed from the "relics" of the old psychiatric/intellectual disability institutions (Webb, 2002 in personal correspondence). Since this time (1980s), other centres have set up community-based tertiary consultative units. Inpatient beds are calculated on the basis of 1.5 beds per 100,000 of the general population. Community staff to work with this group are calculated on a similar basis eg 0.5 FTE per 100,000.

Dedicated Dual Diagnosis services within New Zealand now exist in Auckland, Hamilton, Wellington, Christchurch and Dunedin. Contracts and models of service delivery are all very different between these services. Professionals employed by these services network and liaise with one another and meet (bi)annually to discuss issues of mutual interest and stay in touch. (Verhoeven, 2002 in personal communication).

2.3 Psychiatry & Mental Health Services

Clinical services associated with psychiatry usually revolve around the treatment of disorders and problems that adversely impact the mental health and well-being of an individual that in turn influences that person's capacity to function and maintain themselves within society (Holland, 1999). People with an intellectual disability are often referred to Psychiatrists as their carers look for clinical insights and assistance with the management of challenging behaviours often masquerade as mental disorders.

The response of psychiatrists within the western nations is varied, some refuse to treat this population, considering their needs most appropriately managed by a psychological approach eg disability or human services provision, Others, such as UK Psychiatrists view this group of people as requiring the skills and expertise of psychiatric and mental health professionals.

2.3.1   Psychiatry of Learning Disability (UK)

Specialists in the Psychiatry of Learning Disability will have completed basic general psychiatric training and a further specialisation in learning disability (equivalent to specialisation in adult, child, older age psychiatry). Some may have qualified in both learning disability and another psychiatric speciality. Their particular skills relate to the diagnosis, treatment and management of psychiatric disorder in people with an intellectual disability or developmental disability who have limited communication, or where the presentation of differs from that in the typical adult.

The RCP Council Report (1996), "Meeting the Mental Health Needs of People with Learning Disability," recommended the development of specialist mental health teams to ensure collaborative and coordinated responses to the needs of adults with dual diagnosis. The RCP argues that mental health service provision to adults with an intellectual disability must operate within an extensive network of care that must include components of health, social care, education and non-government agency involvement (RCP, 2000). The RCP recommends that there is a minimum of one consultant per 100,000 of the general population. This psychiatrist typically leads a multidisciplinary team.

The RCP argues that appropriate community based treatment service should ideally involve dedicated ay and inpatient services, as well as out patient services. Local collaboration with need to be intimated involved. An adequate range of service responses includes secure facilities (RCP, 2000).

Psychiatrists have an important contribution to make to the mental health needs of adults with an intellectual disability. They are often gatekeepers to a range of required services and a multidisciplinary team would be incomplete without their contribution. Dialogue with the RANZCP should be contemplated with the view to discussion regarding the applicability and relevance of the RCP approach to adults with an intellectual disability to the Queensland/Australian setting.

o   Models

Analysis of service provision to adults with an intellectual disability, who have co-existing mental health needs at both the national and international level, does not identify preferred models of service delivery. Most international service responses reflect generic or specialist approaches. The generic approach has resulted in various services operating within mainstream mental

health or disability service provision. For example, in the United Kingdom, many National Health Service Trusts provide dedicated inpatient beds for adults with an intellectual disability within psychiatric services that cater for the general population.

A range of specialised approaches can be identified across the UK although there is a significant amount of variation in how the models are implemented and the roles and responsibilities of staff employed (Bouras & Szymanski, 1997). Specialised services may use the medical model (eg employ a psychiatrist and or nurses to provide clinical services and support or alternatively adopt of model of service provision that is more oriented towards the social construct of disability). The specialist approach argues for a continuum of care. For example, there are a number of NHS Trusts that coordinate an integrated service that involves an inpatient treatment and assessment unit and a community outreach service that prevents admission, supports community living options and follows people post discharge.

By comparison, the USA and Canada have preferred to adopt other models include collaborative approaches including university affiliated clinical services that integrate training and education. Additionally the USA and Canada have developed interagency committees use triage functions to provide appropriate service responses.

2.4.1   Model Options

Please refer to the continuum of eleven Model Options at the end of this chapter. Key features of the range of models have been presented in the following eleven model options/types. The following comments related to each model option and should be read in conjunction with the eleven Model options. Dot points provide different options regarding how such models could be operationalised within the Queensland setting.

Further examples and service descriptions of a range of international service initiatives that have adopted these configurations or models are included in the Appendices of Chapter Three.

Option One: University Affiliated Dual Diagnosis Service

Background

This model is best demonstrated through consideration of the USA Centres of Excellence in Developmental Disabilities Education, Research and Services that have been described in this chapter. These centres are located in major cities and can be found in every state and territory in the USA and tend to provide lifespan services to children and adults with developmental disability.

Mission

Collaboratively funded, community-based university affiliated **multidisciplinary training and service provision model** that includes assessment, state of the art diagnosis, and treatment clinics for individuals with developmental disabilities, their families, and the community-at-large.

Includes developmental assessment and treatment clinics, providing consultation, technical assistance, continuing education and capacity building for local care providers and families. Access to inpatient treatment and assessment beds is necessary. Some Centres, and other similar models/initiatives in Canada also incorporate an Interagency Referral Committee (IRF) The Centre coordinates the IRF. Participating agencies use their current identification and intervention procedures. When a client emerges for which these measures are not effective, a referral to the interagency referral committee can be made. At this meeting participants decide on appropriate assessment or intervention options. Services may be provided by the Centre or participating agencies.

Option Two: Collaborative Case Management

Background

This model established an integrated collaborative partnership that adopts case management. The collaborative partnership is established and operated through a community based agency that is primarily involved in community outreach, networking and does provided some specialist service provision. This model of service provision is in operation in parts of Canada and the USA. This model operates using a multiprofessional team that ideally includes the involvement of a Psychiatrist.

Mission

- This model is based upon the concept of a one-stop shopfront.

- Clients fitting the eligibility profile are referred to one location.

- Following triage, the client may be referred to another agency with assistance, or may undergo assessment by the ICP.

- Following assessment, specific services may be provided by the ICP or the client may be referred with assistance to another agency.

Comments

This model will only be successful when a continuum of services is available, including inpatient treatment and assessment services

Option Three: Specialist Dual Diagnosis Community Outreach Team

Background

A number of models described within this chapter identify assertive outreach as a component of that model. Assertive outreach or community outreach is emerging within the literature as an approach well suited to meet the needs of people with mental illness who have multiple, long-term and complex needs (Sainsbury, 2001). Efficacy with adults with an intellectual disability has not been explored within the literature at this stage.

This model suggests that clients should only be accepted for a time-limited period where the team identifies time-limited tasks as the most appropriate form of intervention (e.g. assistance to re-engage with mainstream services). The team is therefore expected to have a high degree of tolerance for challenging or problem behaviour (Sainsbury, 2001).

Mission

The goal of assertive outreach is to actively seek out the client group who most need the service. Responsibility for well-being and creation of a coherent individual support system is central to successful outreach.

Location

Contact with clients primarily takes place within the community and not in an office base, which would not be known, to the client group. Therefore the possible use of home, café, park etc. may, as much be the setting for contact as GP surgeries or hospital. Client contact takes place where the person is most likely to be at times that most likely meet their needs and in an environment most conducive to developing an alliance.

Roles

The work focuses on the improvement in the quality of the clients' everyday life thereby reinforcing the experience of community as a satisfactory alternative to institutional life. Particular attention is therefore paid to such basic matters as benefit, money management, food, clothing, housing, psychiatric and medical care. Referrals are made for other services but the day-to-day quality of practical living will primarily lie with the team.

Identifying and making available other services which can provide a containing matrix of care and support is another role of the outreach worker (Sainsbury, 2001). Easing the client's contact with agencies and advocating vigorously on their behalf is a central responsibility. This advocacy is particularly necessary for extremely vulnerable individuals. Adults with an intellectual disability who have complex needs clearly fit the category with potential to benefit.

This mobile team provides acute assertive outreach through a community based outreach team that goes to where the clients are and offers:

- Crisis services and problem solving (Monday to Friday, no weekend);
- Early intervention;
- Therapeutic interventions;
- Carer teaching, training and mentoring; and

- Intensive support.

The team works proactively to engage clients and reduce chaos in care that is provided to them from a range of service providers. There is a key role in the formulation of working care plans that cut across agencies.

Lead agency

- Government partnership eg DSQ + Housing + Queensland Health
- Non-government partnership eg put to tender
- Government and non-government partnership eg St Vincent's model
- DSQ alone
- Queensland Health alone eg Mental Health Unit

Team status

- Full time
- Part time
- Full and part time members

Team membership

- Mental health and disability professionals eg professionals with expertise working with dual diagnosis
- Mental health professionals only
- Disability professionals only
- Other professionals

Clients

- Intellectual disability
- Capacity to communicate – including augmentative communication, signing etc
- Age:

  18 years and over

  16 years and over

  18 – 65 years

  15-25 years

  Lifespan

  Children only

Eligibility

- Open to all agencies
- Lead agency/agencies clients only
- Regional service
- Tertiary – whole of state

<u>Roles</u>

- Comprehensive assessment of **challenging behaviour**, development of response package and mentoring/training of carers
- Comprehensive assessment of **mental health problems,** development of response package and mentoring/training of carers
- Tertiary consultancy and advice offered to community

Entry

- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (unit has manager from social sciences background, not necessarily psychiatrist)
- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (psychiatrist is unit manager but does not hold decision making responsibility for entry)
- Via psychiatrist
- Via unit manager who has social sciences background

Location

- Hospital (generic)
- Hospital (psychiatric)
- Private hospital eg Belmont or Toowong
- Community location (independent shop front)
- Community - located within lead agency

Team Profile

- Core = clinical psychologist, social worker, occupational therapist, psychiatrist plus funds to broker additional therapy requirements/assessments
- Core without brokerage budget
- Core – psychiatrist
- Core with half time psychiatrist
- Part time team

Length of Stay

- Short term – less than 12 weeks
- Longer term – max 6 months
- As negotiated

Options

- Accept or decline forensic clients

Comments

- Requires vehicles
- **If regional may require budget that deals with travel costs**
- Need for contractual arrangements with carers that bed is retained
- May form part of an integrated service
- May require access to therapy/assessment rooms.

Option Four: <u>Integrated Specialist Service</u>

<u>Background</u>

This approach combines inpatient treatment, assessment and management unit with specialist outreach team that is involved in both preventative and community support role eg upon discharge from unit. Residential assessment and treatment is only provided where intensive therapeutic input is required that cannot be provided within a community setting.

Patterson et al, 1995 described a US approach to the generic versus specialist debate where a collaborative system of care was developed between a community mental health centre and the mental retardation agencies in Washington state. This model is one of the few approaches that have been evaluated. The research showed that the model led to a more efficient service over a two-year period and also reduced interagency tensions.

The model specifically aimed to develop collaborative interventions and interaction between health, human services and disability services. The aim was to reduce the severity of the social ramifications of both mental health and challenging behaviour problems experienced by adults with an intellectual disability through targeted health and well-being interventions that were both social and therapeutic.

This model involves the establishment of a community-based agency that has programmes and services that are integrated with both generic mental health services and disability services. In addition to clinical outreach, education and research activities may be undertaken. Ideally there is also a relationship with other key stakeholders eg health or education. Services are locally accessible and may can be flexibly delivered eg outreach, inpatient and outpatient access.

Advantages include less reliance upon the residential model of service provision and the location of accessible resources and vices in the community. Community location ideally results in less distress and change for the client eg the person may be seen at home or at clinic. The model also relies upon the specialist services liaising with generic services therefore transferral of expertise and knowledge. Finally, generic mental health services are utilised when appropriate and possible. (Bouras et al, 1995).

This community-based, non-institutional model has been in operation within two London boroughs for more than 15 years. (Bouras et al, 1994; Bouras & Holt, 2001). This community-based service utilises generic mental health facilities including acute and medium stay in-patient beds and a variety of community resources. It should be noted that the pivot of this model is the Consultant Psychiatrists who work within this service. They are experienced clinicians who have specialist training in the Psychiatry of Learning Disability.

There is multidisciplinary team involvement in the assessment, diagnosis and treatment of adults with an intellectual disability who have high through to low support needs eg mild through to severe levels of intellectual disability (Bouras & Holt, 2001). This specialist service forms part of the generic mental health service, alongside psychogeriatrics, adolescent mental health services etc. This model adopts a lifespan approach to mental health needs. Conjoint funding is provided by learning disability and mental health services.

Evaluation of this service demonstrated that 60% of patients had a mild intellectual disability, 25% had a moderate intellectual disability and 15% had a severe intellectual disability (424 consecutive new referrals) (Bouras & Holt, 2000). 47 patients were admitted to generic psychiatric wards (11%). The majority of admissions were people with psychosis (45%) with the remainder having diagnoses of depression and personality disorder. Physical aggression appeared to be an important trigger for admission and was displayed by 50% of admitted patients (Bouras & Holt, 2000). This services has been now strengthened by the opening of a small 6 bed specialist inpatient unit in response to continued pressure for admissions for assessment and treatment of mental disorders in adults with an intellectual disability.

Most existing facilities do not have the expertise or the desire, to support people with an intellectual disability when they have complex needs. Anecdotal evidence suggests that this model of care provided good outcomes for people with mild levels of intellectual disability but failed to provide well for those with more severe levels of intellectual disability (Hassiotis et al, 2000). Other criticisms focussed on the length of time spent as inpatients, suggesting that people with an intellectual disability often required longer lengths of stay that was impossible in generic mental health inpatient settings (Allen M, Bouras N, Holt, G, 1999, A Strategy for People with Learning Disabilities and Mental Health Needs and/or Challenging Behaviour; London: South London and Maudsley NHS Trust. Additionally younger people with an intellectual disability and older people with an intellectual disability may have also experience problems fitting within this model. (Hassitiotis et al, 1999).

Lead agency

- Government partnership eg DSQ + Housing + Queensland Health

- Non-government partnership eg put to tender
- Government and non-government partnership eg St Vincent's model
- DSQ alone
- Queensland Health alone eg Mental Health Unit

Clients

- Intellectual disability
- Capacity to communicate – including augmentative communication, signing etc
- Age:

    18 years and over

    16 years and over

    18 – 65 years

    15-25 years

    Lifespan

    Children only

Eligibility

- Open to clients from all agencies
- Lead agency/agencies clients only
- Regional service
- Tertiary – whole of state

<u>Roles</u>

- Residential service and community outreach service that offers comprehensive assessment of challenging behaviour, development of response package and support in community settings
- Residential service and community outreach service that offers comprehensive assessment of mental health problems, development of response package and support in community settings
- Residential service and community outreach service that offers comprehensive assessment of mental health problems and or challenging behaviour, development of response package and support in community settings
- Training opportunities for clinicians – placement for psychologists, occupational therapists, social workers, medical students etc
- Training opportunities for direct care staff needing to acquire particular skills eg PART training
- Tertiary consultancy and advice offered to community

Entry

- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (unit has manager from social sciences background, not necessarily psychiatrist)
- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (psychiatrist is unit manager but does not hold decision making responsibility for entry)
- Via psychiatrist
- Via unit manager who have social science background

Location

- Hospital (generic)
- Hospital (psychiatric)
- Private hospital eg Belmont or Toowong
- Community – suburban house/flats/duplex
- Community – purpose built facility
- Jail or forensic service

Staffing Profile

- Nursing staff – RNs or psychiatric trained
- RCOs or equivalent
- Rehabilitation Therapy Assistants (Wolston Park Hospital)

Length of Stay

- Short term – less than 12 weeks
- Longer term – max 6 months
- As negotiated

Options

- Include or exclude respite
- Accept or decline forensic clients

Comments

- Problems with bed blocking
- Need for contractual arrangements with carers that bed is retained
- May form part of an integrated service

Option Five: <u>Specialist Day Services</u>

Background

The failure of generic disability and mental health services to meet the complex needs of adults with an intellectual has resulted in the non-government and private sectors rising to meet the needs. In the UK, large amounts of money have been spent by social and health services when forced to purchase mental health services from private organisations or agencies (Bouras & Holt, 2001). Private organisations are often providers of specialist day services. This is an underdeveloped option within Australia for adults with an intellectual disability.

Day services can be varied but often provide resources or programmes that are not otherwise easily accessible in the community eg hydrotherapy, snoozelan and other therapies. Staff can also support service users to access leisure and educational opportunities within the community.

Mission

Specialist day services provide specialist assessment and treatment programmes that do not include an overnight or residential option. The day services aim to assist individuals to maintain their community placements eg priority given to those at risk of losing their community placement due to challenging behaviour and or mental health problems or suspected mental health problems.

Lead agency

- Government partnership eg DSQ + Housing + Queensland Health
- Non-government partnership eg put to tender
- Government and non-government partnership eg St Vincent's model
- DSQ alone
- Queensland Health alone eg Mental Health Unit

Clients

- Intellectual disability
- Capacity to communicate – including augmentative communication, signing etc
- Age:

    18 years and over

    16 years and over

    18 – 65 years

15-25 years

Lifespan

Children only

Eligibility

- Open to clients from all agencies
- Lead agency/agencies clients only
- Regional service
- Tertiary – whole of state

Roles

- Day services that offer comprehensive assessment of **challenging behaviour** and development of response package
- Day services that offers comprehensive assessment of **mental health problems or suspected mental health problems** and development of response package
- Day services that offer comprehensive assessment of challenging behaviour, mental health problems or suspected mental health problems and development of response package
- Training opportunities for clinicians – placement for psychologists, OTs, social workers, medical students etc
- Training opportunities for direct care staff needing to acquire particular skills eg PART training
- Tertiary consultancy and advice offered to community

Team

- Multiprofessional team involvement
- Transdisiplinary team involvement

Entry

- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (unit has manager from social sciences background, not necessarily psychiatrist)
- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (psychiatrist is unit manager but does not hold decision making responsibility for entry)
- Via psychiatrist
- Via unit manager who have social science background

Location

- Hospital (generic)
- Hospital (psychiatric)
- Private hospital eg Belmont or Toowong
- Community location modified for purpose
- Community – purpose built facility
- Jail or forensic service

Staffing Profile

- Multiprofessional team only that includes nursing staff – RNs or psychiatric trained
- Multiprofessional team that excludes nursing staff
- RCOs or equivalent
- Rehabilitation Therapy Assistants (Wolston Park Hospital)

Length of Stay

- Short term – less than 12 weeks
- Longer term – max 6 months
- As negotiated or decided by intake team

Options

- Relationship with respite care
- Relationship with integrated service
- Accept or decline forensic clients

Option Six: Psychiatrist (Dual Diagnosis)

Background

The Royal College of Psychiatry (UK) has had a faculty of Learning Disability Psychiatry since 1975. The majority of Consultants trained in learning disability psychiatry (intellectual disability) are dually trained eg have completed their general training in psychiatry as well. This well respected faculty coordinates not only the curriculum for psychiatric trainees but also a range of other educational initiatives and ongoing training events and opportunities for consultants. In the UK there is one consultant in learning disability psychiatry per 100,000 in the general population. The Department of Health also calculates that inpatient treatment and assessment beds for adults with an intellectual disability should be provided on the basis of 4 beds per 100,000 general population. Consultants would admit adults with an intellectual disability to these beds as appropriate although the majority of adults with an intellectual disability would be treated and supported within community settings eg within their own home environment.

Services

Consultants and Registrars provide clinical services through outpatient clinics or specialist dual diagnosis services. There is virtually no private practice in the UK National Health Service. Demand also outstrips supply eg psychiatrists are in short supply with many posts not filled across the UK. Psychiatrists work closely with multiprofessional teams.

Comments

In the Queensland setting there is an urgent need for Psychiatrists to be trained in mental health aspects of intellectual disability. If the UK approach was adopted in the Queensland setting, a trainee post would need to be funded and supported. This trainee post would be most effective within a multiprofessional setting that was involved in cross boundary clinical service delivery and outreach.

Option Seven: Specialist Residential Assessment & Treatment Unit

Background

Integrated Mental Health Services across Queensland are experiencing increasing pressure and expectation that they should provide acute inpatient mental health care for adults with an intellectual disability who are living within community settings. Whilst Queensland Health and Disability Services Queensland acknowledge the importance of hospital-based acute mental health care, professionals who work within Integrated Mental Health Services lack skills and expertise to work with adults with a dual diagnosis.

There is scant research or information available about the experience of adults with an intellectual disability within acute inpatient psychiatric units. A recent survey of Queensland Psychiatrists by the Developmental Disability Unit (yet unpublished) suggests that Psychiatrists are concerned about the quality of care that adults with an intellectual disability receive when inpatients. However, some researchers are acknowledging the needs of this population and have identified this group as a tertiary care subpopulation (Cochrane et al, 2000).

Many of these units can be identified within the UK NHS system and within some areas of the USA. The majority operate at a local area, giving preference to their catchment population. However, some offer a national service. In the UK the specialist inpatient units develop and maintain close and collaborative relationships with the network of learning disability and mental health services in their area. They are often viewed as foci of expertise when service providers are attempting to manage adults with an intellectual disability who have complex needs eg where to turn to for assistance, information, advice and in extreme, assessment. Unfortunately, evaluation of these units is not well reported in the literature.

Disadvantages of specialist inpatient assessment and treatment units include: (Cullen, 1999)

- Invariably full to capacity;
- Great difficulty in discharging people;
- Insufficient community based services to follow up and support post discharge;
- Special teams;
- Referrals are typically for people with challenging behaviour; and
- Waiting lists.

One study from a London inpatient unit evaluated 64 people who had been inpatients. The research showed that 84.2% of these inpatients were improved and discharged into

community placements, although only 17.5% had been admitted from community placement. (Xenitidis et al, 1999).

Mission

Specialist residential assessment and treatment unit that specifically aims to assist individuals to maintain their community placements eg priority given to those at risk of losing their community placement due to challenging behaviour and or mental health problems or suspected mental health problems. Residential assessment and treatment is provided with expectation that the client will return to their community placement as soon as possible.

Lead agency

- Government partnership eg DSQ + Housing + Queensland Health
- Non-government partnership eg put to tender
- Government and non-government partnership eg St Vincent's model
- DSQ alone
- Queensland Health alone eg Integrated Mental Health Services

Clients

- Intellectual disability
- Capacity to communicate – including augmentative communication, signing etc
- Age:

    18 years and over

    16 years and over

    18 – 65 years

    15-25 years

    Lifespan

    Children only

Eligibility

- Open to clients from all agencies
- Lead agency/agencies clients only
- Regional service
- Tertiary – whole of state

- Residential service that offers comprehensive assessment of **challenging behaviour** and development of response package
- Residential service that offers comprehensive assessment of **mental health problems or suspected mental health problems** and development of response package
- Residential service and community outreach service that offers comprehensive assessment of challenging behaviour, mental health problems or suspected mental health problems and development of response package
- Day services – participated in programmes but not overnight
- Training opportunities for clinicians – placement for psychologists, OTs, social workers, medical students etc
- Training opportunities for direct care staff needing to acquire particular skills eg PART training
- Tertiary consultancy and advice offered to community

Team

- Multiprofessional team involvement
- Transdisiplinary team involvement

Entry

- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (unit has manager from social sciences background, not necessarily psychiatrist)
- Via consensus or majority of multidisciplinary clinical review – this team provides clinical and therapeutic input (psychiatrist is unit manager but does not hold decision making responsibility for entry)
- Via psychiatrist
- Via unit manager who have social science background

Location

- Hospital (generic)
- Hospital (psychiatric)
- Private hospital eg Belmont or Toowong
- Community – suburban house/flats/duplex
- Community – purpose built facility
- Jail or forensic service

Staffing Profile

- Nursing staff – RNs or psychiatric trained
- RCOs or equivalent

- Rehabilitation Therapy Assistants (Wolston Park Hospital)

Length of Stay

- Short term – less than 12 weeks
- Longer term – max 6 months
- As negotiated

Options

- Only open residential setting
- Only closed residential setting
- Open and closed residential setting
- Include or exclude respite
- Accept or decline forensic clients

Comments

- Problems with bed blocking
- Need for contractual arrangements with carers that bed is retained
- May form part of an integrated service

Option Eight: Dedicated Acute Beds for Adults with an Intellectual Disability

Background

In order to insure that people with a dual diagnosis access the mental health services they require, it may be appropriate to dedicate beds for this purpose. These beds may need to be located within a part of an integrated mental health service that allows the inpatients appropriate care eg close to the nurses station. Purpose built accommodation may need to be considered.

Across western nations some general psychiatric units are prepared to accept admissions of patients (for assessment, treatment, rehabilitation and case management/care planning) with an intellectual disability. Some generic integrated mental health services may be prepared to earmark or priority access beds. These arrangements are usually most suitable for individuals with borderline to mild levels of intellectual disability that may be vulnerable in these mainstream settings. It is unlikely that the needs of adults with an intellectual disability who have high support needs or severely challenging behaviour would be welcomed by integrated mental health services.

Anecdotal experience suggests few generic mental health services are prepared to accept admissions of adults with an intellectual disability regardless of their support needs eg there is a persisting view that this group cannot be well-managed in a general ward setting. Problems

and disputes can arise when inappropriate admissions take place eg social admissions or discharge is problematic. Whilst on the ward, patients can be bullied or potentially vulnerable from other unwell patients and vice versa. This phenomenon is experienced across the western nations.

Mission

- Mental health teams and Psychiatrists in private practice can admit patients to dedicated beds within mental health units for adults with an intellectual disability.

- The UK Faculty of Learning Disability Psychiatry (RCP) recommends the provision of 4 beds per 100, 000 in the general population for adults with a dual diagnosis.

Comments

- Admission should only take place when assessment and treatment cannot be provided within the community setting.

- Admission should be accompanied by guarantees or contacts that the community placement is retained.

- Discharge needs to be accompanied by community outreach and support that needs to be developed in consultation with community service providers prior to discharge.

Option Nine: Generic Mental Health Service

Background

The generic approach to the provision of mental health and disability services is based upon the assumption that services and treatment programmes are most appropriately provided within the wider community as opposed to institutions. For example, generic mental health services are inclusive of both primary and secondary health care provision. This approach assumes that adults with an intellectual disability can and should be supported by ordinary mental health services within the broader community (Day, 1994).

Mission

- Mental health team working within integrated mental health services, that assesses the mental health of adults with an intellectual disability eg may present with mental disorder, suspected mental health problems or challenging behaviour.

- The mental health team oversees services provided to adults with an intellectual disability entering "generic" mental health services.

- The team is involved in supporting mental health service providers or facilitating access to other community services, including disability service provision.

Membership

- Part time team
- Full time team
- Mental health professionals that come together on an as needed basis
- Psychiatrist involved or not involved

Options

- State-wide service
- Regional service

Option Ten: Mental Health Team for Intellectual Disability

Background

Community based integrated mental health services have developed substantially in recent years with many offering assertive outreach: professionals go to clients; crisis and case management services, with 24 hour availability. Some teams within the UK have specialised in regard to the provision of clinical services and supported case management to adults with an intellectual disability who have complex mental health needs and or challenging behaviour.

Although there is no consensus regarding what constitutes case management or care management, it is generally agreed that at the individual level, it means that the coordination of care for that person who requires a number of different services from different agencies or organisations (Thornicroft, 1991).

Mission

- Members meet regularly to make decisions regarding most appropriate responses to complex clients eg which agency needs to take primary responsibility and agreement regarding support to be provided by partner agencies.

- Support includes manpower and financial resources.

Membership

- Government partnership eg DSQ and Mental Health
- Extended government partnership eg DSQ + Housing + Queensland Health + Education
- Government and non-government partnership

Clients

- Intellectual disability
- Capacity to communicate – including augmentative communication, signing etc
- Age:

    18 years and over

    16 years and over

    18 – 65 years

    15-25 years

    Lifespan

    Children only

Eligibility

- Open to clients from all agencies
- Lead agency/agencies clients only
- Regional service
- Tertiary – whole of state

Meeting Roles

- Clinical coordination
- Meetings convened as required

Entry

- Senior agency officers make internal arrangements regarding how referrals are made eg internal criteria developed
- External referrals possible eg from general practitioners etc
- Meeting membership makes decisions regarding appropriateness of referrals eg develops criteria for referral

Location

- Set location
- Changing location

Option Eleven: Behaviour Management Team

Background

These services have traditionally responded to challenging behaviour and have usually
relied heavily upon the contributions of clinical psychologists. The
model tends to utilize community outreach without residential inpatient
treatment or assessment services (Newman & Emerson, 1991). In the
UK these teams can be located within social services (Australian
disability services) or mental health services. The teams have tended
to work independently of each other.

Evaluation of a behaviour management team operating in Wales within the UK demonstrated
that the model was able to bring about significant changes in challenging behaviour, mental
health problems, client skills and quality of life (Allen & Lowe, 1996). The model was cost
effective when compared to institutional models (Allen & Lowe, 1995) and was associated with

significant reductions in both short stay and long stay admissions to institutional care (Allen, 1998).

This approach is considered as being inappropriate to meet the need of people with an intellectual disability who have mild intellectual disability and concurrent mental health problems. The relationship between learning disability services and mainstream psychiatric services has remained somewhere removed from the influence of these teams (Bouras & Holt, 2001).

Mission

Team working within Disability Services Queensland that assesses the mental health of adults with an intellectual disability eg may present with mental disorder, suspected mental health problems or challenging behaviour.

Where mental health problems are identified and team identifies need for involvement of mental health services, team makes contact with mental health services using agreed protocols.

Membership

- Part time team
- Full time team
- Disability professionals that come together on an as needed basis
- Psychiatrist involved – private practice (agreed arrangement)
- Psychiatrist involved – through mental health services (agreed arrangement)

Options

- State-wide service
- Regional service

2.5   Conclusion

The mental health needs of people with an intellectual disability are complex, involving interconnected clinical, organisational and service factors. Achieving sustainable improvements in service provision adults with an intellectual disability who have mental health problems and or complex needs is going to require coherent policies to guide its development. Broadly speaking, there needs to be a commitment to an evidence-based approach, with a recognition that all levels of staff have a contribution to make in the assessment process, the provision of treatment, and the longer term support of the individual and his/her carers.

Research suggests that some western nations believe that their services to this population have reached a crisis point (Bouras & Holt, 2001; Jacobson, 1999), characterised by unclear policies, inter-agency disagreements and limited service responses with unpredictable consequences for the quality of life of users, their families and carers. The issues and models considered in the report will hopefully contribute to a clearer formulation of these complex issues on the part of clinicians, planners, commissioners, providers and managers of services.

It is apparent that specialist psychiatric services are increasingly becoming the preferred option in many countries (Molony, 1993; Day, 1994; Bouras and Holt, 2001). However, policy guidance in the UK and the USA has been very broad and open to wide interpretation (DoH, 1989; DoH, 1992; DoH, 1993; DoH, 1994; Royal College of Psychiatrists Council Report, 1996; Bouras and Szymanski, 1997). Different local areas have developed different service models depending on their local situation (Gravestock and Bouras, 1997; Bailey and Cooper, 1998). Some services centre around residential, usually hospital, provision perhaps with out-reach work, whilst others are more community-based sometimes with access to in-patient facilities (Bouras and Holt, 2000; Bouras and Holt, 2001 in press).

Assessment and treatment services for people an intellectual disability who have mental health problems, challenging behaviour or other complex needs have evolved in a variety of ways across the country, based on a range of factors such as geography, the pattern of other local services, and professional interests. The published research evidence available on service models is scarce and because of the diversity it is difficult to compare approaches even within nations.

Regardless, anecdotal experience suggests that the following factors will be important to consider when designing services:

- A local philosophy and culture agreed between health, mental health and human/disability services which focuses on supporting people in their usual environments wherever possible and appropriate support services (including communication and occupation as well as a place to live) designed around individuals, including recruitment and training of staff teams;
- Flexible use of health and social services resources can help this training for both support workers and first line managers to ensure that early warning signs are picked up and acted on and that consistent approaches are agreed and adopted to supporting individuals. This needs to be a continuous process, not a one-off partnership approaches between community based mental health and disability services professionals to ensure that local expertise is available to support and treat people;

- Local agreement about the circumstances in which admission is likely to benefit individuals, and about "safety valve" services such as respite to allow an individual to leave their usual place of residence or day occupation for a short time;
- Links with generic mental health services (Integrated Mental Health Services) to ensure that people with an intellectual disability do not "fall between the gaps";
- Crisis response services and protocols that do not only provide rapid assessment and advice, but also provide access to intensive that is flexible enough to meet a range of needs.

Most experienced academics and clinicians strongly argue that it is totally inappropriate to try to prescribe or ascribe to a single model (Webb, 2002; Emerson, 2002; Holland, 2002 – all in personal communication). This belief is founded upon the assertion that community-based services need to reflect local circumstances. However, the general principles outlined above could be used to shape dialogue between key stakeholders.

Models of Service Provision for Adults with an Intellectual Disability with Co-existing Mental Illness
(Dual Diagnosis)

Service Model OPTION	*University Affiliated Dual Diagnosis Services* OPTION 1	*Collaborative Case Management* OPTION 2	*Specialist Dual Diagnosis Outreach Service* OPTION 3	*Dual Diagnosis Service within Integrated Mental Health Services* OPTION 4	*Specialist Dual Diagnosis Day Services* OPTION 5	*Psychiatrist (Dual Diagnosis)* OPTION 6
Location	University - either teaching hospital or community setting with academic links	Mental health setting	Community with usually no centred based roles or activities	Integrated Mental Health – regional service provision in teaching hospital with academic links UK (Bouras & Holt, 2001)	Usually "service within service" eg in psychiatric hospital or disability residential setting UK (Day, 1994)	Clinics through specialist OPD or community clinic
Origins	USA (Patterson, 1995; Woodward, 1993), Canada, Developmental Disability Unit, The University of Queensland is modified version of this model	SA, Canada	USA, Canada, UK, Qld, NSW, Victoria,			Consultant in Learning Disability – specialty of RCP since 1975 – one consultant psychiatrist in learning disability per 100,000 general population
Aims	Tertiary continuum of specialist services and supports across and within	Enable multisystem service responses Provide coordination	Dedicated multiprofessional team involved in	Provide comprehensive range of mental	Provide structured therapeutic interventions &	Assessment, diagnosis & treatment, often adjunct to

	sectors. Integrate mental health & intellectual/ developmental perspectives Holistic approach to prevention of mental health problems, maintenance of health & well-being in community setting, facilitation of appropriate admission as needed, community outreach & follow-up upon discharge. Focus for development of both clinical & practical expertise in developmental disability Provide Tertiary support & mentoring to clients, carers & service providers	between participating service providers Increase appropriate service responses including appropriate admissions & discharges Reduce interagency tensions	community based prevention, maintenance & support (outreach)	health services Triage, refer & provide services as required eg refer to generic mental health services if more appropriate Respond to challenging behaviour Provide inpatient treatment & assessment Provide outpatient follow-up through clinics	activities on a day basis Provide mentoring & carer training opportunities Provide opportunity for formal assessment, observation & monitoring	multiprofessional teams from either mental health & or disability services Biopsychosocial approach – rational psychopharmacology (diagnostic linked) In UK manage complex health care problems including epilepsy, ageing related, physical morbidity

Staffing	Multiprofessional team including psychiatrist, psychiatric nurse, senior professionals with dual diagnosis expertise	Multiprofessional team including psychiatrists & professionals	Psychiatrist & core: psychologists, social worker & OT Other therapists desirable including speech pathology	Psychiatrist & multiprofessional team	Nurses & health professionals supported by psychiatrists	N/A
Clinical services	Assessment & diagnosis through clinics & mobile outreach – triage access to inpatient treatment & assessment beds Therapeutic interventions & treatment Triage access to specialist day service programme	Expansion of mental health service responses to include crisis intervention responses Inpatient residential treatment & assessment services Behaviour management specialists provide tertiary consultation services 7 days per week	Assessment in cooperation with mental health services & disability services Therapeutic interventions Community outreach & crisis management	Assessment in cooperation with mental health services & disability services Therapeutic interventions	Therapy including group therapies Assessment	Assessment, diagnosis and treatment including psychopharmacology and psychotherapy Many involved in academic teaching and research activities No private practice
Education, training & research	Multiprofessional, multiagency training & education initiatives	Multiprofessional, multiagency training & education initiatives	NO	Important & integral component of this model – development &	NO	Training posts for registrars & residents Actively encouraged by RCP to undertake

				enhancement of dual diagnosis knowledge & skills across all sectors & all providers of services including psychologists, direct service staff etc		research Actively contribute to emerging evidence based
Interagency communication mechanisms	Cross-agency referral committee coordinated – involves government & non-government partners in service provision Education & training events provided across & between agencies Tertiary consultancy & advice available to all dual diagnosis stakeholders	Cross-agency referral committee coordinated – involves government & non-government partners in service provision Education & training events provided across & between agencies Tertiary consultancy & advice available to all dual diagnosis stakeholders	Informal networking & interaction that is client driven	No formal mechanisms although training & educational initiatives used strategically to achieve ends	NO	NO but training support partnerships & continuum of care

Comments						
	Inpatient assessment & treatment beds – either dedicated beds in generic mental health system with additional support OR specialist inpatient unit beds Size of the programme reflects the true costs associated with deinstitutionalisation & community care eg required to respond to the mental health & physical vulnerability of this population Enhances existing service delivery Provides a foci for attracting specialist expertise & clinical/practice excellence	Seen as "owned" by mental health services despite interagency committee function. May be constrained by priorities of lead agency	Outreach is client intensive May need to make time restrictions on outreach interventions Relies heavily on existing services eg enhances what is provided Community based ambulant team but tendency to become isolated & removed from stakeholders eg resource intensive therefore focus upon small group of clients in need	Similar to Option 4 but does not have an interagency committee Relies heavily upon Consultants in Learning Disability eg Psychiatrists trained in dual diagnosis	This model emerged in UK where there remain large residential settings therefore is a response aimed at community entry	Argue requirements for 4 inpatient treatment & assessment beds per 100,000 general population No private practice in UK therefore tend to rely heavily upon teams Strong interest in some regions on psychotherapy Focus for the development of expertise, skills & knowledge Work closely with multiprofessionals Adopt holistic bipsychosocial approach to assessment & treatment Integral part of mental health response

Service Model OPTION	Residential treatment/assessment Unit OPTION 7	Dedicated Acute Beds (General/Mental Health) OPTION 8	Generic Service Delivery eg Case Management OPTION 9	Mental Health Team for Intellectual Disability OPTION 10	Behaviour Management Team OPTION 11
Location Origins	Hospital (psychiatric or general) or disability services (community) All OECD nations	Integrated Mental Health Unit/Service or general hospital UK where specialist units don't exist	Integrated mental health services or disability services All OECD nations – traditional approach to mainstream service delivery	Integrated mental health services UK, USA, Canada	Disability services All OECD nations – traditional approach to adults with an intellectual disability
Staffing	Nursing model with multiprofessional support – heavily reliant upon Psychiatrist	Nursing model with multiprofessional support	Professionals, usually social worker or psychologists	Multiprofessionals with emphasis on behaviour management clinicians	Psychologists – often work alone & without support or supervision
Clinical Services	Group therapy/CBT occupational therapy, psychotherapy etc whilst	No specific services for adults with an intellectual disability –	Limited to crisis resolution counselling & problem solving	Focus upon assessment & diagnosis Capacity to actively	Assessment & behaviour plans CBT & psychotherapy in UK

	inpatient Carer & family support	expected to "fit" into general programs & activities		provide therapeutic or clinical services constrained by budget & number of staff	& USA, Canada Involved in assessment of autism in USA, Canada & UK
Education, training & research	NO although multiprofessional team members may be involved	NO	NO	NO	NO
Interagency communication mechanisms	No formal mechanisms although relationships do develop & may be a key role of some professional teams members	NO	Informal linkages – no formal mechanism	NO	NO

Comments	Forms an integral part of many other models described **There is little doubt that inpatient treatment & assessment beds are required by all models** Preferred by most dual diagnosis clinicians in UK as clients with intellectual disability may find it difficult to integrate into generic mental health services & may be vulnerable in acute ward settings – challenging behaviours may also be disruptive to other inpatients The number of inpatient beds required should be considered in light of the availability & efficacy of community support services Careful consideration should be given to the management of beds eg	Survey of Qld psychiatrist (DDU, 2001) suggests most psychiatrists feel that acute ward settings are inappropriate for adults with an intellectual disability More severe the communication impairment, more vulnerable & less likely to benefit Lack of knowledge and skills in intellectual disability Risk of exploitation Diversity of intellectual disability Managing different needs of severely mentally ill with intellectual disability	Intensive long term work, can be isolated, often resource poor, highly dependent upon advocacy skills of workers & relationship developed within community	Untrained in developmental disability therefore lack expertise, skills & knowledge when working with this population Tends to be used to determine eligibility or ineligibility Could play important role in triage & appropriate referral but restricted by lack of referral options or interest Can be isolated within mental health services & lack linkages with other professionals working in area Does not assist with interagency linkages	Often attracts junior psychologists who are not supervised or mentored therefore leave Isolated from mental health In Australia have tended to attribute psychopathology to environment with lack of recognition of underlying psychiatric morbidity

	who should be admitted & under what circumstances It is critical that carers are actively involved in admissions & discharges Consideration should be given to the value of multiprofessional admission & discharge team rather than a psychiatrist making admission & discharge				

Chapter Three: Conceptual Analysis & Future Directions

Generally, the development of a range of service configurations that meet the mental health and other complex needs of adults with an intellectual disability remain in evolutionary form across western nations. Perhaps the most logical explanation relates to problems associated with recognition, assessment and management of mental health problems in this population. Research suggests that specialised service responses with experience staff is required for accurate detection and treatment because psychopathology manifests itself atypically (Day, 1994, Bouras et al, 1994; Moss, 2000).

Despite the literature recommending that deinstitutionalisation programmes should be accompanied by the development of well resourced mental health services that meet the needs of this population (Day, 1993), this comprehensive approach is underdeveloped within all Australian states, including Queensland. However, despite the development of a range of specialist models in the UK, there is evidence that the use of mental health services by people with an intellectual disability is significantly lower than utilisation by the general population (Dorn& Prout, 1993; Gustafsson, 1997).

People with an intellectual disability who have complex needs challenge and stretch the traditional operating practices of generic mental health services. The needs of this group are frequently multi-dimensional with many service systems being involved. The realities and complexities of providing services to this population have resulted in a range of options being developed.

The models of service provision all differ considerably from each other and differences appear to be related to individual community profiles eg need. Themes such as "developing services in the mainstream community" and in "response to local need" do appear prevalent. The following models have been identified in across the UK:

- Separate specialist psychiatric services within institutional/hospital settings;
- Community based specialist services integrated with mental health services;
- Community specialist psychiatric services integrated with both mental health services and learning disability services;
- Separate "challenging" behaviour services as part of a specialist learning disability service.

Australian policy and service responses directed at the needs of people with an intellectual disability have tended to be educational in nature and focussed upon community care. By comparison, there has been little or scant attention placed upon mental health needs (Bouras & Szymanski, 1997). Despite a number of different approaches to providing dual diagnosis services in the UK, an "ideal" or a preferred model has not been identified. WHO defines the important elements of effective response to mental health and neurological problems as:

- **Psychological and social intervention – independent living skills, social skills training. Vocational training, social support networks, family intervention; and**
- Pharmacotherapy used in conjunction with above.

Treatment efficacy is substantially reduced, WHO suggests, if not delivered within the context of a comprehensive and coordinated delivery service. The "ideal" mental health service model for people with an intellectual disability needs to include WHO principles. Services should be:

- Community based and locally accessible;
- Multi professional including input from psychiatrists, psychology, nursing, social work and other therapists;
- Integrated with generic mental health services and generic disability services;
- Integrated with primary health care services;
- Linked with academic and university faculties with research capacity.

3.1   Models

Critical review of the literature and contemporary service responses to adults with an intellectual disability and cc-existing mental illness across OECD nations reveals an array of different models of service provision. Consideration of both the national and international perspectives reveals little consensus regarding the ideal model of service provision that address the needs of adults with an intellectual disability who have complex problems. A number of service models and configurations are evolving and few approaches have been systematically or objectively evaluated.

There is sparse empirical evidence that demonstrates the most effective approach to meeting the needs of this vulnerable group. However, there is some anecdotal agreement across the OECD nations that demarcation and disputation between agencies is having serious consequences upon the health and well-being of adults of an intellectual disability. Cross agency collaboration and partnerships are required. The United Kingdom has gone so far as to legislate to ensure government agencies work together to meet the needs of adults with a dual diagnosis.

Most nations generally concur that the majority of people with an intellectual disability can and do live satisfactory lives within a range of community based living options. There is also widespread agreement that some of this group will require inpatient assessment and treatment within a mental health facility sometime during their lifetime. Although there is no broad consensus within the literature or the field as to whether generic or specialist mental health service provision is warranted (Chaplin & Flynn, 2000), there is strong anecdotal evidence that most service providers and clinicians believe that specialist or tertiary responses are required.

Uncertainty regarding the most appropriate model of service provision for adults with a dual diagnosis is reflected within the available literature (Trower et al, 1998). Although elements of

service provision can be identified, how they are combined remains the subject of considerable debate (Day, 1994). Three approaches can be identified although there is considerable overlap:

- Residential service provision;
- Non-residential community based service provision; and
- Partnerships and interrelationships.

3.1.1 Generic Services

The generic approach to the provision of mental health and disability services is based upon the assumption that services and treatment programmes are most appropriately provided within the wider community as opposed to institutions. For example, generic mental health services are inclusive of both primary and secondary health care provision.

This approach assumes that adults with an intellectual disability can and should be supported by ordinary mental health services within the broader community (Day, 1994). Specialised services are refuted on the basis that these services result in stigma, labelling and negative professional attitudes (Newman & Emerson, 1994). Regardless, many professionals, including psychiatrists argue that generic service provision to adults with a dual diagnosis (for example within Sweden, Denmark and the USA) has not been successful. Reasons have included negative attitudes, inappropriate settings, and poor staff knowledge about the mental health needs of adults with an intellectual disability lack of psychiatric input.

3.1.2 Specialised or Tertiary Services

The literature suggests that adults with an intellectual disability who have mental health needs cannot be effectively served by generic services because their complex needs are beyond the capacity of mental health service provision (Day, 1994). Problems relate to deficiencies in availability, accessibility and adequacy. Generic service provision only tends to occur because there are no alternatives eg specialist service responses are simply not available.

In response, some nations such as Canada and the USA have responded to the need for a specialised response and developed tertiary services. Tertiary services can be defined as specialised interventions that are delivered by highly trained professionals (Wasylenki et al, 2000). These interventions can be provided when adults with an intellectual disability have a dual diagnosis, mental health problems or challenging behaviours that are complex and refractory to primary and secondary care. Often the mental health sector, the disability sector and other community sectors struggle to provide appropriate service responses. Reasons for referral revolve around the need for higher levels of specialised assessment and then guidance in regard to ongoing support or management.

Tertiary services can be provided flexibly and do not need to be tied to particular settings, time frames or even inpatient assessment and treatment (Wasylenki et al, 2000). For example, a mobile or portable tertiary care model such as assertive community treatment means the location is irrelevant. The level of care is linked to the person in need rather than being dependent upon a particular setting. Services can be provided for contracted timeframes or specific purposes, ie negotiated between the providers and the client or their carers.

Tertiary services may be delivered through clinics that exercise mobile outreach, assertive community treatment and/or specialised outreach teams, community based residential programmes eg day services, or inpatient assessment and treatment services. This approach is an important strategy for maintaining community placement options. Other advantages include the ability of tertiary services to develop high levels of dual diagnosis expertise, to train and educate a range of professionals including medical practitioners, and finally to expand the

capacity of primary care and secondary care systems to respond to the needs of adults with an intellectual disability who have co-existing mental illness.

7 3.2   Elements of Successful Service Responses

Disability service provision that meets the needs of adults with an intellectual disability across Queensland has tended to be occur across two streams: residential support options provided through government and non-government sectors; and ambulant multiprofessional support teams that have been community-based and focussed. Historically these teams have typically involved different versions of behaviour support with some specialist teams emerging. These developments reflect international trends where community based teams have adopted behavioural approaches although many are eclectic with multiple orientations (Allen & Felce, 1999).

Team interventions whether from the mental health or disability sectors, have been expected to compensate for deficient resources and inadequate systemic supports. This response fails to meet the needs of adults with a dual diagnosis and is inappropriate in the 21st century, particularly in light of the international evidence.

Adults with a dual diagnosis who have complex needs require services that cannot be provided through one solo agency. Treatment and support challenges require distinct responses by a number of services (Patterson et al, 1995). The needs of adults with a dual diagnosis are multifaceted and can change over time. Services required need a cohesive and cooperative response from a range of agencies and professionals. A network or continuum of care is needed. Elements of a successful service system that responds to the mental health needs of adults with an intellectual disability include:

- Cross-boundary teams with experience in addressing both the mental health and primary needs of adults with an intellectual disability;
- Dedicated inpatient assessment and treatment beds within the continuum of community to inpatient services to ensure access to a therapeutic environments;
- A community-based habilitative support system with the capacity to provide varying degrees of support over lifetimes in recognition of fluctuating needs, relapsing and/or recurrent mental health problems or disorders;
- Enhanced communication networks between not only mental health and disability services, but all other service providers including housing and education;
- Linkages between the academic, research and community sectors to improve practice by accessing and contributing to the growing evidence based about the mental health needs of adults with an intellectual disability;
- Multiprofessional and cross agency approach to dual diagnosis education and training of professionals and direct service delivery staff that come into contact with adults with a dual diagnosis.

3.2.1   Four tiered approach

Models of service provision currently in operation across western nations that are described in this chapter tend to incorporate components or elements that can be structured into a pyramid like framework. Some nations have adopted an integrated approach that supports a continuum of movement between the bottom tier through to the top tiers whilst others have adopted a more limited approach. This pyramid of support looks something like this (Williams & Richardson, 1995):

tier 1:   most adults with an intellectual disability have contact with this level that consist of primary generic services including allied health professionals, teachers, general practitioners etc;

tier 2:   generic services, usually community based either at home, school, in day centers etc;

tier 3:   specialist teams dealing with areas such as parenting skills, self injury, and the assessment or management of autism etc; and

tier 4:   secondary or tertiary inpatient treatment and assessment with support from lower tiers and movement back down the pyramid of support.

Appear to have a tiered approach with models adopted in various western nations taking either components, or a cohesive "whole" approach.

3.2.2   Dimensions of Service Provision

The models appear to vary across four major dimensions although there is a continuum of options:

Aims and purpose: including the target group served and associated eligibility criteria, from solely residential accommodation through to assessment, treatment and therapeutic interventions and support;

Duration: day services, short term through to long term and variations between eg respite or brief assessment and treatment periods that might be contracted;

Location: institution based, mental health or disability service within a service (instition through to hospital through to community), in-home, assertive community outreach, clinics locally based in the community, or continuum approaches that link the options; and

Provider: government funded private organisations, self-funded private agencies through to government departments, and collaborative partnerships between stakeholders – some providers have received or provide specialist training, some use the medical model and others the social construction of disability carers may come from diverse backgrounds.

The models considered have also operated on different levels:

- Primary
- Secondary
- Tertiary
- Combinations of above (collaborative or multidimensional models)

3.2.3 Other Elements of Models of Service Provision

Common elements within models described in the chapter include the importance of:

- **multidisciplinary, interdisciplinary or trandisciplinary teamwork** – specialist skills for diagnosis, treatment, care and rehabilitation of mental illness in adults with an intellectual disability;

- **comprehensive coverage** – no gaps in service availability or delivery – birth to death – lifespan approach – protocols hammered out in regard to active referral process;

- **community-based service delivery – clinical outreach – pathway of treatment and assessment as inpatient if required** – continuum of sustained care and monitoring on discharge – involvement of specialists and multidisciplinary team members; and

- **access to tertiary support and advice –** not takeover of generic services but consultative experts – support and advice – consultancy – skilling up of other experts and professionals (support, information and advice).

3.3 Options Framework

Critical review of the literature reveals that there exists an array of different models of service provision suited to the needs of adults with an intellectual who have complex needs. Some models considered in the report have developed in response to other target groups eg children and adolescents but these too have some applicability. The majority of people with an intellectual disability can and do live successful and satisfactory lives within a range of community based living options. However, some vulnerable people will require inpatient assessment and treatment within a mental health facility sometime during their lifetime.

The report has briefly reported on the very limited evidence available about the models. The literature and evidence that is available is mostly descriptive and informative. Available studies comment on the need for dual diagnosis services and provides descriptions of the characteristics of clients and their carers or family members. The scarcity of empirical studies has already been stated. It is unlikely that a perfect model of service provision for adults with a dual diagnosis exists. A more pragmatic and logical approach would be to clear about what purpose the model seeks to achieve and then what outcomes are desired. Therefore it is important to consider the process and how such outcomes can be realised and how they should be prioritised**.**

Model choices need to be developed within the context of what local options are most likely to deliver on these outcomes. There are serious risks when models are borrowed or modified from other nations – their environments (historically, politically, socially, morally, legally etc) are so different that comparisons and relevance becomes problematic. The contextual issues may be important in determining both the operation and effectiveness of models.

o   Conclusion

Most experienced academics and clinicians across the western world would strongly argue that it is totally inappropriate to try to prescribe or ascribe to a single model (Webb, 2002; Emerson, 2002; Holland, 2002 – all in personal communication). This belief is founded upon the assertion that community-based services need to reflect local circumstances. This report demonstrates that:

- There is **no clear definitive model of preferred service delivery** in any western nation and the literature fails to provide a preferred best practice model;

- Detailed comparisons are problematic given the different service systems in each of the countries;

- One significant difference is that only in the UK have psychiatrists been prepared to be actively engaged in the provision of mental health services to people with an intellectual disability; and

- Some similarities across all western nations eg failure of community care policy in so far that generic mental health services have been unable to meet the needs of this group.

It is also apparent that the mental health needs of people with an intellectual disability who live within Queensland *cannot* be met satisfactorily within mainstream mental health services or disability service provision. Specialised service responses are required. The development of appropriate service responses that meet the complex mental health needs of adults with an intellectual disability should aim to develop and enhance the capacity of current community services to respond. This response capacity should not be restricted to the mental health and disability sectors, but needs to involve other stakeholders such as housing and education. The international experience suggests that specialist services are required to support and guide mainstream service providers. Additionally, specialist service responses are often required to support those people with dual diagnosis with the most challenging needs (Mansell, 1993).

Collaborative partnerships that draw upon existing developments and encourage emerging expertise and interest should be encouraged and enhanced. Priorities for service improvement appear to cluster around:

- Highly skilled assessment and diagnosis that draws upon evidence-based practice;
- Access to short term inpatient treatment and assessment that specifically caters to the mental health needs of adults with an intellectual disability;

- Access to longer term rehabilitation and treatment that specifically caters to the mental health needs of adults with an intellectual disability;
- Development of a range of supported accommodation options that enable adults with a dual diagnosis to live within community settings;
- Better co-ordination and integration of care for adults with a dual diagnosis;
- Comprehensive case management by a single individual or agency who is responsible for the client & assists with cross-agency collaboration;
- Improved information systems and sharing between stakeholder agencies;
- Holistic approach to needs and care planning that integrates the interface between community-based teams and inpatient care;
- Offering seamless specialist services with a single point of access;
- ?Improved partnership working between agencies and professions (cross agency, cross boundary approaches that address relationships between professionals as well as agencies); and
- Improved training about management of the complex needs of adults with an intellectual disability, for staff at the coalface across all involved sectors.

To guarantee appropriate service response that meet the mental health needs of adults with an intellectual disability across Queensland, government must identify models that work outside of the traditional mental health/disability dichotomy. Generic services across all sectors must have access to highly skilled teams consisting of clinicians and professionals who can competently cross the mental health/disability service divide. Clinicians and professionals within these teams must have expertise in working with both systems so that the needs of adults with a dual diagnosis can met holistically.

There is a range of options available that hold potential for the Queensland setting. The main challenge is to engage all the relevant stakeholders in genuine endeavour to meet the mental health needs of adults with an intellectual disability. Queensland needs to develop cross sector specialised services for adults with a dual diagnosis who have complex needs. The model of service provision should ensure that there are coordinated responses to adults with a dual diagnosis that draws upon mental health and disability services expertise. The preferred model must ensure that adults with an intellectual disability have access to:

- The full range of mental health services including generic and specialist services inclusive of inpatient treatment and assessments services;
- A system that is person focussed rather than organisation focussed eg flexible and able to respond to adults with a dual diagnosis whose needs cross boundaries;
- Appropriate admissions and discharges including required follow-up and support (reduce inappropriate admissions and discharges); and
- Appropriate community support and services that maintain both physical and mental health and well-being eg assertive outreach teams.

Key program components should include:

- Community based consultation and outreach through a multidisciplinary team of senior clinicians (psychiatrist, clinical psychologist, social worker and OT at minimum) to individuals living at home with their families, in contact with either disability services or

mental health services. This team would work across agency boundaries and would work with all professionals and service providers, including carers and family members.

- Consultation with mental health services and disability services – consultation, assessment, diagnosis, program recommendations, triage and liaison including system facilitation, crisis planning, education and training.

- Triage and access to inpatient treatment and assessment beds staffed by psychiatric nurses and residential care staff for short term, time limited assessment and treatment development. Access to these beds should be only available through the community based consultation and outreach service multidisciplinary team.

- Education, training and research opportunities that are university based (undergraduates and graduates) cross-agency and multiprofessional in nature. Formal and information initiatives would target medical practitioners (consultants and trainees), health, mental health (including nurses) and disability professionals, managers, direct care staff, families, carers etc These events and programmes would aim to provide opportunities for networking, collaboration and interaction between all dual diagnosis stakeholders.

- Interagency communication mechanisms that provide formal and informal opportunities to network, develop continuity of service provision across sectors and promote best practice and evidence based approaches to clinical excellence. These mechanisms should also be used prevent, manage and resolve interagency issues and conflicts.

Future Directions

There are a range of possible responses that emerge from this report. These options need to be carefully considered by the Queensland agencies that are involved in the provision of services to adults with a dual diagnosis. The following options should be carefully considered in the search for models of service provision relevant to Queensland. Eleven models of service provision have been identified as operating across the OECD nations. An outline of these models is attached. These models have been identified as Option 1, Option 2 etc through to Option 11. Examples of some international service responses are also included within the Appendices.

A unique model of service provision may need to be specifically developed in Queensland. The most practical approach would involve assimilation and modification of aspects of dual diagnosis service delivery that are currently in operation across OECD nations.

Selected References

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Appendices

Appendices

Examples of Models of Service Provision

<u>United Kingdom</u>

Residential Options

There continues to be a distinct group of people who have required extended lengths of stay as inpatients in both acute and long-stay mental health settings (King et al, 2000). First identified in the UK approximately two decades ago (Mann & Cree 1976) the "new long-stay" group was described as being people who had a range of disabilities, mostly schizophrenic, poor social skills, few family ties and poor physical health of people spend long periods of time within hospital settings. Other descriptors included people with an intellectual disability who had challenging behaviour or those people who were difficult to place (Clifford et al, 1991).

The complex needs of this group mean they are difficult to support and sustain in community placements. They provide significant challenges in regard to both clinical needs within the context of community based accommodation options. Many appear to require some kind of structured residential facility with high levels of professional support. The impact of challenging behaviour or mental health problems in adults with an intellectual disability is one of the leading reasons why this group of people is returned to restrictive residential arrangements (Davidson et al, 1999). Dual diagnosis and complex problems can be a direct threat to successful community placements.

Despite strong public policy support for a range of community care, few residential options that suit the needs of people with a dual diagnosis have emerged and institutionalised service response remain the only option for many people with an intellectual disability who have complex behaviours. Until viable alternate options are developed that suit their multi-faceted needs, change is likely to be slow.

Long Stay Hospitals

Substantial UK literature on the quality and costs of long stay hospitals demonstrates very poor quality across the whole range of quality indicators (Hatton & Emerson, 1996). Reviewed publications between 1980-96 and found that these institutions did not show improved outcomes compared to other service models on any indicator of quality. In fact this research suggested considerably poorer outcomes on:

- User and parent satisfaction;
- Material and social environment;
- Privacy, choice and personal possessions;

- Use of community facilities;
- Development of user skills;
- Observed levels of minor challenging behaviours;
- Receipt of medication;
- Participation in domestic activities; and
- Staff support.

Although this research was unable to identify any clear cost differences between long stay hospital and alternative models, it closure is evidence-based (Hatton & Emerson, 1996).

NHS Residential Campuses

National Health Service residential units involve several living units being congregated upon a single site with centralised service responses. Research that has evaluated this approach (Emerson et al, 1999 and 2,000) found that residents tended to have severe and complex needs. When compared to community based accommodation options, the evaluation concluded that there were few advantages. This model demonstrated:

- Larger, less homely and more institutionalised settings;
- Lower staffing ratios;
- Less access to advocacy;
- Poorer internal planning procedures;
- More anti-psychotic medication;
- Less choice;
- Smaller social networks;
- Less access to day services; and
- Fewer and less variety of recreational/community based activities.

This model cost slightly less than community based living options although there was significant costs variation dependent upon individual needs (Emerson et al, 2000).

Village and International Communities

This residential model is usually managed by non-government service providers. The communities involve several living units based on a single site with central services (Emerson et al, 1999, 2000). Residents tended to be more independent and without physical health, mental health or behavioural problems. Costings were slightly cheaper than for community based housing options, not surprising given the relative independence and autonomy of the residents.

Hostels & Large Residential Care Homes

In the western nations demand for large residential care home models appears to be declining in preference for more home-like, individualised housing in local communities. In the UK the numbers of people living in hostels providing beds for 10-25 people is reducing although larger residential homes catering for 4 people upwards remain is substantial numbers (Emerson et al, 2000). The residential care home is likely to be the most popular housing model in the UK

(Emerson & Hatton, 2000). Hatton & Emerson, 2000 suggest that this model has some advantages over the long stay hospitals.

Small scale ordinary homes

Community based homes that cater for between two to 6 people is a the preferred accommodation model in the UK (Emerson & Hatton, 2000). Research suggests that generally improved outcomes in small scale ordinary housing compared to long stay hospital, NHS campuses and community based hostels (Hatton & Emerson, 1996; Emerson et al, 1999, 2000).

It is important to remember that there exists considerable variation within each service model eg small can sometimes be just as bad or just as good as big and vice versa. Elements of effective accommodation or residential support services for people with an intellectual disability are now relatively well known and evidence-based. Services need to:

- Be small in nature eg homelike;
- Enable small numbers of people living together;
- Employ staff who are well trained with good support by managers;
- Enable staff to actively support clients
- Assist clients to be engaged in meaningful community-based activities;
- Facilitate daily routines that reflect the rhythms and routines of ordinary daily life; enable clients to develop relationships with others;
- Develop and maintain socially appropriate behaviours (Cullen, 1999).

Assessment and Treatment Units

These model parallels a similar approach to mental health care provided within acute mental health wards although they often additionally aim to offer behavioural assessment and treatment for people with all degrees of intellectual disability (RCP, 1996).

Unfortunately few services using this model of care have been evaluated and there is no objective evidence to enable advantages or disadvantages to be considered. There is some anecdotal evidence that the effectiveness of these units can be compromised by problematic "mixes" of capability or skills. Given the diversity of people with an intellectual disability, this is of little surprise.

Ward-in-house or Hospital Hostel

Since the 1990s the UK Department of Health (DoH) encouraged the development of "hospital hostels" or "ward-in-a-house" facilities as alterative placements (Young, 1991). This model combines features of high quality hospital based treatment and care. For example, high staffing levels, intensive professional input. This approach enables the development and implementation of highly individualised programmes within a setting that is homely and domestic in both scale and operation ie ordinary normalised routines of a day of life within a community setting.

This model may be effective for a number of the most difficult, younger patients currently presenting to services – benefits may be unequal eg a proportion may progress to more independent living after skill development, others may benefit with skills maintenance in a supportive living environment (Young, 1991).

Advantages of this model are that the service type can cope with severely challenging behaviour when purpose built. One study showed some success for clients although this unit contained a seclusion room for the management of severely disruptive incidents – separated from and in isolation from the other residents (Hoefkens & Allen, 1990). Disadvantages of this model include bed blocking because of the lack of availability of alternative accommodation for admitted clients post interventions.

For example: <u>Cambridge Psychiatric Rehabilitation Service</u>
                                         (Addenbrookes NHS Trust)

This service was originally opened in 1986. Located on the edge of the psychiatric hospital site, the residential unit comprised eight beds. The aims of the services was to provide high quality residential accommodation with no upper limit on inpatient stay (King et al, 2000). This service was recently evaluated. The published study examined residents who had lived there between 1986-1993 (n=20). The research shows that 90% of the service clients had schizophrenia with the remainder having psychoses (had been there between 7-89 months with the mean of 25.8 months). Those who successfully resettled (n=8) into the community showed stable improvements in functioning over time. Further studies are warranted before the strengths and weaknesses and limitation of these models of care can be understood eg small numbers and no other studies replicating the findings.

Mental Health Day Services

Generic day programmes will also sometimes accept people with an intellectual disability although cognitive deficits and challenging behaviour typically compromise the success of such placements. There may also be waiting lists for day services and assessment processes prior to acceptance in the programme. Some programmes may be time limited with clear goals to programme involvement.

For example: Lewisham Day Centres

Lewisham Social Services offer day centres with activity programmes tailored to individual needs and preferences, but with an emphasis on social contact in a safe, non-discriminatory environment for people who may otherwise suffer social exclusion and isolation, and lack the confidence to access community facilities.

In addition to the Independence Day Centre, Compass Day Centre, Northover Support Centre, the Out of Hours Service provides an extension of the day centre service during normal working hours, to provide limited evening cover on some weekdays and weekends. The Volunteer Project (Rise Pop-in) enables volunteers to complement paid staff at the Northover Centre and provide a drop-in type service at the Rise Centre at weekends.

Specialised Services

<u>Specialised Day Services</u>

Specialised day services provide solely to a targeted population. The National Autistic Services (UK) provides an excellent example. Day services can be quite extensive, providing a one stop approach to other services.

For example: **National Autistic Services Adult Centres (UK)**

The National Autistic Society (NAS) provides a wide range of residential and day services for adults with autistic spectrum disorders. This range includes residential and day provision in urban and rural settings offering flexible, specialised support to individuals with varying needs.

The aim of all services is to offer access to as full, enjoyable and meaningful a life as possible to each individual. Programmes are designed to offer additional help in communication and social skills and to compensate for difficulties in imagination - all barriers to achievement of a full and enjoyable life. Unless part of a time-limited, therapeutic regime, services are generally offered on a long term basis in order to provide essential stability, continuity and personal security.

<u>Specialist Services and Teams</u>

Specialist teams of mental health professionals may be established to serve particular populations.

For example: **MIETS Service, South London & Maudsley NHS Trust**

The Mental Impairment Evaluation & Treatment Services (MIETS) is a comprehensive **national** service that caters for the needs of adults with mild learning disabilities, severe challenging behaviour and in many cases additional mental health needs. The unit offers specialist multi-disciplinary assessment and treatment. It is located at the Bethlehem Royal Hospital (South London and Maudsley NHS Trust).

An outreach team also operates within MIETS. The aim is to provide treatment interventions and guidance in the patient's own setting when admission to the units is felt unnecessary. The work undertaken can serve to reduce an admission or can act as an effective tool in the safe transfer of an individual between the inpatient units and the local teams

The aim, once treatment is complete, is to work in conjunction with local services to relocate the client in their local area to the least restrictive service provision. The service has gained a reputation as a national and international centre of excellence in the assessment and treatment of adults with mild-learning disabilities who have or may have:

- A history of offending
- Autistic Spectrum Disorder
- Other mental disorder
- Challenging behaviour
- The design of the new unit will offer:

- Seventeen en suite bedrooms
- Gender segregation
- Low dependency flat
- Facilities for one to one and group-work across a range of therapies

The MIETS team is also planning to provide an Intensive Care Facility. Movement to new facilties will afford the multi-disciplinary team the ability to assess risk in a structured format. This will be achieved in a low secure environment. The team continues to look forward to being able to provide a seamless service to this population by working in close collaboration with local services. The unit will be called Monks Orchard House, reflecting the heritage of this site and was chosen by the current users and staff. It will be built in close proximity to the existing orchards. Work has recently begun on the foundations for the new building, which should be completed by early 2002. Following commissioning it is anticipated it will be occupied by summer 2002.

Private Specialised Residential Facilities

In the UK, generic mental health services have often been unable to meet the mental health needs of people with mild intellectual disabilities, as a result of which an increasing number of private facilities have opened in an effort to fill the gap in services. In the early 1990s, some NHS Trusts also developed inpatient assessment and treatment units when replacing some of their institutional based services, so attracting extra funds from other districts.

Large sums have been spent by social and health services in buying psychiatric services from these specialist private units. In recent years there has also been an increased number of secure and medium secure units to care for people with mild intellectual disabilities who are usually detained under a forensic section of the Mental Health Act. Unfortunately, these new facilities are often a long way from a person=s home, family, supporters and friends, making it difficult to retaining links and to plan for an eventual return home. The implications for the local services are also detrimental because they are deprived of the funds necessary to develop their required services.

For example: **St Andrews Group of Hospitals** (Northamptonshire, Essex, Middlesex)

The Developmental Disabilities Division at St Andrew′s offers specialised services for Adults with mild/borderline learning disabilities and challenging behaviour who may also have a mental health problem and/or a forensic history. The services are currently based at the following units:

Geoffrey Hawkins Unit and Victoria House on Smyth Ward provides a package of care for adults requiring a medium secure forensic service. A specialised service is offered for male and female adults with a mild/borderline learning disability, who have forensic needs and mental health problems. The male service is provided on the Geoffrey Hawkins Unit and the female service is at Victoria House, Smyth Ward.

The treatments offered may include specialised arson and sex offending packages, drugs and alcohol awareness programmes, activities of daily living, cognitive behaviour therapy, and psychotherapy with individual care plans written for each patient.

Admission Criteria is:

- Male patients to the Geoffrey Hawkins Unit and female patients to Victoria House.
- Age: 18 - 50
- earning Disability Level - Mild/borderline learning disability
- Patients who are treatable and require a medium secure environment
- Evidence or risk of offending behaviour

There is an expectation that the patient will be able to move on to a less secure environment. Patients are detained under the Mental Health Act.

The Geoffrey Hawkins Unit is a 17 bed, ground floor unit. The unit has direct access to a secure garden. There are single rooms with washing facilities. There is a spacious lounge, separate smoke room and meeting/interview room. There are two therapy rooms within the unit.

Victoria House is a 7 bed, second floor, refurbished secure facility. Single rooms with washing facilities are also provided, as it a spacious lounge and separate dining room. There is a smoke room and a therapy room within the house.

The multidisciplinary team includes a Consultant Forensic Psychiatrist, one Staff Grade/Associate Specialist, a Consultant Forensic Clinical Psychologist, one Consultant Psychologist , Social Worker, Teacher, two Occupational Therapists with Technical Instructor support, a Physiotherapist , Speech & Language Therapist, Dietician, Art Therapist, Psychotherapist and administrative support. The Unit is staffed by nurses.

The prices range from an initial observation rate of £550 per day up to 6 weeks following admission. Thereafter £395 per day with £412 per day for patients in receipt of specialist programmes e.g. Sex Offenders or Arson Treatment programmes. Special nursing costs are included within the daily fee, (Prices valid to 31 March 2002.£380 per day).

Separate Specialist Mental Health Services within Hospital/Institution

This "service within a service" model usually includes inpatient and outpatient facilities that are linked with specialised psychiatric units meeting the needs of people with mental illness or behaviour problems, offenders and the elderly.

This approach is frequently criticised because it is reminiscent of institutional approaches to services provision (congregate care). Economies of scale may be achieved and locality to generic mental health and often tertiary mental health services can be advantageous eg networking, advice, information, staff interaction etc. Other advantages of this approach include:

- provision of a range of services,
- economic use of specialist staff time,
- sharing of onsite therapy or recreational facilities for clients, p
- provision of those who require mental health care/asylum (Day, 1988).

For example: <u>**The Learning Disabilities Services**</u>, Chase Farm Hospital, Enfield Primary Care Trust

Services provided include a Community Team and an inpatient Assessment and Treatment Service. Naturally a cooperative relationship exists between the teams.

The Community Team (CT) is an outpatient health service for people with learning disabilities. It is made up of a multidisciplinary staff group who are involved in assessment and treatment in the community. The CT serves the London Borough of Enfield and a neighbouring part of Hertfordshire, including Cheshunt.

Team members see clients, carers, family members at their own homes, in centres or other venues in the community or at Chase Farm Hospital. The venue of an assessment is largely dictated by what is most appropriate for the individual client e.g. some people may have difficulty in getting to Chase Farm Hospital.

Bowman House and Lea Villa are two separate units on the Chase Farm site that provide fifteen bedded acute assessment and treatment service for people with learning disabilities, who have additional challenging behaviour or mental health problems. An inpatient stay is only considered when the challenging behaviour or
mental health problems are of such a severity that the individual concerned cannot be safely supported in the community.

The assessment and treatment within this unit is primarily aimed at the rehabilitation of the individual concerned back into a community setting. The unit is designed for people who are eighteen years or older. Occasionally there will be younger people on the unit when their circumstances are such that there is no other suitable resource for them.

The inpatient service takes referrals from Consultant Psychiatrists specialising in learning disabilities from the local community team and the neighbouring areas of Harringey, Tower Hamlets, Hackney, Newham and occasionally other areas.

<u>**Specialist Inpatient Assessment and Treatment Units**</u>

For example: <u>**Weston Unit**</u> (South London & Maudsley NHS Trust)

A 24 hour inpatient specialist treatment and assessment service that is located within the York Clinic of Guys Hospital, London. Outpatient services and follow up are provided. The unit is staffed by Community Psychiatric Nurses who have access to multiprofessional support through the local Learning Disability Teams.

The service is integrated with generic mental health services within the Trust covering the same catchment area. This is an inpatient unit with strong community provision for Lambeth, Lewisham and Southwark

For example: **Behavioural Disorders Unit**, South London & Maudsley NHS Trust

This 17-bedded inpatient unit provides specialist multi-disciplinary assessment and treatment to a *national* client group. The unit is located at the Bethlehem Royal Hospital. The unit's main focus is working with individuals who have an Autistic Spectrum Disorder and/or co-morbid mental health issues and challenging behaviour. Adult mental health and complex needs are also treated. The aim, once treatment is complete, is to work in conjunction with local services to relocate the client in their local area to the least restrictive service provision.

The current clinical focus of the BDU is adults with complex mental health needs, and adults with an autistic spectrum disorder. People admitted to the unit usually have significant diagnostic uncertainty and also present with behaviours that have proved too challenging for their local services to manage.

Recent analysis of the clinical outcomes of the BDU demonstrated a very significant reduction in the frequency and severity of socially inappropriate behaviours in people treated on the unit; in addition although over 90 per cent of our patients were admitted from hospitals/courts, and under a section of the Mental Health Act, over 85 per cent are discharged to community settings.

Specialist Integrated Mental Health Services

For example: **Specialist Services: The Estia Centre** (South London and Maudsley NHS Trust)

The Estia Centre is part of a range of services for adults with learning disabilities and additional mental health and/or challenging needs. The centre's main aim is to develop a variety of training initiatives for those supporting adults with learning disabilities and additional mental health and/or challenging needs.

This model, similar to that described by Patterson, 1995 when analysing an American model, advocates that advantages of partnership and networking between generic mental health services, community based learning disability teams and specialist service providers (dual diagnosis).

The model also provides access to inpatient treatment or assessment, in addition to outpatient support on the basis that experienced clinicians believe it is more sensible to adopt the approach that people should be supported in their own homes for as long as possible, but many people will require periods of inpatient assessment or treatment

This service is for adults (over 18) with learning disabilities and additional mental health and/or challenging needs in Lambeth, Southwark and Lewisham. The Estia Centre enjoys a close relationship with dual diagnosis service providers within its catchment area.

By working in close collaboration with clinical services the Estia Centre aims to improve the care of people with learning disabilities through evidence-based practice. The Centre

purposefully draws together the three essential components of clinical skills, training and research. Through this focus the Centre can help to promote high quality community services.

For example: **St Georges Hospital Medical School,** University of London

The Department of Psychiatry of Disability is a multidisciplinary department within St George's Hospital Medical School. Its mission is to contribute to achieving a better quality of life, services and opportunities for developmentally disabled people by improving the understanding and management of their health problems in partnership with disabled people and other stakeholders. These goals are achieved through the provision of the psychiatric component of a progressive, community-oriented clinical service for adults with developmental learning disabilities.

The wide range of expertise and interests among members of staff make it a unique centre for research, service development, teaching and clinical practice. The Department has four broad aims:

- To develop the Department as a regional centre for ideas, leadership and support to the process of informed change for all relevant stakeholders in Southwest London and beyond.

- To conduct research in the field of developmental disability, relating to the evaluation of services, mental and physical health, and the dynamics of families and other small groups providing care for people with developmental disabilities.

- To provide an effective teaching programme in developmental disability for all those who require this, including undergraduate medical students and postgraduates.

Members of the Department make a major contribution to health service delivery and innovation in South West London, delivering specialist mental health services to people with learning disabilities within a population of 1,000,000 people.

In addition to membership of multidisciplinary community teams, the Department provides the psychiatric component of an innovative, tertiary outreach service for people with learning disabilities and mental health or challenging needs. The service works alongside families and social care providers to assess clients, and develop sustainable interventions that reduce identified problems and enhance the choices and community participation available to them.

A dual diagnosis inpatient unit has been established to provide assessment and treatment services for people who require admission to hospital. A specialist epilepsy clinic is provided.

The Department is also at the forefront of developing and delivering psychological therapies to people with learning disabilities. A major aim is to break the cycle of abuse, leading to better outcomes for individuals and wider social benefits. Two weekly psychotherapy groups are provided, in addition to individual therapy. Psychotherapy supervision and theoretical seminars are provided for NHS and voluntary sector staff. Members of the Department are involved in the Disability Team at the Prudence Skynner Family Therapy Clinic.

A specialist outpatient service for children and adults with autism offers diagnostic assessment and advice about management and placement. There is a particular focus on the needs of

more able people with autism and Asperger Syndrome. Close links are maintained with Primary Care Services, the Regional Forensic Services, Psychotherapy and Family Therapy services, Child and Adolescent Psychiatry Services and the National Deaf Mental Health service.

<u>Continuum of Care Model</u>

For example: **Leeds Community and Mental Health Services, Leeds NHS**

This comprehensive service address needs holistically in one location. However, services provided have a collaborative relationship with the community eg the view is towards the community rather than *an institutional or inward looking approach to service provision.*

Day services

Day Services are provided to in-patients of the Trust (at Woodland Square, Armley, Foxwood). The service provides resources that are not otherwise easily accessible in the community eg hydrotherapy, snoozelan and rebound therapy. Staff also support service users to access leisure and educational opportunities within the community.

City-wide Learning Disability Services

Woodland Square is an in-patient service based at St Mary's Hospital, Greenhill Road, Armley, Leeds and provides the following City-wide Learning Disability Services which are:

- 5-bed Integrated Respite Care Unit for people with profound multiple disabilities who require specialist health interventions
- 5-bed Integrated Respite Care Unit for people with special needs including challenging behaviour and who require specialist health interventions
- 5-bed Assessment and Treatment Unit for people who need intensive assessment/treatment on a short-term basis
- 8-bed Special Needs Unit for people who have complex health needs and exhibit challenging behaviour

The aim of the service is to:

- Act as a support to the Community Support Service for non-NHS individuals living in the community who may occasionally require more intensive psychiatric and therapeutic interventions through the assessment and treatment units
- To provide an integrated care service including respite and support for carers
- To actively collaborate with all service providers towards a unified system of support for people with Learning Disabilities in Leeds

Group homes

Leeds Community & Mental Health Services Teaching NHS Trust currently provides inpatient accommodation and support for a small number of people with learning disabilities and complex

health needs. The Group Homes provide accommodation to people who have severe learning disabilities. These people also experience additional complex health needs, such as physical disabilities, sensory impairments, communication difficulties, episodes of mental ill-health, mobility problems, and self-injurious and aggressive behaviours.

Group Homes are staffed round the clock by a dedicated team of professionally qualified nurses and support workers. Their specialist skills and knowledge are needed to help the people overcome the problems which prevent them from achieving full, active, enjoyable and healthy lifestyles.

Assessment / Treatment Service

The aim of the service is to provide nursing care to people with Learning Disabilities who have identified assessment/treatment needs which necessitates admission to the in-patient services. These services are provided at Woodland Square. The Unit aims to provide high quality nursing, medical and multi-disciplinary care to people who need specialised or intensive hospital in-patient assessment and/or treatment, on a short-term basis.

The Unit is separated into 2 x 4 bedded areas which both provide structured and supported environment for clients. Strategies and interventions are developed through individualised care planning, promoting health gain and enabling discharge to take place. The services are provided by registered nurses trained in the speciality of Learning Disabilities and a team of professionals working collaboratively to produce individual care packages.

Integrated Respite Service

The aim of the service is to provide nursing care to people with learning disabilities who have identified health needs and live in the family home in the Leeds area. Emphasis is put on the fact that the individual remains part of the community and respite is seen as an integrated part of the person's life. Referrals are made to the Consultant Psychiatrist, by submission of a comprehensive assessment package, which is completed on behalf of the individual by either a community nurse or a social worker. Admission to the service is through a referral panel that meets on a regular basis, and is responsible for reviewing placements on an annual basis or according to change in health needs.

Services for People with Profound Disabilities

The Unit provides a inpatient service for people with profound multiple disabilities who require specialist health interventions at Woodland Square.

Services for People with Challenging Behaviour

The Unit provides an inpatient service for people who exhibit challenging behaviour and who require specialist health interventions. The services provided to both above units are provided by registered nurses trained in the speciality of learning disabilities. Additional support is provided by a team of professionals working collaboratively to produce individual care packages.

13

Learning Disabilities Community Support Service

The Community Support Service is established to support the safe discharge of the people living in the group homes. The service will be continually developed in response to the objectives identified in the Government's 2001 White Paper, Valuing People and the actions laid out in the Leeds Joint Investment plan. The Community Support Service offers advice and support to many agencies, professionals, primary health care teams, service users and carers and Primary Care Trusts. It is a city-wide service and made up of various components.

Adult Learning Disability Team

The registered nurses in the Adult Learning Disability Team, work alongside specialist social workers to provide a multi-disciplinary team approach to adults with a learning disability who have complex health and social care needs. The team has an open referral policy and the nurses role is to undertake health needs assessments and work with clients and carers to meet a number of health needs including emotional and mental health; epilepsy management; behavioural problems; social and sexual health issues; continence etc. Nurses also undertake skills teaching and giving advice and support to clients, parents, carers and other professionals about a range of health issues.

Outreach Nursing Service

The Outreach Nursing Service works closely with the Woodland Square Assessment / Treatment Units to:

- Prevent further deterioration in the mental health status or behaviour
- Maintain or improve health or behaviour
- Support people in their own homes, preparing them for admission to Woodland Square, supporting them as in-patients and providing support after discharge.
- Referrals are received directly from the Learning Disability Consultant Psychiatrists.

Social Model: Learning Disability Teams

Multidisciplinary in nature, these teams have been the cornerstone of community service delivery in the UK. They have multiple functions and activities including community care planning through to service development, advocacy and the provision of clinical services (Bouras & Holt, 2001). In the UK, post deinstitutionalisation any services for adults with an intellectual disability (known as learning disability there) have historically were mainly integrated within community based learning disability services (Bicknell, 1985).

Community care policy considered this team as the focus of community based, easily accessible and coordindated multi-professional services. Community learning disability teams may include learning disability nurses (who have a qualification in learning disability nursing, not mental health or general nursing - although some are dual qualified), social workers, psychologists, speech and language therapists, occupational therapists, physiotherapists - some of these disciplines are in short supply, and districts differ in the details of organisation.

Advantages were obviously the community location (as opposed to institutionalised service provision) but the emergent disadvantage was the artificial separate in location from mental health services (Bouras et al, 1995).

In response to increasing demand for clinical services, particularly from adults with an intellectual disability that have challenging behaviour, these teams have been supplemented with psychologists and other professionals who have expertise in challenging behaviour.   It should be stressed that these teams hold expertise in the management of challenging behaviour where mental health problems have been excluded.

Challenging Behaviour Teams

Some community services across the UK have now developed Community Support Teams, also known as Challenging Behaviour Teams. These teams primarily provide consultancy support as resources are limited and the availability of clinical resources for active treatment interventions is severely limited (Bouras & Holt, 2001). General aims include the provision of advice and support to community services in the management of challenging behaviours. This model has been implemented widely across the UK with positive outcomes reported in the literature (Allen, 1998; Allen & Felce, 1998).

The increasing complexity of problems of people with mild levels of intellectual disability who have concurrent mental health problems has been given as one reason (Bouras & Holt, 2001) with the complexity of their needs, and the increasing evidence of a relationship between biological and environmental factors also being highlighted (Hillery, 1998; Bouras & Holt, 2000). Van-Minnen et al, 1993 described positive outcomes arising from the use of multidisciplinary outreach team working with people who have a mild intellectual disability and severe behavioural and or psychiatric disorders. This approach focussed upon the client:social environemt (van-Minnen & Hoogduin, 1998

Challenging Behaviour Services

Although providing a specialised service, typically to other Learning Disability Team clients, this service can also be located within or form part of Learning Disability Services. These services rely upon the roles and responsibilities of psychologists and predominantly rely upon community outreach without residential inpatient services (Newman & Emerson, 1991).

For example: **Community Based Specialist Intensive Support Service (ISS)**

This well established specialist team has been established in Glamorgan, South Wales since 1989. The service is specifically for people with challenging behaviour. It involves a small team of well-resourced clinicians with a budget and access to a six bed admissions unit.

Evaluation showed the model was able to bring about significant changes in challenging behaviour, mental health problems, client skills and quality of life (Allen & Lowe, 1996); to be cost effective when compared to institutional models (Allen & Lowe, 1995) and to be

15

associated with significant reductions in both short stay and long stay admissions to institutional care (Allen, 1998).

Another study by Allen, 1999 compared two groups from South Glamorgan who have been maintained by the ISS: one group with severe challenging behaviour had been successfully maintained in the community (n= 33) and the second group had experienced placement breakdowns and been returned to institutional care (n=14).

Thorough assessment revealed few differences in psychiatric morbidity or challenging behaviour but major differences were identified in the adaptive behaviours of the groups. Individuals who were more capable were in the breakdown group (Allen, 1999) – therefore more dependent people with challenging behaviours were able to be maintained in the community.

Multiagency Collaboration

For example: Partnership in Action; Croydon

The Healthy Croydon Partnership was launched in January 1999 and was set up to develop partnership working in order to improve health and social care services in Croydon. The Partnership works at the highest possible strategic level and its membership comprises the Croydon Health Authority, Croydon Council, Primary Care Groups, local NHS Trusts, Croydon Community Health Council, the Police and Probation Service, as well as voluntary and business sector representatives.

The Partnership members are board members, with chief officers in attendance. Its primary purpose is to develop and agree Croydon's Strategic Plan for health and social care, the Health Improvement and Modernisation Programme. A system of multi-agency Joint Planning Teams undertake planning on specific areas under the umbrella of the Healthy Croydon Partnership. A Steering Group of chief officers oversee the planning of the agenda for the Partnership. A unit jointly funded by the Health Authority and the Council supports the Partnership. Support on particular items, is provided by the appropriate officers of the Partnership agencies.

Partnership in Action; Croydon was the first authority in London to have registered a partnership arrangement with the Department of Health for the use of the new powers under the Health Act 1999 for joint commissioning and joint provision of services in order to improve services to the public.

USA

Collaborative Interagency Case Management Model

This model involves a coordinated, multi-agency approach that involves various service providers that are seeking a common solution to problems or needs within a region or area.

For example: **Interagency Consortium,** Spokane, Washington (Patterson, 1995)

Agencies responsible for developmental disabilities and mental health services in Spokane, Washington state developed a collaborative system of care in 1989. Involved the development of an interagency consortium to promote coordination of services between the community mental health centre, the state hospital, the county human services agency, the state regional development disability service agency, the state institution for the developmentally disabled and several community agencies supporting people with developmental disabilities.

Between 1990-1992 admissions to the state hospital were more likely to be appropriate admissions eg people with developmental disabilities experiencing mental disorders. This group was discharged more efficiently and crisis respite ser vices were used in place of hospitalisation, In addition, anecdotal report cited a reduction of interagency tensions (Patterson, 1995).

For example: **Interface Project,** Hamilton County, Ohio (Woodward, 1993)

The Interface project was established in 1979 as a collaborative undertaking of the Hamilton County Community Mental Health Board, the County Board of Mental Retardation and Developmental Disabilities. The project was based at the University Affiliated Cincinnati Centre for Developmental Disabilities with the goal of establishing multi-system services for adults with a dual diagnosis.

Through this project three unique programmes were developed:

- multi-system community and inpatient crisis intervention service developed through the expansion of existing mental health services;
- an increase in community mental health services in the five existing community mental health centres; and
- building of a mental health community residential setting specifically for adults with a dual diagnosis.

A contractual agreement between hospital and disability services resulted in funding of three behaviour management specialists where one was available seven days a week – provided tertiary consultancy advice to generic psychiatry mobile teams, inpatient and outpatient services, including accident and emergency; discharge follow up was later added. Simultaneous multi-professional, multi-agency training and educational initiatives were also conducted.

The residential provided 24 hour supervised independent living training for people moving from institutions to the community as well as inpatient assessment and treatment for people living within the community. As the project unfolded, additional service developments took place eg the article reports 24 hour residential living, crisis intervention and community mental health services now being in place (Woodward, 1993).

For example: **Collaborative Interagency Project,** Minnesota Institute on Community Integration

In an effort to better address the needs of children and youth with disabilities in Minnesota, the 1998 legislative session has passed an initiative to provide coordinated, multi-disciplinary interagency services to children and youth with disabilities ages 3 to 21 by the year 2003. This new legislation states that each child and any young adult who has a disability will have an individual interagency intervention plan and each community will have an interagency intervention system.

The new law also requires the development of an 18-member State Interagency Committee (SIC) to oversee the development of the new coordinated, interagency system. This system is intended to provide the opportunity for Minnesota agencies to work together to build a partnership that makes it easy to access services, reduce duplication, and coordinate a child's educational plan from the time they enter school all the way up to adulthood.

In response to this new legislation, the Institute on Community Integration (ICI) has applied for and received a one-year, $175,000 grant from the Minnesota Department of Children, Families, and Learning to collaborate with and support the work of the State Interagency Committee. This effort, called the Collaborative Interagency Project, specifically focuses on serving youth with disabilities who are between 9 and 21 years old.

One of the main responsibilities of this project is to provide technical assistance, training, and support across the state to Community Transition Interagency Committees (CTICs) and others working with this age range at a local level, including parents and youth with disabilities. The assistance focuses on creating understanding of the system changes that will be taking place. Information and updates on these changes will be disseminated through a new newsletter called What's Working in Interagency Collaboration, and an interagency Web site with information about the coordinated interagency initiative. Other project activities include reviewing and making recommendations to the SIC about protocol for:

- Interagency data collection procedures.
- Interagency assessment and evaluation processes.
- Integrated funding of services.
- Interagency service coordination and case management.
- Interagency development of each child's Individual Education and Transition Plans.

For example: **Mental Health Services for Regional Center Clients,** California

The California State Department of Developmental Services (DDS) contracts with regional centers to provide services to people with developmental disabilities. Regional Centers are

private, nonprofit corporations. There are 21 regional centers located throughout California, each serving a specific geographic area. The regional center is the main point of contact for individuals with developmental disabilities. The regional center is obligated to make sure that individuals with developmental disabilities and their family receive the services and supports they need and want. These services are specified in an Individualized Program Plan (IPP). Regional centers provide some services itself, such as case management, and assists consumers in getting services from other agencies.

Regional centers must provide services to individuals: with developmental disabilities; who are at high risk of giving birth to a child with a developmental disability; and infants and children less than 36 months old who have high risk of becoming developmentally disabled. State law excludes disabilities that are solely physical in nature. DDS regulations exclude disabilities that are solely learning disabilities or psychiatric disorders.

The regulations only exclude individuals whose disability is solely a psychiatric disability. If a person has other developmental disabilities, then the regional center should not deny eligibility based upon that exclusion. The fact that a person has a specified psychiatric disorder does not necessarily mean that impaired social or intellectual functioning is the result of the psychiatric disability or for purposes of regional center eligibility that the disability is solely the result of the psychiatric disability.

Regional centers provide services to people of all ages who have developmental disabilities. Regional Centers must:

- search out and identify people who may need regional center services;
- provide intake and assessment services to determine eligibility;
- provide preventive services to potential parents who may be a high risk of
- parenting a child with developmental disabilities;
- develop an Individual Program Plan (IPP) that reflects the individual's needs
- and choices, identifies the supports and services they want to receive and
- ensure that the services and supports identified in the IPP are provided.

Emergency and crisis intervention services include such things as mental health services and behavior modification services that an individual with developmental disabilities may need to remain in his/her chosen living arrangement. Crisis services should first be provided without disrupting the individual's living arrangement. For example, the regional center can provide extra staff in a group home, or behavioral support in the individual's home. If crisis services are not successful, then emergency housing must be made available in the individual's home community. If an individual must leave her/his
home, the regional center must make every effort to return the individual to his/her preferred living arrangement, with all necessary supports, as soon as possible.

Coordination of Dual Diagnosis (psychiatric and developmental disability)

In order to insure that people with a dual diagnosis (psychiatric and developmental disability) get the specialized services they need, regional centers and county mental health departments (CMH) are required to coordinate services. Since July 1, 1999 each regional center and CMH has been required to have a memorandum of understanding (MOU). Each MOU must identify

the staff who will identify consumers with dual diagnosis; coordinate activities between the two agencies and resolve problems.

The regional center and CMH must develop plans and procedures for crisis intervention, case conferencing and discharge planning for consumers who are admitted to psychiatric inpatient facilities, and training for service providers. When the local agencies cannot resolve a disagreement about these services, DDS and state DMH must help them resolve the disagreement, if both agencies request their assistance. At least once a year, the directors of the regional center and CMH must meet to review the agencies' collaboration, address any unresolved issues, and establish the direction and priorities for the two agencies to work together. The agencies must send copies of the MOUs to DDS.

If an individual's placement in the community is at risk of failing, and the individual might be sent to a developmental center, the regional center must immediately inform the individual, his/her parents, legal guardian or conservator and DDS. DDS has designated the Regional Resource Development Projects (RRDPs) to handle these situations. A representative from the local RRDP must conduct an assessment of the situation. If the RRDP determines that emergency services are needed, the regional center must provide them. An IPP meeting must be held as soon as possible and should include a representative from the RRDP. The team should review the emergency services and determine if the individual's ongoing needs for services and supports to be able to stay in her/his home community.

For example: **Interagency Case Management Projects** Division of Behavioural Health Sciences, Arizona, USA

The Division of Behavioural Health Services, Arizona provides coordination, planning, administration, regulation and monitoring of all facets of the state public behavioural health system. Interagency Case Management Projects (ICMPs) are fully implemented in Maricopa and Mohave Counties. These projects operate through the Bureau of Children's Services, Phoenix, Arizona. These pilot projects are designed to reduce the duplication of case management services for children and families currently served by multiple agencies. The purpose of ICMP is to centralize, coordinate, and manage the utilization of publicly administered services, and funds for state agencies serving children.

The Maricopa and Mohave ICMP Projects differ in structure, but have the same key goals:

- serve children with multiple needs which cannot be met though existing collaborative efforts;
- demonstrate that a cooperative, collaborative effort can be achieved between State agencies;
- develop an effective, efficient coordinated service delivery system;
- ensure families and children receive appropriate and timely assessment and services;
- improve the cost effectiveness of the service delivery system; and,
- recommend ways to streamline administrative processes across agencies.

Both projects are in their fourth year of implementation. As of July 1, 1999, the Maricopa County ICMP has provided multi-agency case management services to almost 200 children, and the Mohave County ICMP has provided Multi-Agency Team (MAT) services to about 100

multi-agency children. The number of referrals to the project continues to increase steadily, as school personnel and agency case managers become more familiar with the project. 60% of the children currently served in the Maricopa ICMP and 62% of the Mohave ICMP children have a serious emotional disturbance.

A comprehensive, multi-year evaluation of the Maricopa ICMP was completed recently. An interim process report, released by the contracted program evaluators, shows that the project appears to be moving towards its intended goals. An evaluation of the Mohave County ICMP is being considered for next year. The Mohave Oversight Committee, an interagency committee which provides local oversight and direction to the project, has concentrated its efforts on expanding agency staff in the "wraparound" philosophy of service provision. These efforts will continue during the next year through further training and implementation strategies.

The ICMP Case Management Work Group, an interagency work group responsible for providing technical expertise and guidance for the operation of the ICMP projects, continue to work on implementation issues encountered by the projects. Major issues raised included duplicative paperwork requirements when a child's case is open to multiple agencies; numerous and duplicative case staffing requirements when a child's case is open to multiple agencies; and incompatible data systems maintained by each agency which precludes the development of a comprehensive database on multi-agency children. Interagency subcommittees are currently addressing many of these issues, while others are being addressed by the Case Management Work Group, responsible for ongoing implementation of the project.

Other significant accomplishments include the development of Interagency Cost-Sharing Guidelines to streamline the process of cost sharing for services between agencies, and the development of a comprehensive service plan to satisfy case planning requirements for all involved state agencies. A contracted evaluator is currently working on a comprehensive, multi-year evaluation of the project. Issues that remain to be resolved include duplicative paperwork and data entry requirements, and the lack of a single database to collect information on the multi-agency children served by the project.

Wraparound services and other components are being developed with these funds, and parent/family and cultural diversity advisory councils have been established to support this system of care project. The grant requires participation in a national longitudinal study beyond the five year limit of funding.

Application for a federal grant was made to CMHS under a new Child and Family Initiative in April 1999. The grant was awarded in September, 1999 and will be used to implement an interagency case management model project, "Project Match". The project will bring $6.3 million dollars to Arizona over five years and will serve high-risk children and adolescents in Pima County.

Staff from the Bureau of Children's Services also participated in a number of additional collaborative efforts to improve the system, including:

- Collaboration with the Maricopa County Juvenile Court in the development of special procedures to expedite referrals of model court cases for Title XIX funded services.

- Collaboration with ADJC on the implementation of a new process for expediting referrals into behavioural health services for youth being discharged from correctional institutions and reintegrated back into their communities. This collaborative project will expanded throughout the state and involves all the ADJC correctional institutions.
- Collaboration with the Administrative Office of the State Supreme Courts on improving the care of children whose competency to stand trial is in question.

An interagency team addresses restoration of these children and adolescents to competency in settings other than inpatient & residential treatment centres. A number of mental health experts presently conducting competency evaluations assisted with the development of an outpatient restoration program. The final outcome involved new policies for the Courts addressing these children's needs and an increase in the number of agencies providing outpatient restoration programs.

- Collaboration with AOC in the development of a program to ensure that children who enter juvenile detention at either Durango or SEF have access to behavioural health services.
- Coordination with the Governor's Office on the "No Wrong Door Initiative" created in September, 1998, via an Executive Order creating a children and families' service delivery improvement team.

This team's mission is to develop recommendations for service integration across state agency boundaries which are designed to enable children and families to more easily receive appropriate services regardless of the agency they initially contact for assistance. Recommendations focus on relieving families of unnecessary duplicative application and case management processes. After assessing all the services and programs provided by state agencies to children and families, the team identified ways to connect multiple agencies, using technology and other tools. They then recommended ways to assist children and families in accessing needed services across all agencies, regardless of the agency they initially contact for assistance.

For example: <u>Comprehensive Systems of Care,</u>Tulsa County, US
Department of Health and Human Services

Phase I funding will be used to assist Tulsa County in building consensus to adopt a comprehensive care model for children called Systems of Care. The Systems of Care model is designed to meet the needs of children and adolescents with serious emotional disturbance (SED) and their families. It is based on three tenets: mental health service systems are driven by needs and preferences of the child and family, services are community based and built on multi agency collaborations, and services offered are both responsive and sensitive to the cultural context and other characteristics of the population being. The consensus building strategy involves identifying and involving key stakeholders and crating a community wide advisory board determining community readiness, assessing community needs and resources, and reporting summarizing and sharing these finding with the community.

CMHS is charged with leading the national system that delivers mental health services. The goal of this system is to provide the treatment and support services needed by adults with mental disorders and children with serious emotional problems. Almost 50 million adults in the

United States are affected by mental illness in any given year, and more than 5 million adults and children are diagnosed each with a severe mental illness, such as schizophrenia, bipolar disorder, or severe depression.

People with serious mental illnesses often need assistance with treatment, employment, housing, transportation, and other aspects of community participation. CMHS administers programs and funding for the delivery of these services. Mental illness can be treated effectively, and people can and do recover. Most people with mental illnesses experience success at work, raise healthy families, and live in harmony with their neighbours. However, recovery depends on getting services when and where they are needed-preferably early in the course of the illness and close to home.

As the 21st century ushers in dramatic changes in the health and human service environments, CMHS is in a unique position to help States and local communities meet the challenges and opportunities these changes will bring. Making these changes in ways that work best for people with mental illness requires leadership, leadership CMHS can provide. To this end, CMHS is assessing carefully new programs to better understand what works and why, and how to tailor successful programs to fit communities. CMHS also is rigorously evaluating programs to learn how many private and government services are involved, how many tax dollars are spent or saved, and how individual lives are improved. Working with its partners, including State and local governments, the private sector, service providers, and consumers of mental health services and their families, CMHS is helping to lead the Nation's mental health services into state-of-the-art systems of care for the 21st century.

For example: **Interagency Case Management Project (ICMP),** Arizona
                               Department of Health Services

This is an integrated multi-agency disability service, across the county, which works towards a unified model of care delivery with a single point of access, to ensure appropriate service delivery to people with physical and sensory disabilities by: developing and trialling new models in consultation with key community service providers

The Interagency Case Management Project in Lake Havasu City, Arizona serves to coordinate care and manage multi-service access for children with serious emotional disturbance and/or behavioural problems. The multi-agency team (MAT) is comprised of representatives from Child Protective Services, Developmental Disability Services, Juvenile Corrections, Probation and Parole, and local school systems.

The team meets on a regular basis and has access to mental health flexible funds for most consumers. The MAT also utilizes behavioural coaches when available. This process provides improved coordination of care, utilizes creative problem solving, receives high level of parent satisfaction and at least anecdotally produces positive outcomes for children and systems. According to an Interim Impact Study Report in January 1999, children in the ICMP project experienced a statistically significant decrease in the restrictiveness of their out-of-home placements during the time period reviewed.

Models of Consultation

- Childrens and families worker attends review of young person who appears to meet criteria for adult services.
- transition plan information is passed on to adult services, adult team worker undertakes an assessment of need during the final year (age 18/19).
- Specialist children with disabilities team liaises with school and health professionals, and develop a plan. Undertake joint work with adult team, to ensure information is shared.
- Transition worker based in children's team undertakes a similar role
- Employment to collate information and track programmes.
- Transition worker based in adult team undertakes an assessment for adult services, and has a role in developing a range of residential and day service provision.
- Adult services worker undertakes an assessment of need or eligibility under Community Care or Disabled Persons Act legislation and identifies appropriate services.
- Specialist Adult community learning disability team undertake an assessment of need and support young person and their family to identify services.
- Joint funded projects - Social Services departments together with Health Trusts, Voluntary Sector and/or Education to co-ordinate plans, provide support, monitor progress, provide a range of information

One Stop Shop: Integrated Collaborative Service

This model establishes a single point of contact for the adults with an intellectual disability or their carers. A community-based service primarily involved in outreach, relationships are developed with other agencies and service providers to ensure a continuum of services are available.

For Example: **Building Bridges of Support,** Kentucky, Department for Mental Health and Mental Retardation Services

This is a three tier version of the integrated collaborative model that has been established within Kentucky. Building Bridges of Support: One Community at a Time (The Bridges Project) is a six-year, project funded by the federal Centre for Mental Health Services (CMHS), part of the US Department of Health and Human Services. The CMHS is charged with leading the national system that delivers mental health services. The goal of this system is to provide the treatment and support services needed by adults with mental disorders and children with serious emotional problems.

The Kentucky Department for Mental Health and Mental Retardation Services was awarded the grant in 1998, and has contracted it out to three Community Mental Health Centres (CMHCs) in the Appalachian region of the state: Mountain Comprehensive Care (Region 11, Big Sandy ADD); Kentucky River Community Care (Region 12, Kentucky River ADD) and Cumberland River Comprehensive Care (Region 13, Cumberland Valley ADD). The grant is building on Kentucky IMPACT, the system of care for children and youth with severe emotional disabilities that has been in existence state-wide since 1990.

The major goals of the Project are to redesign and enhance our existing system of care through:

- service expansion;
- school-based partnership;
- parent/family involvement;
- system level improvement; and
- training/education opportunities.

Bridges is taking the system of care forward by placing Student Service Teams in schools. A Student Service Team consists of an Intervention Specialist, a Student Service Coordinator, and a Family Liaison. The team members work in Bridges offices in the schools, enabling them to become familiar with, and a part of, the school climate. This has helped reduce stigma often associated with receiving mental health services, especially in these rural areas. Additionally, this arrangement has allowed Bridges staff and school staff to work more closely together and on a daily, informal basis. Bridges utilizes a three-tiered service model (universal, targeted, and intensive) in the schools, as described below

Universal Intervention

- Involves all students and school personnel in promoting a safe and positive climate that enhances learning and supports healthy psychosocial development
- Development of a school-based behaviour support team comprised of representatives from all populations within the school that makes school improvement decisions based on available data
- Provides a forum for developing consistent behavioural expectations for students and staff, identifying shared climate concerns, and developing strategies for improvement

Targeted Intervention

- Focuses on children and youth who are beginning to exhibit signs of an emotional or behavioural disability and attempts to prevent further exacerbation by teaching pro-social coping strategies and building on existing strengths and resources
- Interventions may include mentoring, tutoring or other academic support, and the development of a positive behaviour intervention plan

Intensive Intervention

- Targets children and youth with serious problems and attempts to improve daily functioning across life domains
- Development of a wraparound team that includes the family, child, school and agency personnel, and others who are involved with the child and family in a supportive way
- Provides collaborative development and implementation of a strengths-based plan that focuses on meeting the unique needs of the child and family through utilization of formal and natural supports

For example: **Interdisciplinary Service Delivery Model: The Dawn Project,** Indiana Division of Mental Health

In Marion County, Indiana, recognition that standard approaches for providing services were not meeting the needs of children with the most serious emotional and behavioural needs led to a collaborative effort to integrate and coordinate comprehensive care for these youth. In the mid 1990s, representatives from the various systems that work with children with emotional and behavioural challenges and their families, including mental health, child welfare, special education, and juvenile justice, came together to form a consortium.

The goal of the consortium was to develop an interdisciplinary service delivery model, which they titled the Dawn Project (Indiana Division of Mental Health, 1999). Dawn was developed to reflect an evolving philosophy in children's mental health reform emphasizing that services for children with multi-system needs should be community based, child and family centreed, culturally competent, individualized, and coordinated, utilizing non-categorical, flexible funding to finance service provisions (Stroul & Friedman, 1986).

The Dawn Project, currently completing its 3rd year of operation, is an interagency collaborative effort designed to serve a specific population of children and youth with emotional and behavioural disabilities in Marion County, Indiana. Marion County is Indiana's most populous county with over 813,000 residents, including over 216,00 residents under the age of 18. Eligibility criteria for Dawn include: (a) being a resident of Marion County; (b) being between 5 and 18 years old; (c) having a DSM-IV diagnosis or special education designation; (d) having functional impairments in at least two of four domains, either social, family, community, or school; (e) being involved in two or more child serving systems; and (f) being at risk for or already involved in residential placement (Russell, Rotto, & Matthews, 1999).

Using these criteria, children and youth can be referred to Dawn by any of the consortium stakeholder groups, and, to date, almost 300 children and families have participated (Russell et al, 1999)

University Based Specialist Services

This model involves the establishment of a community-based multidisciplinary clinics being operated under the auspices of a University. The centres of excellence typically provide clinical services but are also involved in education or training and research activities. The DDU in Queensland operates within a modified version of this model.

The University based services can provide primary services, specialist services, tertiary services or a combination. The centres are usually joint initiatives of government funded human services and the university of choice. The centres will also compete for tenders and grants.

For example: **Tarjan Centre for Developmental Disabilities** at UCLA, California

On May 14, 2001 the faculty and trainees of the former UCLA University Affiliated Program joined members of the community-at- large to celebrate the dedication of the *Tarjan Centre for Developmental Disabilities at UCLA*. Dr. George Tarjan (1912-1991) pioneered the study of mental retardation and developmental disabilities. Dr. Tarjan's clinical experience and innovative training models contributed to his appointment to the National Advisory Mental Health Council (1960) and his work as the Vice Chair of President John F. Kennedy's Panel on Mental

Retardation (1961). With clinical experience as the director of the Pacific State Hospital (later Lanterman State Hospital), Dr. Tarjan provided leadership for the University Affiliated Facility (UAFs) from 1969 through 1987 and also guided the faculty from 1987 through 1991 when we assumed the new name University Affiliated Program (UAP).

In 1965, Dr. Tarjan became the director of the Division of Mental Retardation and Child Psychiatry at the <u>UCLA Neuropsychiatric Institute</u>. He designed training programs at UCLA that emphasized interdisciplinary research and training in developmental disabilities and mental health. Throughout his career at UCLA, he worked directly with patients, taught classes, and guided UCLA graduate students to national medical careers, while serving on government agencies, foundations, and organisational boards. Several current Tarjan Centre faculty members trained under Dr. Tarjan's supervision. He also encouraged the scholarship of foreign medical graduate students, advising them of programs and training opportunities within the American Psychiatric Association. His vision was both local and global.

The core functions of UCLA's UCE stem from its links to the Neuropsychiatric Institute and its faculty's research. We provide academic training, clinical and technical assistance, health care services, and state-of-the-art diagnosis and evaluation for individuals with developmental disabilities, their families, and the community-at-large.

For example: **Nisonger Centre** (Ohio State University & Ohio Department of Health)

The Nisonger Centre was established in 1966 as a result of the Mental Retardation Facilities and Community Mental Health Centres Construction Act of 1963. The Centre moved into McCampbell Hall on the medical campus of the Ohio State University 1972. In the 1970s the centre helped to pioneer the concept of interdisciplinary professional training and service in the field of intellectual and developmental disabilities.

The Nisonger faculty helped to develop the "Adaptive Behaviour Scales" of the American Association on Mental Retardation; these scales began the process of de-emphasizing IQ as the primary determinant of the diagnosis of mental retardation and for the need of services. In the 1980s Centre faculty were at the forefront of educational inclusion and early intervention. In the 1990s, the faculty gained international prominence regarding dual diagnosis (intellectual disability and mental illness) and research on the use of psychotropic medications in this population.

In 1995, the Nisonger Centre established community-based, interdisciplinary developmental clinics in four Appalachian counties, funded by the Ohio Department of Health (ODH). The interdisciplinary team involved a developmental pediatrician, physical therapist, occupational therapist, psychologist, speech therapist and a clinic coordinator. A public health nurse from the local health department conducts a home visit prior to the evaluation, serves on the interdisciplinary team, and coordinates implementation of the team recommendation. County health departments provide the space for the clinics. Clinic activities are coordinated with existing local networks of programs including early intervention collaborative groups, county health departments, school departments, Head Start, county boards, and physicians. Local community service organisations, such as the Grange and 4-H, have provided support for the clinics.

Training and Service Provision Model (Pickaway Interagency Council, Ohio)

In 1999 Nisonger Centre and the Pickaway County Interagency Council developed a local program to meet the needs of children with developmental disabilities and behavioural concerns. Through a collaborative effort, a training and service provision model was established to provide a more efficient and coordinated system of care for these children and their families that maximized utilization of current resources.

Each local agency uses their current identification and intervention procedures. When there is a child for which these measures are not effective, a referral to the local interagency committee is made to decide on evaluation or intervention options. This Interagency Council partners with a team from the Nisonger Centre which travels to Pickaway County to conduct clinics, providing consultation, technical assistance, continuing education and capacity building for local care providers and families.

Inter-institutional collaboration and coordinated treatment for crisis intervention services (University of Louisville (U of L), Department of Psychiatry & Seven Counties Services)

The development of our regional crisis intervention system was completed during this period. This program, a joint project of the Department of Psychiatry at U of L, Seven Counties Services (the regional community mental health centre), Central State Hospital, and the Department of Mental Health and Mental Retardation, provides an integrated service system, with an emphasis on increased diversion of patients into community-based treatment.

All acute admissions from the Seven Counties referral area now occur at University of Louisville Hospital rather than Central State Hospital. The focus for the admissions to Central State Hospital is for patients who need intermediate length care, and for those appropriate for admission to specialized programs and forensic psychiatry.

The core of the regional crisis program is the Emergency Psychiatric Service at the University of Louisville, jointly staffed by faculty from the Department of Psychiatry and staff from Seven Counties Services and University of Louisville Hospital. In addition, a new psychiatric unit opened at the University of Louisville Hospital, bringing the total bed capacity at ULH to 40 beds. This new units complements the holding beds capacity in the Emergency Psychiatric Service at ULH, the intensive outpatient program in the Ambulatory Care Building, jointly operated by Seven Counties Services and the Department of Psychiatry, and an array of integrated services throughout the community. This program provides a unique model of inter-institutional collaboration and coordinated treatment for crisis intervention services.

Life span perspective

Another collaborative approach, however this model adopts a lifespan perspective across the developmental stages eg birth through the older age. This model provides either services or the co-ordination of services throughout life and particularly at critical transitions. This approach reflects awareness of the lack of quality throughout a person's life and also mental health and physical health vulnerabilities that can be associated with progression through the developmental stages. A holistic approach is adopted to maintain the whole picture and avoid

artificial barriers or fragmentation in service delivery eg between leaving adolescent services and moving to adult services.

For example: Mental Health and Developmental Disabilities Centre,
UCLA California

To be eligible for services funded by the California Department of Developmental Services, individuals must have a developmental disability as defined in Section 4512 of the California Welfare and Institutions Code. Section 4512 defines developmental disability as: "a disability which originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature."

The MHDDC's mission is to enhance the quality of mental health services for Californians with mental retardation, autism, cerebral palsy, epilepsy, and related developmental disabilities. Our team is dedicated to assisting professionals and direct care service providers in *both* the developmental disability and mental health service systems to better understand the mental health needs of children and adults with developmental disabilities. We are also committed to assisting consumers, parents, and other family members in their quest for timely, appropriate mental health services.

For example: Southeast Louisiana Hospital (USA)

Southeast Louisiana Hospital is a 483 bed licensed psychiatric hospital providing acute/ intermediate care to adults (residing in Regions 1, 3, 9 and JPHSA) as well as adolescents and children state-wide. The hospital offers a range of integrated programmes. Within services described below, is a specific service/inpatient unit programme for adults with a dual diagnosis and complex needs.

- *Adult Services* admits both males and females, 18 years of age and older, and is divided into acute (closed) and open wards. Acute wards provide surroundings of physical protection with close supervision of disturbed patients. Open wards provide a certain amount of freedom through a system of increasing privileges, while still providing a therapeutic environment.

- *Adolescent Services* is divided into two separate sixteen bed units, one male and one female. This program is for the evaluation and treatment of acutely emotionally disturbed and/or psychotic adolescents (14 - 18 years of age). After a seven-day evaluation, patients can move through four distinct treatment levels, each having a hierarchy of privileges, responsibilities and therapy programs. Family involvement in treatment and discharge planning is an important focus of this program. is divided into two separate sixteen bed units, one male and one female. This program is for the evaluation and treatment of acutely emotionally disturbed and/or psychotic adolescents (14 - 18 years of age). After a seven-day evaluation, patients can move through four

distinct treatment levels, each having a hierarchy of privileges, responsibilities and therapy programs. Family involvement in treatment and discharge planning is an important focus of this program.

- *Children's Services* provides treatment of severely emotionally disturbed children, ages 5 - 13. The service is physically separate within the hospital, and includes one 20--bed dormitory and one 22-bed dormitory, an activity building, a cafeteria, and a school. A wide range of therapeutic modalities, especially behaviour modification and family intervention, are utilized in close concert with the school program. provides treatment of severely emotionally disturbed children, ages 5 - 13. The service is physically separate within the hospital, and includes one 20--bed dormitory and one 22-bed dormitory, an activity building, a cafeteria, and a school. A wide range of therapeutic modalities, especially behaviour modification and family intervention, are utilized in close concert with the school program.

- *Special School District #1* is a joint venture between the Department of Health and Hospitals and the Department of Education to provide on-site education for Grades K - 12. is a joint venture between the Department of Health and Hospitals and the Department of Education to provide on-site education for Grades K - 12.

- *New Hope* is a 20-bed, acute adolescent unit that provides intense treatment. Various therapies, including, milieu, coed psychotherapy group, family and social skills, and experiential groups are provided. Family intervention and therapy are key components of this program. is a 20-bed, acute adolescent unit which provides intense treatment. Various therapies, including, milieu, coed psychotherapy group, family and social skills, and experiential groups are provided. Family intervention and therapy are key components of this program.

- *The Developmental Neuropsychiatric Program (DNP)* is divided into a 16-bed acute unit and a 9-bed transitional unit. Adolescents with a dual diagnosis of mental illness and developmental disability are initially admitted into the acute unit and must "graduate" to the transitional unit. This program is composed of five distinct, but integrated, modules: Behavioural, Social Skills, Academic, Habilitation, and Family Training. Emphasis is placed on integrating learned behaviour and entry back into the community.

- *Challenges* is a partial hospital (day treatment) program with Children and Adolescent components. The program hours are approximately 8:00 a.m. - 3:30 p.m., Monday through Friday, with multi-family group therapy and parent education programming provided one evening each week. Treatment modalities include milieu, coed psychotherapy, social skills groups, educational groups, substance abuse groups, individual and family therapy. Clients are enrolled in school provided by Special School District #1 is a partial hospital (day treatment) program with Children and Adolescent components. The program hours are approximately 8:00 a.m. - 3:30 p.m., Monday through Friday, with multi-family group therapy and parent education programming provided one evening each week. Treatment modalities include milieu, coed psychotherapy, social skills groups, educational groups, substance abuse groups,

individual and family therapy. Clients are enrolled in school provided by Special School District #1

- Southeast Louisiana Hospital also staffs and manages an **18-bed adult acute psychiatric unit located at the** *LSU Washington/St. Tammany Regional Medical Centre* in Bogalusa. This is a brief stay unit (14-day stay) designed for adults in acute emotional distress. It serves only Region 9 and is a tri-agency venture, i.e., Southeast Louisiana Hospital, Region 9 Community Health Services and Louisiana State University Medical Centre.

- *DNP Outpatient Services* is a collaboration between Southeast Louisiana Hospital and Region I Office of Mental Health. It is an assertive community treatment program, housed in New Orleans, that provides outpatient services to persons aged 2 to 22 who are dually diagnosed with a developmental disability and psychiatric disorder and who reside in Regions 1, 3, 9 or JPHSA. This program provides intensive community-based, specialized, comprehensive and empirically driven behavioural, stabilization, maintenance, rehabilitation and treatment to its clients and their families. is a collaboration between Southeast Louisiana Hospital and Region I Office of Mental Health. It is an assertive community treatment program, housed in New Orleans, that provides outpatient services to persons aged 2 to 22 who are dually diagnosed with a developmental disability and psychiatric disorder and who reside in Regions 1, 3, 9 or JPHSA. This program provides intensive community-based, specialized, comprehensive and empirically driven behavioural, stabilization, maintenance, rehabilitation and treatment to its clients and their families.

- *The Aftercare Support Program* provides a continuum of care into the community in which hospital treatment team members continue to deliver psychosocial rehabilitation to adult patients after discharge. Home visitation and follow-up are conducted on patients meeting the criteria for the program and occurs from the time of discharge for up to six months post hospitalization.

Neuropsychiatric model (University of Massachusetts Medical School)

There is no recognised medical specialty in the USA in regard to adult developmental disability. Medical practitioners interested in the area can have backgrounds in paediatrics, psychiatry, neurology or they may be physicians. There is no established model of training across the US although some states have established various training approaches to develop expertise in the medical profession.

For example: **Neuropsychiatric Disabilities Fellowship**

The neuropsychiatric disabilities fellowship provides a unique and exciting opportunity to develop a broad base of expertise in the area of dual diagnosis (mental retardation and mental illness). The fellow will work closely with a number of faculty who have extensive backgrounds in the assessment and treatment of individuals with mental illness and mental retardation. Many of the faculty members are national leaders in this specialized area. Settings include several nationally recognized programs such as the Shriver Centre, the Sovner Centre, and the UMass Memorial Health Care (UMMHC) Neuropsychiatric Disabilities Unit (NDU). Applicants

must have at least completed the requirements of a general psychiatry residency. The Neuropsychiatric Disabilities fellowship at the University of Massachusetts offers PGY-5 residents a one-year program of supervised clinical, research, and teaching experience.

Clinical experience will be gained in both inpatient and outpatient settings. The fellow will work part time on the Neuropsychiatric Disabilities Unit, a 10-bed locked inpatient unit specialized in serving individuals with acute psychiatric and behavioural disorders and mental retardation. The unit is one of only a handful of specialty units in the United States applying an intensive multidisciplinary-care model to the assessment and treatment of individuals with mental illness and mental retardation. The fellow will work closely with other multidisciplinary team members on the Neuropsychiatric Disabilities Unit, including Van Silka, MD, and Laurie Charlot, PhD. As part of the experience on this service, the fellow will care for patients as a primary clinician. Duties will include initial psychiatric evaluations, seeing the patient on a daily basis, writing orders and progress notes, and participating in admission and discharge planning. In addition, the fellow will attend multidisciplinary team meetings and be involved in developing comprehensive treatment plans, including close collaboration with other team members to integrate the use of a multimodal treatment approach.

The fellow will also have the opportunity to work with Susan Abend, MD, FACP, an internist and endocrinologist on the team who has had extensive experience managing the medical needs of patients with mental retardation, to learn about the impact of comorbid medical problems that frequently impact on the psychiatric presentation in this population. The fellow will also have the opportunity to learn about service systems and administrative concerns through attending related administrative meetings between members of the NDU administration and Massachusetts Department of Mental Retardation staff.

Outpatient experience will be provided in a variety of settings. The fellow will also have the opportunity to work in the Shriver Centre affiliated specialty outpatient clinic, a developmental disabilities evaluation and referral centre directed by Kathleen Braden, MD. This exciting new centre will provide a wide array of services to children and adults with developmental disabilities. Other opportunities include working one afternoon per week in the UMMHC Neuropsychiatry Clinic with Sheldon Benjamin, MD. Dr. Benjamin is boarded in both psychiatry and neurology and served as a behavioural neurology fellow during his training. He has extensive background in the assessment and treatment of individuals with complex and severe behavioural and neurologic problems and he has written and lectured widely on this topic.

The fellow will also spend one day per month attending treatment team meetings with the Sovner Centre clinicians including Sherman Fox, MD, Ludwik Szymanski, MD, and other experts in the field of dual diagnosis. The Sovner Centre is a nationally recognized model program providing community care to individuals with dual diagnosis. Research projects will be ongoing within both inpatient and outpatient services. The fellow will also have the opportunity to participate in a DBT group for individuals with developmental disabilities at the UMMHC outpatient psychiatric clinic.

Canada

At Queen's University and in south eastern Ontario, academics and clinicians are attempting to develop a model of community-based care and training that targets those mental health professionals who have a special interest in this subpopulation. The model of service provision assumes that a mental health team comprising a psychiatrist, a psychiatric social worker, a clinical psychologist, an occupational therapist, and a part-time speech language pathologist is available for every 100 000–150 000 persons.

The mental health team oversees care in three "generic" services (for example, an emergency department, a mental health clinic, and an acute management program, a specialized assertive community treatment team, and an extended treatment unit). Traditional community behaviour-management programs are already in place across Ontario. The other specialized programs are innovative and based upon the experience in the Netherlands (van Minnen etal, 1997) and the UK (.Xenitidis etal,1999).

Attracting and training mental health professionals in the field of intellectual disability and also dual diagnosis is a continuing challenge for Canada. Once the complete model system established in the Kingston, Ontario, area, it is proposed that the existing training programme that at present only includes psychiatrists, is extended to include other mental health team professionals. The view is that it is desirable to train all professionals together so that they may learn not only about dual diagnosis but also how to function effectively in a team. Evaluation of the model services will generate data that can be applied across Ontario and beyond.

Community Services Centre, Calgary, Canada

From 1979 the Community Inclusion Support Team has provided inclusive, community based outreach services to people with disabilities in the Calgary region. The Team has been part of the Community Rehabilitation (CORE) Program at the U of C for the past twenty years. As part of its role within the university infrastructure, there has been a focus on finding innovative ways to bridge practice and knowledge. The Team has a commitment to the education of practitioners in human service fields and provides students from the University of Calgary with both classroom and applied learning experiences. Students come from a variety of other academic institutions both locally and internationally. A commitment to research and the creation and dissemination of knowledge is also part of the Team¹s mandate. Other ways of influencing practice include providing professional development opportunities to front line practitioners and consultation service to agencies and human service/educational systems.

Over time, the Community Rehabilitation Studies Program has revised and expanded its mission and mandate in ways that reflect emerging practice and educational trends. These changes include increasing its multi-disciplinary and cross disciplinary vision, becoming more inclusive about its focus on disability through expanding its boundaries beyond educating practitioners for the field of cognitive disability, and becoming less "regional" by expanding into the use of distance learning technology to deliver educational opportunities. The Team strives to continue to reflect the mandate and mission of CORE by exploring ways to adjust its focus and mandate accordingly.

The Team avoids duplicating services that are already available in the community and endeavours to serve primarily those clients who are having difficulty accessing needed resources because of the nature or complexity of their needs. Since the team began operations in the late Œ70s (as the Behavior Support Team) it has maintained the practice of serving as an "agency of last resort" which would see clients who, in spite of obvious and serious support needs, had been refused service elsewhere. Typically, these people have presented a combination of mental health problems and cognitive deficits, including both mental retardation and "borderline" intellectual functioning. We serve people with mental health problems stemming from organic etiologies, with severe developmental disabilities in the absence of cognitive disability, e.g., autism or Asperger¹s Syndrome, and unusual engagement or case management problems. In doing so we have spanned numerous systems boundaries and have garnered both a local and international reputation for excellence and innovation in providing community counselling and support services to clients with a wide range of disabilities, including those inherent in very serious and persistent mental disorder. Not only do we possess an unrivalled degree of experience in providing community outreach services, we also play a major role in advocating for a truly integrated system of school and community programs, and educating professionals to work across disability and service system boundaries.

As its mandate has shifted, expanded and changed over the years, the constellation of position descriptions on the Team has also been modified. There has been an increased "professionalisation" of the Team and a diversification of the backgrounds and disciplines of Team members. This trend is likely to continue for some time into the future, especially since funding mechanisms have evolved from government tendered block contract formats into a diffuse system of small local funding organisations which provide financial supports through limited term service contracts, discrete projects and individual client contracts. Service providers have had to expand their range of expertise and services and become more flexible, more creative and more collaborative to survive and thrive in the changing culture of public funding. The Team will continue to be a fluid and dynamic initiative and will "shape shift" with the times in order to provide responsive service to the client community and the university community as both move into the 21st century

New Zealand

Canterbury District Hospital Board, Mental Health Services operates a Psychiatric Service for Adults with an Intellectual Disability (PSAID) at the Princess Margaret Hospital, Christchurch.

This services under the umbrella of the Intellectual Disabled Persons′ Health Service that is also provided under Mental Health Management. PSAID provides a 15-bed inpatient, a day hospital programme, outpatient work and community housing.

For example: **Auckland Dual Disability Team: Psychiatric Disorder with an Intellectual Disability or Brain Injury**

The Dual Disability service is based in Auckland but operates at a *tertiary* level. The aim of the service is to provide specialist support and consultation to core Mental Health Services, thereby enhancing the principle of integration and reducing social stigma for clients. Access to the service takes place via the referral process (detailed below). This process is widely publicised and referral forms will be available for all possible referral sources.

This team holds five beds in a community service we are clinically responsible for. This is not a respite service but provides a medium to long stay. The team does hold a respite budget and may support people by providing extra staffing in their own home eg at times of crisis. It is possible to use mental health inpatient services facilities occasionally, but this approach is considered to be last resort.

The philosophy underpinning the service is community based. Clients are visited in their own home. A major aim of the services is to keep clients in their own environments or to access alternative community services if needs require a transfer.

The Auckland team argues that the needs of client with a dual diagnosis are specialised and often require specialised clinical input (Verhoeven, 2002, in personal communication). Behaviour is often interpreted as just that, and signs and symptoms of mental health problems are easily misinterpreted or overlooked. Also medically these people may be complex, eg epilepsy (and it's effects on use of psychotropic medication), diabetes, organic problems. In addition traditionally these people have been put on cocktails of medication, without clear rationalisation. Decreasing long term meds use is again a specialised task.

Breaking down of barriers - good communication skills, good clinical skills, not being pedantic about taking people on, helping others out, asking support when needed, networking, continual education of other providers, acting as a support person/being available when people have queries, but most of all, doing a thorough and professional job. The model of service delivery has not been reviewed or evaluated.

Dual Disability Interface Policy and Protocols

Service Philosophy

The philosophy of the service is to ensure that clients with significant Intellectual Disability or Head Injury and Psychiatric Disorder receive the specialist support and treatment that they require, to maximise their independence and participation in ordinary lifestyle events and to minimise the impact upon their quality of life. The non-government services.

This is achieved by:

- Utilising principles of normalisation
- Seeking least restrictive treatment options
- Advocating and role modelling non-aversive treatment styles
- Providing specialist expertise and support to clients, families and primary care givers
- Being readily accessible, responsive and mobile
- Working in partnership with generic mental health services

Service Criteria

The Dual Disability Team is a mobile regional team which provides further assessments, intervention and treatment service for clients in the Auckland/Northland Region, who meet the following criteria:

- Aged 19 years and over with some flexibility based upon emotional, physical and social maturity
- Who have been assessed as having moderate to severe intellectual disability or head injury, which has resulted in significant cognitive deficit
- Who have a co-exisiting psychiatric disorder

Consultation, advice and training services will be provided throughout the Northern region for clients, families, primary care givers, community agencies, general practitioners, secondary and tertiary health care providers.

Exclusion Criteria

- Assessed as having IQ over 70
- Not eligible for service from a CMHC
- Not having a DSM IV Axis 1 or 2 diagnosis

Referral Policy

Purpose

The purpose of the referral policy is to ensure that all referral sources are able to access services in a timely and effective manner.

Process

- Appropriate referrals will be accepted directly from secondary and tertiary health care providers in the Northern Region for the purposes of assessment and treatment of clients
- Primary health care providers, community agencies and the general public will access services via their local point of contact to mental health services, or their GP if they are not currently under a Community Mental Health Centre.
- All referrals will be responded to within set timeframes ie. Within 24hrs or the next working day for urgent referrals, within 5 days for non-urgent referrals.
- Crisis calls will be responded to by the local crisis response team. The specialist Dual Disability Team can be requested to assist on crisis calls during working hours.
- Requests for consultation, advice or training services will be accepted from community and health care providers in the Northern region. The first point of contact for external agencies may be direct to the team.

Process for accessing advice consultation and liaison services

Telephone contact numbers will be made widely available to primary health care and community providers. Clinicians involved in a client's treatment may access the team directly

for telephone advice or consultation. In the event that assessment or treatment services are subsequently required the following process will be used:

- A written referral is completed by the referral source.
- In the case or urgent telephone referrals, written information must be supplied as soon as possible (prior to the assessment occurring), to ensure that all critical information has been passed on.
- Upon receipt of the referral, the team will respond within the specified timeframes, within 24hrs for urgent referrals and within five days for non-urgent.

Interface Protocols

The Dual Disability Team is able to offer specialist assessment, screening, consultation, advice and support to generic Mental Health Services. This will be best achieved by utilising a partnership model as described below. Upon receipt of a referral from an accepted source, a member of the team will respond within the specified time frame. The Dual Disability team member/s will contact the referrer. Agreement will be reached about how to progress, including:

- Clarifying the requirements of the client
- Clarifying the expectations of the referrer
- The role of the referrer in the clients treatment eg. Case management
- The role of the Dual Disability Team in the clients treatment eg. Specific key work or treatment planning advice.
- Regularity of contact between the referrer and the Dual Disability Team
- Regularity of contact with the client
- Setting a date for evaluation of progress.
- Planning for service handover to appropriate follow up agencies, or back to the referral service.

Service Delivery

The Dual Disability Team is a tertiary specialist service, with clients primarily cared for by their respective District Health Board mental health services. Clients may also be supported by intellectual disability services, head injury services or other non-governmental organisations in residential facilities or the community. Responsibility for management of intellectual disability or head injury and accommodation remains with community agencies. The Team will generally see people within their home environment. Clients may choose to voluntarily disengage from the Service at any time.

The Dual Disability Team provides the following services:

- *Assessment of mental illness, intellectual disability and cognitive function.*
- *Clarification and development of treatment/management plans.*
- *Consultation on medication and medical treatment regimes.*
- *Psychological consultation and assistance with the management of behavioural disturbances.*
- *Development and monitoring of behavioural programmes to be implemented by caregivers in the place of residence of the client*
- *Limited provision for specific interventions, to support the initial implementation of behavioural programmes in the place of residence of the client.*
- *Liaison, consultation and case conferences with the primary care team.*
- *Support for the maintenance of recovery through psychiatric case reviews*
- *Primary care/case management for the five clients with Pathways Trust, under the Dual Disability Residential Rehabilitation contract.*

The Dual Disability Team will have a mobile specialist multi-disciplinary team consisting of a Psychiatrist, one and one-half Psychologists (one being located in the Auckland region and the half being located in the Northland region) a Social Worker and a Registered Nurse.

Service Handover Protocol

To ensure that all clients who are referred to this service are appropriately discharged from the service the following protocol will be followed:

- Prior to the completion of specialist dual disability input, the initial referral source is alerted to the expected date of discharge from service.
- A handover meeting is arranged including the client and all involved people and/or services.
- The ongoing roles of all involved care providers are clearly detailed and agreed to.
- Consideration is made of any risk or safety management issues for the client.
- Contingency plans are developed, including service re-entry instructions.

Interagency Collaboration Projects

Other examples of interagency collaboration projects can be identified within New Zealand although not specifically for adults with a dual diagnosis.

For example: **The Child and Adolescent Liaison Team Inter-Sector Initiative (Auckland Healthcare Services, New Zealand)**

The Child and Adolescent Liaison Team (CALS) was set up in January 1998. It was established to encourage co-operation, collaboration and co-ordination between Mental Health and the Child Youth and Family Agency (CY&FA). The CY&FA population has a lot of the risk factors for mental health problems.

The CALS team provides consultation, assessment and training to CY&FS staff. This encourages early identification of mental health problems and referral on to appropriate services. We are contracted, funded and employed by Auckland Healthcare Services. We are one of several teams of the Community Child, Adolescent, and Family service (CCAFS). CY&FA provide some of our resources.

The service is sub-regional covering the greater Auckland area from Wellsford to Mercer. There are three Mental Health Child and Adolescent Services in Auckland, and 10 CY&FA offices in Auckland. Only CY&FA staff can make referrals. The child/young person must be allocated to a CY&FA Social Worker and the case remain open during our involvement. The CY&FA Social Workers remains the case manager to whom we consult with during our involvement.

Crisis situations, particularly immediate risk of self-harm are referred directly by the Social Worker to the local Child and Adolescent Mental Health Services. Cultural advice is sought where appropriate. In Auckland CY&FA have Maori, Pacific Island and Pakeha teams. The

Child and Adolescent Liaison Service provides Liaison and consultation to help Social Workers identify and manage mental health problems in children and adolescents.

Social workers can request consultation with members of the team to discuss any concerns. Assessment (including face to face assessments and screening) is carried out with the child/young person and their families at the CY&FA office or other agreed location. Education and Training is provided on topics relevant to child and adolescent mental health. Topics include, diagnoses, child development, risk management, assessment and treatment. We are able to provide education and training on topics relevant other mental health topics