

Victorian Dual Disability Service

Psychiatric Inpatient Care for People with a Dual Disability in Victoria: Prevalence, Nature and Impact of Multiple Mental Disorders

Report prepared by Dr. Chad Bennett, Andrew Pridding and Felicity Lawrence

Table of Contents

| | |
|---|----|
| Executive summary | 3 |
| Context | 10 |
| Results | 18 |
| Prevalence..... | 19 |
| Table 1: Duration in Mental Health Care in months..... | 19 |
| Nature..... | 20 |
| Table 2: AMHS Diagnosis..... | 20 |
| Table 3: Mini PAS-ADD Results | 21 |
| Table 4: Level of ID..... | 21 |
| Impact | 21 |
| Comparison of Patients on Acute units with those in SEC and CCU..... | 28 |
| Service Provision Survey | 31 |
| Discussion | 36 |
| 1. Prevalence | 36 |
| 2. The nature of the mental disorders..... | 36 |
| 3. Impact..... | 41 |
| a. Legal status..... | 42 |
| Conclusion | 47 |
| Prevalence..... | 47 |
| Nature. | 47 |
| Impact | 47 |
| Recommendations | 49 |
| References | 52 |
| Appendices..... | 55 |
| Appendix I AMHS De-identified Case List..... | 55 |
| Appendix II Inpatient Manager and Staff Survey..... | 56 |
| Appendix III - Demographic and Service Provision Survey..... | 59 |
| Appendix IV Mini PAS-ADD..... | 62 |
| Appendix V Response Difficulty Survey..... | 63 |
| Appendix VI - Health of the Nation Outcome Survey – Learning Disabled | 64 |
| Appendix VII - Health of the Nation Outcome Survey | 65 |
| Appendix VIII - Life Skills Profile LSP-16 | 66 |

Executive summary

People with intellectual disability (ID) are at higher risk of mental health problems and for a variety of reasons may have difficulty in accessing appropriate services. There is an increasing body of evidence that suggests that this group do not fit into a generic model of service delivery and that this results in poor outcomes for the client and frustration in the system. A previous project identified that this might be particularly evident in the long stay population in Mental Health Services (MHS) with 20% of one unit's patients having an ID. In recognition of these problems the Mental Health Branch funded the Victorian Dual Disability Service (VDDS) to undertake this current project.

This project aimed to identify the number of people with an intellectual disability (ID) in the rehabilitation component of mental health services, their diagnosis and psychopathology and the subsequent effects that this has had on the patient and the service system. On the basis of these findings recommendations are made in relation to service delivery for this group.

The following methodology was employed:

1. The target population was identified as those patients in Secure Extended Care (SEC), Continuing Care Units (CCU's) or who had been on an acute in-patient unit (IPU's) for longer than 2 months at the time of the study and had previously had a diagnosis of ID based on DSM-IV criteria or was registered with Disability Services (DS).
2. Relevant unit managers in the 21 AMHS were asked to identify the target population in their care and to nominate a member of staff who knew the person well enough to provide accurate information concerning their current status. This person was then interviewed with validated instruments using a semi-structured interview format designed to elicit psychopathology (Mini-PAS- ADD), severity of mental health problems (HoNOS & HoNOS-LD) and level of disability (LSP-16). They were then asked to complete a questionnaire that collected demographic and service provision information that included reviewing factors that complicate service delivery in relation to the nominated patient. The unit managers and the staff member they had nominated were then asked to complete a survey that explored their perceptions and attitudes in relation to managing a person with an intellectual disability in a generic ward setting.

The main findings of the project are as follows:

1. 35 patients were identified who had an ID with a mean age of 41 and who on average had spent 17 years in mental health care. Of these 11 were in SEC, 17 in CCU's and 7 in IPU's. This gave a prevalence rate of 7% in rehabilitation mental health beds. This is higher than the general population rates of ID and is probably a result of the higher rates of mental illness and functional deficits in this group.
2. Most patients had a mild or unspecified level of ID.
3. According to clinical diagnoses, Schizophrenia was the commonest clinical diagnosis in 30 cases (85.7%) and 2 (5.7%) had a diagnosis of Autism. In contrast, the Mini-PAS- ADD indicated that 17 (48.6%) had psychopathology consistent with active psychosis and 13 (37.1%) had evidence for an Autistic spectrum disorder. This suggests that there may be a number of patients with an undiagnosed Autistic spectrum disorder.
4. There were 7 patients with an ID who had been on an acute IPU for an average of 6 months. This represents a small proportion of the total number of beds in Victoria with a prevalence rate of 1.6%. However, if the average duration of an admission to an IPU is 12 days, then these 7 patients are the equivalent of 102 standard admissions. Interestingly, the HoNOS, HoNOS-LD and LSP scores of this group were significantly higher than those of the patients in SEC and CCU. This suggests that this group has high levels of psychopathology, high needs and are relatively more disturbed in their behaviour and it is this combination of factors that is preventing their discharge.
5. There were 8 patients who had did not score above the Mini-PAS-ADD thresholds. This suggests that factors other than psychopathology are preventing their discharge. Examination of their HoNOS scores for this group indicated that they have significant cognitive problems; difficulty in caring for themselves in conjunction with antisocial behaviours and difficulties in interpersonal relationships and it may be these factors that prevent their discharge. These difficulties probably arise from the combined effects of mental illness and ID.
6. The LSP informed that the population has an average total LSP score of 23.8, with 8 people rated with a total score above 30. This is relatively high compared to other mental health samples and indicates significant impairment in functioning and the need for high levels of support. The average of the total HoNOS scores was 18.9 with the lowest being 3 and the highest being 36 (the highest possible score is 48).

This falls into the top 15% of HoNOS scores across various mental health settings and is similar to scores of patients being admitted to acute inpatient units.

7. The major difficulties in caring for these patients are as follows:
 - a. 28 patients (80%) were reported to display some form of problem behaviour, with 20 (71.4%) of these, exhibiting more than two problem behaviours.
 - b. According to the HoNOS and HoNOS-LD, about 80% had problems with aggression, and in 25% of the group, this was at a moderately severe or very severe level.
 - c. 62.9% of patients were considered violent.
 - d. 70.1% make repeated demands that could not be met,
 - e. 82.9% reported as exhibiting sudden changes in mood and behaviour.
 - f. 51.4% had frequent crises.
8. In contrast the following were not identified as problems:
 - a. The majority do not having problems related to self-injury (82.9%), property damage (68.6%) or personal behaviour (82.9%).
 - b. 2.9% had a drug or alcohol problem.
 - c. 2.9% were considered a suicide risk.
9. The results also demonstrated that only 34.3% were not cooperative, with 80% of the sample rated as being compliant with treatment.
10. Most of the patients do not access other services with only 37.1% having a Disability Service case manager, and few receiving active input from Behaviour Intervention Support Teams (BIST) or Specialist Services from Disability Client Services.
11. 71% of the sample had not been seen by the VDDS.
12. Health does not appear to be a major issue with 74.3% being rated as having good to moderate health
13. Although 50% attend a recreational service, this does not occupy much time as the patients spend 12 out of a possible 14 hours on the unit, and the vast majority (62.8%) had not left the unit unescorted at any time in the last three months.
14. Problems with occupations and activities were identified as significant and is likely to reflect the fact that this group is often unable to participate in unit activities that are often not tailored to cater for their conceptual and communication deficits. A lack of meaningful activity, sparse environment and limited engagement with the

environment or others can result in increased aggression or other challenging behaviours.

15. Considerable problems are reported in all areas of self-care and most patients would have difficulty in contributing to domestic chores and in accessing the community independently. This could be consistent with issues related to either mental illness or intellectual disability and is likely to be a combination. The implication is that these patients require significant support to simply survive on a day-to-day basis.
16. The staff survey indicate that 90% of nursing staff agreed with the statements that patients with an ID needed increased input to manage a variety of issues.
17. 78.5% thought that the in patient unit was detrimental.
18. 75% of staff indicating that interventions that they would normally use were ineffective in this group.
19. 70% did not think the inpatient unit was adequate for most people with an intellectual disability.
20. 82% thought that these patients required a specialised unit.
21. Given the difficulties illustrated above, it is perhaps not surprising that 61% agreed with the statement that most nursing staff do not want to work with this group of patients

The following recommendations are made:

1. An assessment unit for patients with intellectual disability admitted to acute inpatient units for longer than 2 months, or who have complex needs, or any individual with an ID being considered for placement at a CCU or SEC. This may be of value in relieving pressure on the system.
 - a. The service should offer an integrated service model incorporating Mental Health and Disability services and allowing cross system access. A specialised service can provide special expertise and experience in assessment and diagnosis of psychiatric disorder in people with ID in the face of atypical presentation and communication difficulties. It would also provide a secure environment for a people with ID who are vulnerable in general treatment settings. Therapeutic interventions can be designed and modified to account for particular cognitive, communication and social difficulties based. Underlying dependency levels can also be addressed. An additional benefit would be obtained by creating an environment where staff expertise in the assessment, care and management of this group can be developed. Strong links with community services would be required to promote normality with an aim to return the individual to community living with a comprehensive package of care.
 - b. A review of the international literature indicates that specialist services for dual disability seem to give better outcomes than general services. Evidence from a UK study in South London (Xenitidis et al 2004) identifies that there are increased costs associated with inpatient interventions for people with ID in general units. People with ID admitted to a specialist unit were compared with those admitted to general psychiatric units. The intensive and comprehensive assessment, treatment and rehabilitation required by people with dual disability are seen as unfeasible within general psychiatric services. It is reported that improved outcomes can be obtained when people with ID are admitted to a specialist unit for psychiatric care and management.
2. It can be anticipated that some of those admitted will require ongoing care and management in a secure setting. It is likely that a small-scale assessment unit would quickly become blocked unless there is facility for throughput. The project results illustrates that there are reasonably high number of people with an ID in the mental health system with a high level of both psychopathology and functional /social needs

that do not respond to existing service interventions. International opinion highlights the need for long term facilities for individuals with ID who have clear health needs but are unsuited to mainstream health services and whose health care needs cannot be met in standard disability accommodation settings (Vaughan 2003). The development of long stay capacity in community based long-term accommodation that can manage significant levels of disability associated with challenging behaviours may be needed. These should have the capacity to address problems using a combination of medical, psychological and behavioural frameworks and to provide on site recreational and vocational activities. A coordinated service structure that includes Mental Health and Disability Service input would provide a comprehensive array of services that are based on need and have an appropriate therapeutic and rehabilitation focus.

3. It would be important for staff managing these patients to be aware of available options and to make informed decisions about utilising the expertise available in the current service system. Education is required for staff from AMHS, Disability Services and other organisations providing direct care to people with ID, regarding recognition, assessment, treatment and management of psychiatric disorder in people with ID and the roles of other services within the system.
4. When a patient is registered with Disability Services, there should be a greater emphasis on communication and collaborative working between services. Collaboration regarding provision of appropriate occupational and social activities is particularly relevant. THE VDDS could play a role in facilitating these relationships
5. The possibility of Autism should be considered in all patients who have an intellectual disability and mental health issues in the long stay component of mental health services. In relation to this group, an appropriate strategy would be for the VDDS to specifically target this component of the mental health service for an education and training package specifically relating to autism. The aim would be for staff to identify cases in their care that warrant further assessment and to introduce appropriate screening procedures at the point of referral for rehabilitation. Further recommendations would depend on the actual number of cases confirmed to have an autistic spectrum disorder.

6. Consideration could be given to a system for routine collection of data about patients with an ID should be established so that the department has ready access to this type of information.

7. It is recommended that the information in this report be distributed to AMHS area managers clinical directors and other stakeholders for their information.

Context

People with intellectual disabilities (ID) have a greater vulnerability to psychiatric disorders than the general population. They are exposed to increased biological risk factors, such as genetic abnormalities or organic brain damage, as well as increased psychological and social risk factors that predispose them to psychiatric disorder.

Estimates of the prevalence of dual disability (DD) vary considerably between studies, with rates of 60% reported in some institutional samples and there is a high use of psychiatric services reported among former residents of institutions (Burge et al 2002). A general consensus is found in the literature that prevalence rates for mental health problems in people with ID are between 25-35% (Deb et al 2001, Jacobson 1999, Moss et al 1997). Low IQ is reported as a significant factor in the onset and course of serious mental illness (Hassiotis et al 1999) and the presence of psychiatric disorders in people with ID is described as one of the main reasons for either loss of community placement or retention in institutional settings (Bouras et al 1995).

People with ID have high rates of initial institutionalization and re-institutionalization, and problems that were tolerated in institutions are often unacceptable and more difficult to treat in community settings (Davidson et al 1995 & 1996). Furthermore the stressors of community living may cause or exacerbate mental health problems. This increasingly brings them into contact with general psychiatric services who have limited resources, skills and experience in the assessment and management of psychopathology in this population. The mental health needs of this population are highly complex; they are a highly disturbed group, with long lasting problems that require greater resources for a longer period (Moss 1999, Nottestad & Linaker 1999).

There is little research on the number and characteristics of patients with DD in inpatient psychiatric settings, or on how they impact on these services. Information on the impact of treatment regimes on psychopathology in this group is also sparse. Often people with dual diagnosis of ID and severe mental disorders are excluded from studies, or the presence of an ID is not reported. This is further complicated by difficulty in establishing consensus on assessment and identification of ID, as well as difficulty defining what constitutes DD. Therefore much of the available data on people with dual disability is opinion based or relates to small community based samples and specialist intellectual disability services, this data cannot be confidently generalised.

The great variety between the recommended service models for this population make comparisons and conclusions difficult and significantly hinders service planning and policy formation.

In a review of the literature on general psychiatric services for adults with ID and mental illness, Chaplin (2004) highlights the lack of research and the poor quality of existing studies, creating difficulties in establishing what is the most suitable service for this population. A comprehensive review of service provision and expert opinion regarding adults with intellectual disability in Europe by Holt et al (2000) reports that there is no systematic information on prevalence, policy planning or service delivery for people with DD. They conclude that there is a lack of clarity as to how the mental health needs of people with intellectual disability should be met. There is considerable debate as to whether provision can be satisfactorily met within generic mental health services, with the body of international expert opinion arguing that people with ID are both disadvantaged and vulnerable in generic treatment settings (Bouras & Holt 2001, Day 2001, Moss et al 2000, Nottestad & Linaker 1999, Raitasuo 1999, Sovner 1995).

Background

Services for people with ID in Victoria have changed considerably with the move away from institutional based care driven by community and social care policies, and the philosophy of normalisation, integration and inclusion. For people with a DD of intellectual disability and mental illness, this has meant integration into mainstream psychiatric services. However, evolution of the service system post de-institutionalisation has failed to create an infrastructure that adequately meets the mental health needs of Victorians with a DD. Cross system access and communication is limited and either Mental Health or Disability Services primarily serves the individual without necessarily being known to the other.

In response to some of the perceived gaps within the service system, the Mental Health Branch (MHB) of the Department of Human Services (DHS) put out to tender the development of a specialist services to act as an adjunct to the 21 mental health services operating across the State. The Victorian Dual Disability Service (VDDS) commenced in 1999 with the primary aim to improve the mental health of Victorians accessing public mental health who are who have a dual disability. The service achieves this by assisting staff working with Area Mental Health Services (AMHS) to develop skills in the assessment

and management of this patient group and by doing so to increase the capacity and improve the performance of the AMHS's. The VDDS also delivers tailored training and education programs. Systemic developments are pursued via tertiary consultations, research and academic liaison.

The VDDS completed a project in 2002 exploring the prevalence, nature and impact of multiple mental disorders (intellectual disability and other mental disorders) of the patient population residing at one of the State funded Secure Extended Care Units (SEC). The findings highlighted that 20% of the patient population had an ID as well as (an) other mental disorders. The trends identified suggested that the model of residential care currently employed is sufficient to meet many of the identified patients day-to-day needs, however the brief of the services and capacity to tailor intervention and management programs raises legal, systemic and clinical issues. It is not currently clear if these findings are consistent across residential care sectors within the MH continuum of care.

Purpose

There is little information currently available about the numbers and characteristics of individuals with intellectual disability who are inpatients in Mental Health Units in Victoria. The current study aims to determine the point prevalence of DD, the nature of the mental disorders and the impact of DD on the residential care component of the Public Mental Health service system within the state. The information will be used to inform recommendations regarding policy and service development for this population.

Setting

The project was undertaken in the 21 Area Mental Health Services (AMHS) within Victoria. The target population were inpatients with an intellectual disability in the rehabilitation component of mental health services. The settings included were the residential components of the mental health system comprising of Secure Extended Care units (SEC), Community Care Units (CCU) and Acute Inpatient Units (IPU).

Secure Extended Care (SEC) units provide specialised services for consumers of MHS who cannot be managed in the broader community and who require care and treatment for prolonged periods in a supervised/secure in-patient facility. Typically, these are people who suffer severe forms of mental illness marked by unremitting psychotic symptomatology

and/or serious behavioural disturbance, and who present a danger to themselves or others, or are socially unacceptable by current community standards. The main aims of SEC facilities are to provide treatment and care in a secure environment, to provide psychosocial rehabilitation and to help modify disruptive behaviours while maximising social and personal functioning.

Community Care Units (CCU's) provide medium to long term accommodation, clinical care and rehabilitation for people with a serious mental illness and psychosocial disability. Located in residential areas, they provide the residents with "home like" accommodation where they can learn or re-learn everyday living skills necessary for their successful living in the community.

Acute Psychiatric Inpatients Units (IPU's) were included as VDDS experience suggests some patients may be in acute wards awaiting rehabilitation placement. Patients who had been on the acute ward for two months or longer were included.

Method

The study population consisted of patients aged 16-65 who resided within the residential Public MHS in Victoria, and were registered with DS in accordance with the Intellectually Disabled Persons' Services Act (1986) (IDPSA), or, who had an established diagnosed ID using DSM-IV criteria at the time of the survey was administered.

The Area Manager from each AMHS was contacted and provided with an explanation of the project aims and methodology. They were asked to inform Unit Managers from each SEC, CCU and IPU in their area about the project. Each Unit Manager was then contacted and asked if there were currently any inpatients with ID on the unit. A meeting was arranged during which they were asked to compile a list of patients who meet the project criteria and to identify a corresponding member the treating team who had sufficient knowledge about the patient to complete the necessary assessment instruments.

The project manager of the VDDS obtained a de-identified version of this list (Appendix I). Each Unit manager was also asked to complete a survey instrument comprised of 3 questions about the number of people with intellectual disability admitted to their unit in the past 12 months and also a 23-item questionnaire designed to gather information about the issues in caring for people with an intellectual disability in the in patient setting (Appendix II). In

most cases the project worker from the VDDS administered the survey but an option was provided for managers to complete the survey and return it by post.

A meeting was arranged with the identified primary contact person or case manager for each patient included in the study. Basic clinical, demographic and service provision information about the patient was collected (Appendix III) and the project worker from the VDDS administered the five project assessment instruments (Appendix IV). The primary contact person was also asked to complete the 23-item survey about the issues of caring for people with ID in in-patient settings.

A pilot project was carried out in 4 AMHS in the North Western Metropolitan area of Melbourne to test the methodology. As a result of the pilot it was decided to omit the 'Other Episode' component of the Mini PAS-ADD, as in most cases it was difficult to establish a clear episode other than Present State.

Ethical Considerations

Information obtained in the course of the study was stored in a secure manner in accordance with the policies and procedures of St. Vincent's Health. The information was collected, stored and presented in a de-identified format. The project did not involve the VDDS having any direct contact with patients nor did it involve any direct interventions. Opinion was sought from both the chairperson of St Vincent's Hospital medical ethics committee and from the State Guardian in Victoria. Feedback from these parties indicated that individual patient consent would not be required. The staff surveys were collected in a manner that allowed identification of only whether the respondent was a Unit Manger or a Primary Contact but were otherwise anonymous. Survey information was stored and reported on in a manner that ensured anonymity.

Instruments

1. **Mini Psychiatric Assessment Scale – Assessment of Dual Disability Interview. (Mini PAS – ADD)** (Moss 2002) Designed to provide a structured framework within which informants and clinicians could collect standardised information about mental health problems in people with intellectual disability. This instrument is used to collect symptom information directly from an informant via a semi structured interview procedure based on the diagnostic rules of ICD-10. The focus is on Axis 1 psychiatric disorders. Personality disorder is not included. The schedule provides score relating to psychiatric disorders on 7 scales:
 - i. Psychosis
 - ii. Expansive mood
 - iii. Autism
 - iv. Depression
 - v. Unspecified disorder (including dementia)
 - vi. Anxiety disorder
 - vii. Obsessive compulsive disorder

Threshold scores are provided for each of these diagnostic areas. The psychometric properties of the Mini PAS-ADD were investigated in a robust study in which ratings were obtained from a sample of 68 people with intellectual disability who were in contact with psychiatric services. The information was compared with clinical assessment data and is reported as showing good internal consistency, inter-rater agreement and validity in relation to expert clinical opinion. The study included psychiatrists in learning disabilities and also other members of the community support teams in the UK (Moss et al 1998, Prosser et al 1998).

2. The **Life Skills Profile (LSP)** was designed to measure function and disability in people with chronic mental illness. 16 items are measured on a four-point scale, with a higher score indicating a greater degree of disability. There are four subscales:
 - A. Withdrawal
 - B. Self-care
 - C. Compliance
 - D. Antisocial

A total LSP score can range from 0 to 48. It is a well-known and widely used instrument with good reliability and validity. There are several versions and the LSP 16 item version was used in this project.

3. **The Health of the Nation Outcome Scales (HoNOS)** is an instrument with 12 items measuring the severity of behaviour, impairment, symptoms and social functioning. The scales were developed in the UK as a standard outcome assessment tool in mental health. (Wing 1994). Each item is rated on 5-point scales (0-no problem, 4-severe problem). A review by Trauer (1998) comments on several studies of outcome measures. The item reliability, test-retest reliability and inter-rater reliability of the HoNOS were found to be both satisfactory and adequate; reliability and validity are described as good.
4. **The Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD)** is designed for use with people with an intellectual disability with mental health needs, irrespective of the degree of their disability. An instrument with 18 items, measuring behaviour, impairment, symptoms and social functioning the HoNOS-LD has been tested for inter-rater reliability, convergent reliability, validity to change and acceptability (Roy et al 2002).
5. **Response Difficulty Checklist (RDC)** consisting of a series of 29 Yes/No questions relating to difficulties experienced in responding to the person's needs or behaviours and their level of engagement with services. This instrument was originally designed to give a rating of the difficulty providing a service to a client with a serious mental illness. (Department of Health and Community Services, Victoria 1993). It has been adapted for this project following local consultation. Reliability and validity data are not available for this instrument.
6. The **Demographic and Service Provision Survey** was designed by the VDDS to collect basic demographic information, and information on psychiatric diagnosis, treatment, physical health, level of activity and service provision. Additional information on service provision was also obtained via a survey of the opinions and experience of both Unit Managers and the primary contact for each person. This consisted of 23 statements rated on a seven point Likert Scale from Strongly Agree to Strongly Disagree. Unit Managers were also asked to answer three further questions on whether data about the number of people with intellectual disability admitted to each unit in the past year and whether information about this group was routinely collected.

Analysis.

1. The number of cases who meet the specified criteria for ID determines the point prevalence.
2. The nature of the multiple mental disorders is reported as the results of the Mini PAS - ADD together with information from the Demographic and Service Provision survey such as diagnosis and treatment.
3. The impact is reported as the analysis of the clinical survey HoNOS, HoNOS - LD, RDC and LSP-16.
4. The impact will also be reported in terms of the staff knowledge and attitudes obtained via the questionnaire. This relates to whether Mental Health staff view people with DD as different from non-intellectually disabled patients. Where differences are identified this will be reported as how this effects the service in terms of requiring additional resources.

The statistical Package for social sciences (SPSS-version 11.0.1) was used to analyse data.

Results

The project was generally well received and MHS staff offered a high level of cooperation. No problems were encountered in administering the HoNOS, HoNOS-LD, LSP-16 or RDC and a full set of data was collected for all the cases identified. Respondents in some of the units surveyed reported they had received training on using the HoNOS and LSP. It was observed that during the Mini PAS-ADD interview some of the MHS Staff being interviewed attempted to preempt the questions and needed to be redirected to only respond to the question asked. An example of this is where the respondent stated that there were no depressive symptoms after the first question relating to mood. When redirected to the interview, several symptoms of depression were elicited. This suggests that the staff interviewed are not experienced in providing objective informant based information in a structured format. It was noted that despite verbal reports of disturbed behaviour and also scores on the assessment instruments that indicate disturbed behaviour, there were few documented incident reports.

A large proportion of the staff interviewed voiced their opinion that dual disability was an area that needed to be addressed and that patients with ID caused them some problems with management. The need for behaviour assessment and management was a common theme. Changes in the characteristics of admissions to Mental Health Units were identified as causing concern as the patient profile is reported as generally younger and more disturbed with a high proportion of patients having substance abuse problems. People with ID are seen as increasingly vulnerable in this environment and this frequently resulted in them requiring extra supervision and staff attention. Several Unit Managers suggested that community teams were experiencing significant problems with clients who have dual disability and identified this as an area for further investigation.

63 staff surveys were completed out of a possible total of 70, consisting of 34 Unit Managers and 28 Case Managers for individual cases. This represented a response rate of 90% as some staff were case managers for more than one patient and only completed one survey.

Prevalence

Thirty-five individuals were identified as meeting the project criteria with a breakdown as follows:

| Type of Accommodation | Prevalence |
|-----------------------|------------|
| Secure Extended Care | 11 |
| Community Care Units | 17 |
| Acute Inpatient Units | 7 |
| Total | 35 |

Patients with ID were identified at 26 of the 44 units surveyed. The mean age was 41 years and the median 43 years, with a range between 19 and 64 and a standard deviation of 11.5 years. There was no significant difference between the number of males and females.

The total time spent in Mental Health Service care (Table 1) varied considerably from 2 months to over 40 years, with a mean of 17 years. Patients at SECs had spent the longest time in mental health care with a mean stay of 29 years, the mean for patients at CCUs and IPUs were 17 years and 6.5 years respectively. In contrast, current episode averages 3.1 years suggesting they move through different parts of the continuum of care. Three patients who were over 40 years of age were admitted to institutional care as children and admission dates were unknown

Table 1: Duration in Mental Health Care in months

| | SEC Patients | | CCU Patients | | IPU Patients | | Total (All patients) | |
|-------------|--------------------------------------|----------------------------------|--------------------------------------|----------------------------------|--------------------------------------|----------------------------------|--------------------------------------|----------------------------------|
| | Total time in Mental Health (Months) | Time in Current setting (Months) | Total time in Mental Health (Months) | Time in Current setting (Months) | Total time in Mental Health (Months) | Time in Current setting (Months) | Total time in Mental Health (Months) | Time in Current setting (Months) |
| Mean | 329 | 51 | 203 | 40 | 78 | 6 | 207 | 37 |
| Min | 204 | 15 | 14 | 3 | 2 | 2 | 2 | 2 |
| Max | 516 | 98 | 480 | 96 | 240 | 18 | 516 | 98 |

Nature

The psychiatric diagnosis based on criteria from DSM-IV was recorded from the case notes. Table 2 shows the breakdown by diagnosis.

Table 2: AMHS Diagnosis

| Diagnosis | Number | Percent |
|----------------------|---------------|----------------|
| Schizophrenia | 30 | 85.7% |
| Schizoaffective | 2 | 5.7% |
| Depression | 0 | 00 |
| BPAD | 2 | 5.7% |
| Personality disorder | 5 | 14.3% |
| Autism | 2 | 5.7% |
| Anxiety Disorders | 1 | 2.8% |
| Drug and alcohol | 1 | 2.8% |
| Unknown or none | 1 | 2.8% |

Two Axis I disorders were recorded in 6 cases and one patients had three Axis I diagnoses. One patient had no current psychiatric diagnosis except for ID. Schizophrenia was the most common diagnosis, with the majority of these classed as undifferentiated. 5 patients (14.3%) had an Axis II diagnosis of Personality Disorder, 3 Borderline, 1 Antisocial and 1 was unspecified. There were few diagnoses of ASD, anxiety disorders or substance abuse.

Of the 35 patients included in the study 27 (77%) met at least one threshold on the Mini-PASAD and 17 (48%) patients meeting more than one threshold with one patient rating above threshold across all 7 scales. Psychoses were rated as most commonly occurring disorder (48.8%). The threshold for Autistic Spectrum Disorder was met in 13 people (37.1%). There are 8 (22.8%) patients that do not score above any threshold on the mini-PASAD

Table 3: Mini PAS-ADD Results

| Scale | Number | Percentage |
|------------|--------|------------|
| Depression | 9 | 25.7% |
| Anxiety | 6 | 17.1% |
| Psychosis | 17 | 48.6% |
| Mania | 3 | 8.6% |
| Autism | 13 | 37.1% |
| OCD | 9 | 25.7% |
| Dementia | 3 | 8.6% |
| None | 8 | 22.8% |

The majority of individuals 24 (68.6%) had a mild ID (Table 4), 3 (8.6%) were reported as having a moderate ID and the remainder of cases were reported to have unspecified ID. In all cases, the cause of ID was reported as unknown and there were no congenital malformations or chromosomal abnormalities reported.

Table 4: Level of ID

| | Number | Percentage |
|-------------|--------|------------|
| Mild | 24 | 68.6% |
| Moderate | 3 | 8.6% |
| Severe | 0 | 0 |
| Profound | 0 | 0 |
| Unspecified | 8 | 22.8% |

Impact

Legal Status and family contact

17 patients (48.6%) were detained under the Mental Health Act, 24 (68.6%) had an administrator, and 3 had a health guardian and 2 a formal guardian. One of these had both a formal and health guardian. 9 had informal guardians; this was invariably a relative. All but 1 patient had regular contact with family.

Time spent on the ward

During the past three months, 22 patients (62.8%) had not left the unit unescorted at any time. The remaining 13 patients spent an average of 1.7 hours per day unescorted outside the unit. This group of patients spends an average of 12 out of 14 hours on the unit between 7am and 9pm each day.

Services

Case management provided by Disability Client Services was provided for 13 individuals (37.1%). 18 (51.4%) attended a recreational service. 5 (14.3%) received input from the Behaviour Intervention Support Service (BIST) from Disability Services. Only 3 received an outreach service. One received a forensic service. The VDDS had completed an assessment for 10 people (28.6% of the sample).

Incident reports

Incident reports proved not to be a useful source of data with the majority of patients having no incident reports over the past three months. Incidents, where they occurred, appear to be recorded as running records rather than individual reports.

General health and epilepsy.

12 patients (34.3%) were reported to be in good physical health, 40% in moderate health and 25.7% in poor health. 5 (14.3%) had a diagnosis of epilepsy, with 2 suffering both generalised and partial seizures. Epilepsy was not reported as a significant problem.

Life skills profile scores (LSP-16)

The life skills profile (table 5) indicates that this population has an average total LSP score of 23.8, with 8 people rated with a total score above 30. This is relatively high compared to other mental health samples and indicates significant impairment in functioning and the need for high levels of support.

Table 5: LSP scores

| | N | Minimum | Maximum | Mean | Std. Deviation |
|-------------------|----------|----------------|----------------|-------------|-----------------------|
| Withdrawal | 35 | 00 | 12.00 | 6.3429 | 3.23531 |
| Self Care | 35 | 3.00 | 15.00 | 9.0286 | 3.73761 |
| Compliance | 35 | 00 | 9.00 | 3.8000 | 2.39853 |
| Antisocial | 35 | 00 | 12.00 | 6.3429 | 6.98293 |
| Total | 35 | 7.00 | 40.00 | 23.8286 | 9.20194 |

Response Difficulty Checklist

The Response Difficulty Checklist (Table 6) shows that forming and maintaining relationships is a problem for 91.4%. Sudden changes in mood and behaviour and making demands that cannot be met also rated as significant problems. 68.8% were identified as receiving intensive input from Mental Health services but with limited gain. Over 50% were rated as having difficulty living with others. 60% had experienced significant change or loss. Factors that were not identified as problems include substance abuse and suicide risk; compliance was not seen as a problem, which is consistent with the results of the LSP scores in this area.

Table 6. Response Difficulty Checklist results

| Question | Number of Yes response (%) | Number of No responses (%) |
|--|----------------------------|----------------------------|
| Do the person's problems respond to interventions or treatment? | 12 (34.3%) | 23 (65.7%) |
| Does the person receive intensive input with limited gain? | 24 (68.8%) | 11 (31.4%) |
| Does the person have poor relationships with key workers? | 11 (31.4%) | 24 (68.6%) |
| Is the person unwilling to cooperate with most services? | 12 (34.3%) | 22 (62.9%) |
| Is the person unable to cooperate with most services? | 6 (17.1%) | 29 (82.9%) |
| Does the person disagree with service providers about the nature of their problems? | 17 (48.6%) | 14 (40%) |
| Does the person disagree with proposed solutions to problems? | 16 (45.7%) | 16 (45.7%) |
| Does the person make demands that cannot be met? | 24 (68.6%) | 11 (31.4%) |
| Does the person fail to comply with medical or psychological treatment? | 7 (20.0%) | 28 (80.0%) |
| Is the person prone to sudden changes in mood and behaviour? | 29 (82.9%) | 6 (17.1%) |
| Does the person have problems with illicit drug or alcohol use? | 1 (2.9%) | 34 (97.1%) |
| Is the person a persistent suicide risk? | 1 (2.9%) | 34 (97.1%) |
| Does the person either threaten violence or be violent? | 22 (62.9%) | 13 (37.1%) |
| Are there cultural barriers that limit a shared understanding with the person? | 2 (5.7%) | 33 (94.3%) |
| Are there communication barriers that limit a shared understanding of the person? | 18 (51.4%) | 17 (48.6%) |
| Are there communication barriers that limit successful interactions? | 19 (54.3%) | 16 (45.7%) |
| Does the person have any meaningful relationships? | 22 (62.9%) | 13 (37.1%) |
| Is the person geographically isolated? | 2 (5.7%) | 29 (82.9%) |
| Has the person suffered significant trauma or abuse? | 16 (45.7%) | 18 (51.4%) |
| Has the person suffered significant change or loss? | 21 (60.0%) | 14 (40.0%) |
| Does the person have difficulty in forming and maintaining relationships? | 32 (91.4%) | 3 (8.6%) |
| Does the person often refuse services? | 10 (28.6%) | 24 (68.6%) |
| Does the person have difficulty living with others? | 22 (62.9%) | 13 (37.1%) |
| Are the persons carers usually unwilling to cooperate? | 2 (5.7%) | 29 (82.9%) |
| Has the person been referred to other services but not be eligible to receive them? | 21 (60%) | 14 (40%) |
| Have any other services had a positive impact on the person? | 18 (51.4%) | 16 (45.7%) |
| When other services have been involved, it is easy to coordinate service delivery? Leave blank if NA | 17 (48.6%) | 14 (40.0%) |
| Does the person often have crises? | 18 (51.4%) | 17 (48.6%) |
| Does the person often need an after hours response? | 17 (48.6%) | 16 (45.7%) |

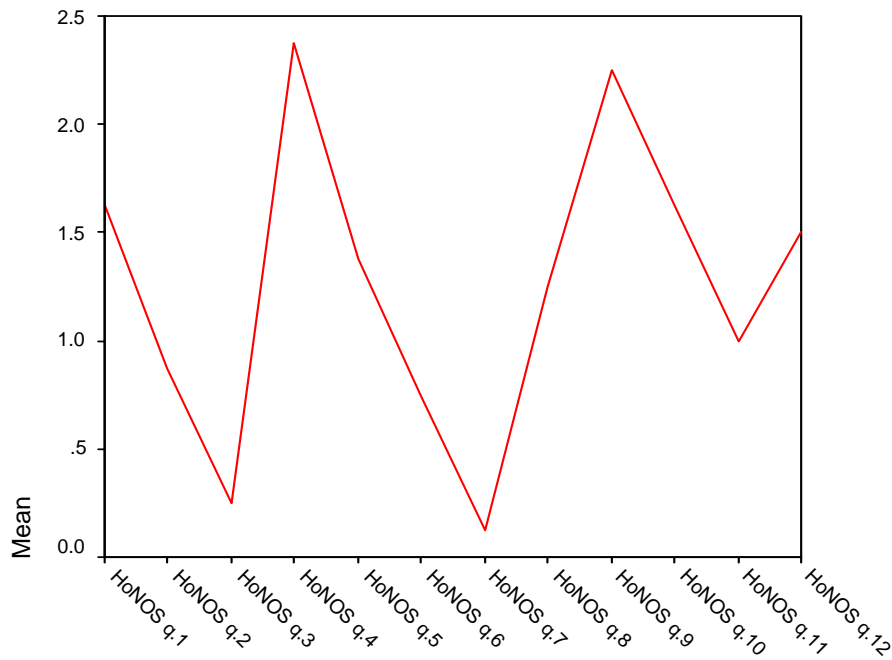
HoNOS

The average of the total HoNOS scores was 18.9 with the lowest being 3 and the highest being 36 (the highest possible score is 48). This falls into the top 15% of HoNOS scores across various mental health settings and is similar to scores of patients being admitted to acute inpatient units. Questions 2 and 3 relate to non-accidental injury and substance abuse and attracted a generally low score, which is consistent with responses on the Response Difficulty Checklist. The results also indicate moderate problems with aggressive and disruptive behaviour (q.1), and with hallucinations and delusions (q.6).

Table 7: HoNOS scores

| HoNOS item | N | Minimum | Maximum | Mean | Std. Deviation |
|--|----|---------|---------|---------|----------------|
| HoNOS q1 Overactive, aggressive, disruptive / agitated behaviour | 35 | .00 | 4.00 | 1.7714 | 1.30802 |
| HoNOS q2 Non accidental self injury | 35 | .00 | 3.00 | .4571 | .95001 |
| HoNOS q3 Drinking or drug taking | 35 | .00 | 2.00 | .0571 | .33806 |
| HoNOS q4 Cognitive problems | 35 | .00 | 4.00 | 2.6571 | 1.02736 |
| HoNOS q5 Physical illness or disability | 35 | .00 | 4.00 | 1.4571 | 1.24482 |
| HoNOS q6 Hallucinations and delusions | 35 | .00 | 4.00 | 1.6000 | 1.35473 |
| HoNOS q7 Depressed mood | 35 | .00 | 4.00 | 1.0000 | 1.21268 |
| HoNOS q8 Other mental health problems | 35 | .00 | 4.00 | 1.8857 | 1.43017 |
| HoNOS q9 Relationships | 35 | .00 | 4.00 | 2.8000 | 1.13241 |
| HoNOS q10 ADLs | 35 | .00 | 4.00 | 2.1143 | 1.27813 |
| HoNOS q11 Living conditions | 35 | .00 | 4.00 | 1.0571 | 1.45406 |
| HoNOS q12 Occupations and activities | 35 | .00 | 4.00 | 2.0857 | 1.54104 |
| HoNOS total | 35 | 3.00 | 36.00 | 18.9429 | 7.71150 |

Figure 1: Mean HoNOS Scores – Acute Unit



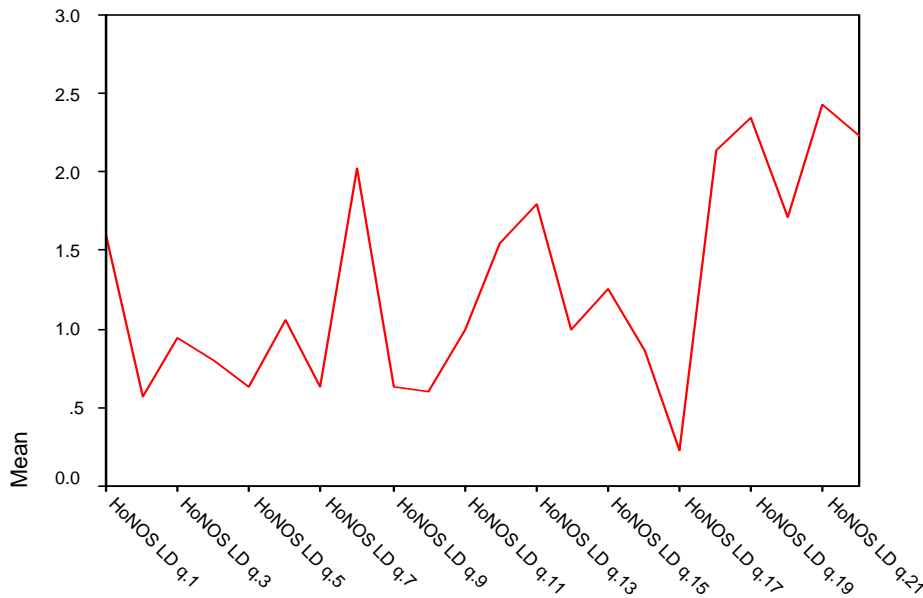
HoNOS LD

The average of the total HoNOS LD scores (table 8) was 27.9, with a range from 8 to 62. (The maximum possible score is 88). If the outlier is excluded then the average is 33.8. The results indicate that this group has moderately severe problems with attention and concentration, relationships, activities and Activities of Daily Living. There are also significant problems with aggression, hallucinations and delusions, mood changes, eating and drinking, and self care. Property damage, personal behaviours, anxiety problems, problems with expression, sleep and physical problems are rated as mild problems. Seizures, self-injury, memory and orientation, and level of understanding are not generally reported as a problem.

Table 8: HoNOS LD scores

| HoNOS LD Item | N | Minimum | Maximum | Mean | Std. Deviation |
|------------------------------------|----|---------|---------|---------|----------------|
| Q1 Behavioural problems to others | 35 | .00 | 4.00 | 1.6000 | 1.26491 |
| Q2 Self-injury | 35 | .00 | 3.00 | .5714 | 1.03713 |
| Q3 Property destruction | 35 | .00 | 4.00 | .9429 | 1.34914 |
| Q4 Personal behaviour problem | 35 | .00 | 4.00 | .8000 | 1.23193 |
| Q5 Rocking, ritualistic behaviours | 35 | .00 | 4.00 | .6286 | 1.13981 |
| Q6 Anxiety, phobias, OCD | 35 | .00 | 4.00 | 1.0571 | 1.10992 |
| Q7 Other problem behaviours | 35 | .00 | 4.00 | .6286 | 1.13981 |
| Q8 Attention and concentration | 35 | .00 | 4.00 | 2.0286 | 1.24819 |
| Q9 Memory and orientation | 35 | .00 | 4.00 | .6286 | 1.16533 |
| Q10 Communication understanding | 35 | .00 | 4.00 | .6000 | .97619 |
| Q11 Communication expression | 35 | .00 | 4.00 | 1.0000 | 1.11144 |
| Q12 Hallucinations and delusions | 35 | .00 | 4.00 | 1.5429 | 1.14642 |
| Q13 Problems with mood changes | 35 | .00 | 4.00 | 1.8000 | 1.36769 |
| Q14 Problems with sleeping | 35 | .00 | 3.00 | 1.0000 | 1.02899 |
| Q15 Problems with eating/drinking | 35 | .00 | 4.00 | 1.2571 | 1.35783 |
| Q16 Physical problems | 35 | .00 | 4.00 | .8571 | 1.24009 |
| Q17 Seizures | 35 | .00 | 4.00 | .2286 | .77024 |
| Q18 ADLs at home | 35 | .00 | 4.00 | 2.1429 | 1.43779 |
| Q19 ADLs outside home | 35 | .00 | 4.00 | 2.3429 | 1.51352 |
| Q20 Level of self care | 35 | .00 | 4.00 | 1.7143 | 1.38418 |
| Q21 Problems with relationships | 35 | .00 | 4.00 | 2.4286 | 1.35659 |
| Q22 occupations and activities | 35 | .00 | 4.00 | 2.2286 | 1.53557 |
| HoNOS LD total | 35 | 8.00 | 62.00 | 27.9429 | 13.75402 |
| Valid (listwise) | 35 | | | | |

Figure 2: Mean HoNOS LD scores per item



Scores on the HoNOS and HoNOS LD are consistently high in the areas of relationships, ADLs and occupations and activities. The RDC also indicates significant relationship and social problems. LSP data indicates significant deficits in self-care. Self-harm and substance abuse are not rated as a problem in any of the instruments employed in the study.

Comparison of Patients on Acute units with those in SEC and CCU

It was of interest to compare the HoNOS, HoNOS-LD and LSP scores and diagnostic profiles for the patients in the acute setting with those in SEC and CCU shows the following:

Table 9: Comparison of Patients

Acute units with those in SEC and CCU on HoNOS and LSP

| | Setting | N | Mean | Std. Deviation | Std. Error Mean |
|-----------------------|--------------|----|---------|----------------|-----------------|
| HoNOS Total | Rehab sector | 28 | 16.7500 | 6.64789 | 1.25633 |
| | Acute | 7 | 27.7143 | 5.08967 | 1.92372 |
| HoNOS total LD | Rehab sector | 28 | 24.5000 | 11.81807 | 2.23340 |
| | Acute | 7 | 41.7143 | 12.91916 | 4.88298 |
| LSP total | Rehab sector | 28 | 21.9643 | 8.62590 | 1.63014 |
| | Acute | 7 | 31.2857 | 7.99405 | 3.02147 |

Table 10: Independent Samples Test

Comparing Patients on Acute Units with those in SEC and CCU on the HoNOS and LSP

| | Sig. (2-tailed) | Mean Difference | Std. Error Difference | 95% Confidence Interval of the Difference | |
|----------------|--------------------|--------------------|--------------------------|--|----------|
| | | | | Lower | Upper |
| HoNOS Total | .000 | -10.9643 | 2.70149 | -16.46051 | -5.46806 |
| | .000 | -10.9643 | 2.29762 | -15.98293 | -5.94565 |
| HoNOS LD Total | .002 | -17.2143 | 5.08181 | -27.55331 | -6.87526 |
| | .011 | -17.2143 | 5.36951 | -29.42767 | -5.00090 |
| LSP total | .014 | -9.3214 | 3.59803 | -16.64168 | -2.00117 |
| | .022 | -9.3214 | 3.43316 | -16.99042 | -1.65244 |

The results indicate that the difference between the HoNOS, HoNOS-LD and LSP scores are significant at the .05 levels.

The AMHS diagnosis of patients in acute units is as illustrated in the table below.

Table 11: AMHS diagnosis of patient on acute units

| Diagnosis | Frequency | Percent |
|--|------------------|----------------|
| None | 1 | 14.3 |
| Schizophrenia (paranoid) | 1 | 14.3 |
| Schizophrenia (undifferentiated) | 3 | 42.9 |
| Bipolar affective Disorder (most recent episode manic) | 1 | 14.3 |
| Bipolar II disorder | 1 | 14.3 |
| Total | 7 | 100.0 |

The mini-PASAD scores of the patients on acute in-patient units is as illustrated in the table below

Table 12: Acute inpatients scoring over threshold on the Mini-PAS- ADD

| Scale | Number | Percentage |
|--------------|---------------|-------------------|
| Depression | 5 | 71.4% |
| Anxiety | 2 | 28.6% |
| Psychosis | 4 | 57.1% |
| Mania | 1 | 14.3% |
| Autism | 3 | 42.9% |
| OCD | 3 | 42.9% |
| Dementia | 2 | 28.6% |
| None | 2 | 28.6%% |

**Table 13: Mean HoNOS Scores
For those people who did not score above threshold on the Mini-PAS-ADD**

| Descriptive Statistics | N | Minimum | Maximum | Mean | Std. Deviation |
|--|---|---------|---------|---------|----------------|
| HoNOS q.1 (Aggressive) | 8 | .00 | 4.00 | 1.6250 | 1.59799 |
| HoNOS q.2 (Self injury) | 8 | .00 | 3.00 | .8750 | 1.24642 |
| HoNOS q.3 (Substance abuse) | 8 | .00 | 2.00 | .2500 | .70711 |
| HoNOS q.4 (cognitive) | 8 | 1.00 | 4.00 | 2.3750 | 1.06066 |
| HoNOS q.5 (physical illness) | 8 | .00 | 3.00 | 1.3750 | 1.18773 |
| HoNOS q.6 (hallucinations/ delusions) | 8 | .00 | 3.00 | .7500 | 1.16496 |
| HoNOS q.7 (depressed mood) | 8 | .00 | 1.00 | .1250 | .35355 |
| HoNOS q.8 (other mental health) | 8 | .00 | 3.00 | 1.2500 | 1.38873 |
| HoNOS q.9 (relationships) | 8 | .00 | 4.00 | 2.2500 | 1.28174 |
| HoNOS q.10 (ADL's) | 8 | .00 | 4.00 | 1.6250 | 1.18773 |
| HoNOS q.11 (living conditions) | 8 | .00 | 4.00 | 1.0000 | 1.85164 |
| HoNOS q.12 (occupations and activities) | 8 | .00 | 4.00 | 1.5000 | 1.85164 |
| HoNOS Total | 8 | 3.00 | 30.00 | 15.1250 | 9.12512 |

Table 14: Mean LSP Scores

For patients not scoring above threshold on the Mini-PAS-ADD

| | N | Minimum | Maximum | Mean | Std. Deviation |
|--------------------|---|---------|---------|---------|----------------|
| Withdrawal | 8 | .00 | 9.00 | 4.6250 | 2.87539 |
| Self care | 8 | 3.00 | 14.00 | 8.5000 | 4.07080 |
| Compliance | 8 | .00 | 8.00 | 3.7500 | 2.60494 |
| Antisocial | 8 | .00 | 11.00 | 5.5000 | 3.96412 |
| LSP total | 8 | 7.00 | 40.00 | 22.2500 | 11.46111 |
| Valid N (listwise) | 8 | | | | |

Service Provision Survey

The results show that there is general agreement among the Mental Health staff surveyed that people with ID are different from other patients, they need increased staff input due to their behaviours that other patients do not normally have and normal psychiatric inpatient settings are considered inadequate for this group. This is consistent with ratings on the RDC that they require intensive input with limited gain. They are vulnerable to other patients and need increased staff supervision. They are seen as remaining in hospital longer than other patients and accommodation is seen as a major problem when a patient with ID is ready for discharge. There is moderate agreement that they do not respond to the normal therapeutic interventions and there are problems providing advice and explanation with a significant number of respondents agreed that they require specialist units with staff trained in their care.

Unit Managers were asked whether they keep data on patients with ID, 28 surveys were completed. 10 managers (35.7%) reported collecting this information on a routine basis. They were also asked to estimate how many people with ID had been admitted in the past year. 19 Managers (70%) reported at least one admission, with the majority of these reporting between 1 and 5 during the past year. 5 units had between 6 and 15 admissions each in the same period. No admissions were reported to the Secure Extended Care Units. 1 respondent did not answer this question. The third question related to admission of people with severe ID. 8 respondents (29.6%) reported an admission of someone with severe ID in the past year. 1 did not answer this question.

Table 15: Survey means

| | Agree | Neutral | Disagree |
|--|-------|---------|--------------|
| 1. In-patients with an ID usually have a serious mental illness | | | Mean: 3.4194 |
| 2. In-patients with an ID are usually admitted for the same reasons as most other patients | | | Mean: 3.4516 |
| 3. In-patients with an ID require more staff input with a range of behaviours that other patients do not normally have. (incontinence, faecal smearing, repetitive questioning, head banging, pica or hair pulling and skin picking) | | | Mean: 2.0000 |
| 4. Nursing staff have to particularly monitor in-patients with an ID to prevent abuse or violence against them by other patients | | | Mean: 2.2903 |
| 5. In-patients with an ID are often admitted for behavioural reasons related to their ID rather than due to a mental illness | | | Mean: 2.6774 |
| 6. In-patients with an ID require the use of seclusion, restraint and high dependency more often than other patients | | | Mean: 3.6271 |
| 7. Most nursing staff do not want to work with people with an ID. | | | Mean: 3.4032 |
| 8. Interventions that are usually successful for most patients often do not work for in-patients with an ID. | | | Mean: 2.7581 |
| 9. In-patients with an ID remain in hospital significantly longer than other patients | | | Mean: 2.5161 |
| 10. In-patients with an ID remain in hospital much longer than is necessary for treatment of their illness. | | | Mean: 2.8065 |
| 11. After discharge patients with an ID are re-admitted more often than other patients | | | Mean: 4.1311 |
| 12. In patients with an ID received significant input from the disability sector (case management, day placement, additional workers) | | | Mean: 4.8983 |


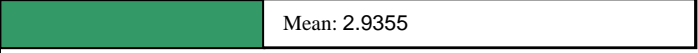
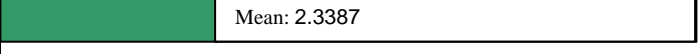
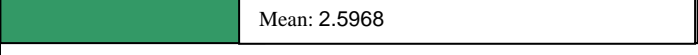


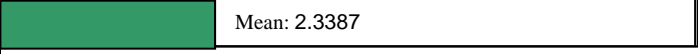



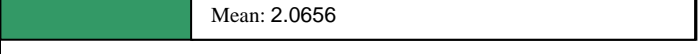
| | Agree | Neutral | Disagree |
|--|---|---------|----------|
| 13. Staff on the ward are confident and competent to assess and manage this group |  Mean: 3.5968 | | |
| 14. People with an intellectual disability often have medical problems that make their care more complex |  Mean: 2.9355 | | |
| 15. This group of patients require care in a specialist unit with staff trained in this area. |  Mean: 2.3387 | | |
| 16. The psychiatric ward environment is more detrimental to people with an ID than to other patients |  Mean: 2.5968 | | |
| 17. Patients with an intellectual disability are not that different from patients without an intellectual disability |  Mean: 5.4839 | | |
| 18. People with an ID are able to make use of the therapeutic programmes run on the ward |  Mean: 4.2903 | | |
| 19. There are problems in providing advice and explanations about their illness and it's treatment to a patient with an ID |  Mean: 2.3387 | | |
| 20. The in-patient facility is adequate for most people with an intellectual disability |  Mean: 5.1290 | | |
| 21. In-patients with an ID have the same number of family and friends visiting as other patients. |  Mean: 4.0161 | | |
| 22. When they are discharged patients with an ID usually return to their previous accommodation. |  Mean: 4.1129 | | |
| 23. Finding accommodation is usually a problem when a in –patient with an ID needs to be discharged. |  Mean: 2.0656 | | |

Table 16: AMHS Diagnosis for ASD subgroup

| AMHS diagnosis by DSM IV code | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------------------------------|-----------|---------|---------------|--------------------|
| 295.20 | 1 | 7.7 | 7.7 | 7.7 |
| 295.30 | 2 | 15.4 | 15.4 | 23.1 |
| 295.90 | 9 | 69.2 | 69.2 | 92.3 |
| 296.70 | 1 | 7.7 | 7.7 | 100.0 |

Figure 3: Mean LSP-16 subscale scores

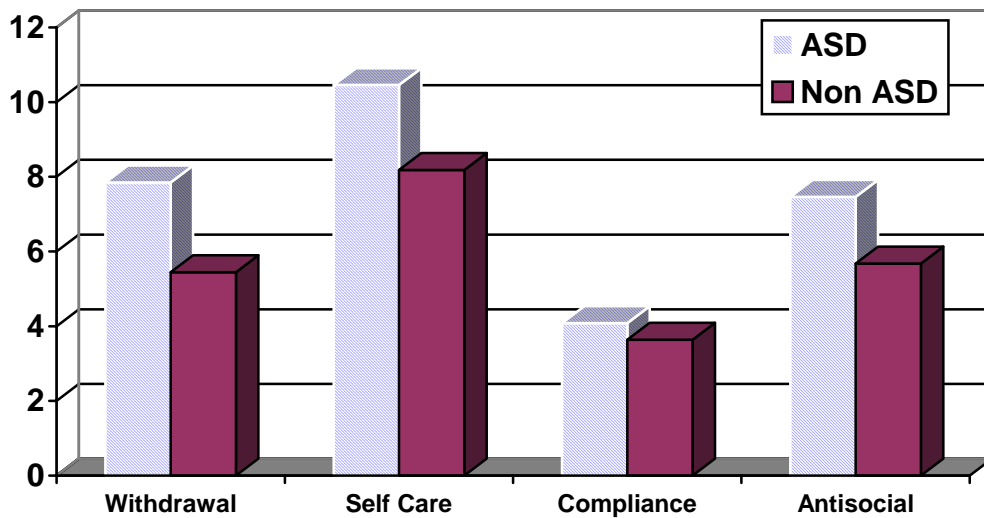
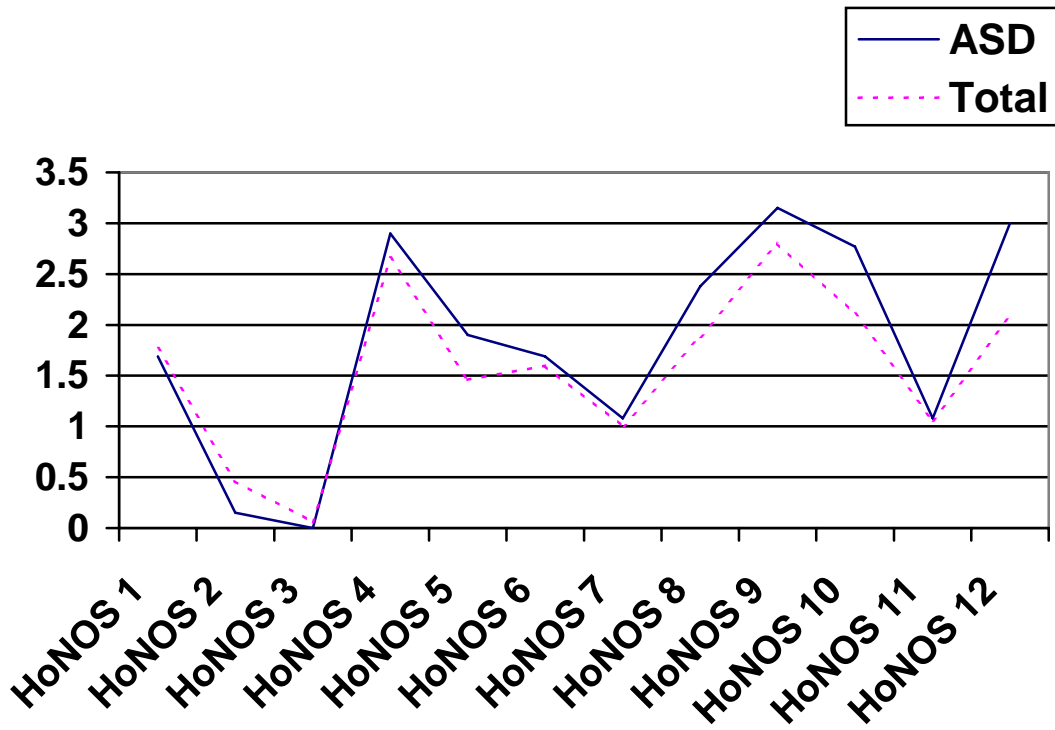


Figure 4: Mean HoNOS item scores



Discussion

1. Prevalence

This survey identified 35 people with an intellectual disability who are current in-patients in mental health facilities with admissions of duration greater than 2 months. The mean age of the patient group was 41 and on average these patients had spent 17 years in hospital. Although the survey included all the relevant in-patient units this figure is likely to be an underestimate of the total number of in patients with an ID as staff at several IPUs reported in-patients that had a diagnosed intellectual disability but did not meet the inclusion criteria of 2 months as an in-patient. In addition, a number of units of all types reported patients who have cognitive, communication and functional deficits and may have an ID, but had either not been formally tested or it had been difficult to establish a clear developmental history.

There are 405 Mental Health rehabilitation beds in Victoria, therefore there is a prevalence rate of Intellectual Disability of 8.6%. This rate falls to 7% when the 7 patients in acute adult inpatient units are excluded. The rate is higher than the estimated 1 to 2% of people with an ID in the general population and is consistent with the hypotheses that there are higher rates of mental disorder in people with an ID, and that these are often more resistant to treatment. As this group are more likely to have functional deficits it is perhaps not surprising to find relatively high rates of people with ID in rehabilitation settings where specific programmes could address these deficits.

2. The nature of the mental disorders

a. Diagnostic profiles.

In relation to the intellectual disability, the majority of individuals 24 (68.6%) had a mild ID (table 4), 3 (8.6%) were reported as having a moderate ID and the remainder were reported to have unspecified ID. The unspecified group was either registered with Disability Services before requirements to formally test IQ for eligibility to Disability services, or had a diagnosis based on evidence of developmental delay before age 18 years but had not received formal cognitive testing.

The low prevalence of moderate ID and the absence of any individuals with severe or profound ID is consistent with other studies of this group in general psychiatric services. There are a number of reasons that might explain why people with an ID are less likely to be admitted to hospital including problems diagnosing psychiatric disorder in people with severe ID, diagnostic overshadowing (attribution of behaviour to ID rather than a mental illness) and attributing problems as 'behavioural' and not psychiatric. It may also reflect difficulty for people with moderate to severe ID in accessing general psychiatric services. Furthermore, it can be expected that people with lower functioning are already receiving a high level of care and support and may not be exposed to the social and psychological stressors experienced by those with mild ID who have fewer supports.

A pre-existing diagnosis of schizophrenia was reported as the treating team diagnosis in 30 cases (85.7%). As this diagnosis is the major focus of modern mental health services, this is not surprising. In contrast, although the Mini-PAS-ADD also indicated that a majority of patients scored above threshold for schizophrenia, the proportion was significantly less than the diagnosis established clinically, with 17 patients (48.6%) having psychopathology indicative of a psychotic illness.

In contrast to the clinical diagnosis, the Mini-PAS-ADD results (Table 3) indicate that there is a high level of psychopathology that clusters into the Autistic Spectrum. 13 people (37.1%) scored above threshold for this diagnosis as compared to 2 patients with a clinical diagnosis of an autistic spectrum disorder (one of whom did not reach threshold for ASD on the Mini-PAS-ADD). This suggests that there may be a number of patients who have an undiagnosed Autistic Spectrum Disorder that may be complicating their treatment and management.

This finding is consistent with VDDS clinical experience. Analysis of routine clinical activity data revealed that out of 67 assessments, 16 patients had a new diagnosis given in the Autistic Spectrum. International literature also indicates that the differential diagnosis between schizophrenia and autism is a complex and difficult task. There is a known relationship with autism and intellectual disability with about 70% of people with autism having an ID and conversely about 15 % of people with an ID having autism.

Anxiety symptoms were rated above threshold for 17.1 % of patients and 25.7% scored above the threshold for depression when rated on the Mini-PAS-ADD, in contrast with only one diagnosis of anxiety disorder by AMHS and no diagnosis of depression, although 2 had a diagnosis of Bipolar Affective Disorder. This may reflect the fact that it is difficult to assess

mood symptoms in people with ID. They frequently present with idiosyncratic symptoms and affective disorders may be more commonly presented as aggressive, irritable, ritualistic and obsessional behaviours. It is common in clinical practice to focus on the more serious of the identified mental illnesses and see the other disorders as secondary to this.

In relation to the treatment of their mental health problems, most were on antipsychotic medication, which would be appropriate given their diagnoses. Of interest, the RDC indicated that 68.7 % receive intensive input with limited gain and that 34.3% fail to respond to treatment.

Three distinct groups of particular interest were identified in the study, those who had been inpatients on acute inpatient units for more than 2 months, and those who were rated above threshold for Autistic Spectrum Disorder and those who did not score above threshold on the Mini-PASAD.

b. Acute inpatient Units

A concern has been expressed that people with an ID remain in acute in-patient settings for too long and block beds; this attitude is reflected in the staff survey responses. It is therefore of interest to note that there are seven patients that have been on the acute wards for longer than two months. This represents a small proportion of the total number of acute beds in Victoria with an estimated prevalence of 1.6%. However these patients have had an average stay of 6 months, which is much longer than the average stay of about 12 days and have thus have the equivalent admission time of 102 average patients.

Of these patients only one did not have a diagnosis according to the treating team and this person was still reported to be in an assessment phase. The mini-PASAD scores of this group show that all but 2 scored over at least one threshold for a likely mental disorder (one scoring over threshold on all seven scales) indicating a high level of psychopathology. Of note one of the patients not scoring over any threshold had a diagnosis of a personality disorder, which would not be identified by the mini-PASAD. Interestingly, when the HoNOS, HoNOS-LD and LSP scores of this sub-group are compared with the combined scores of the patients in SEC and CCU's they are significantly higher.

The higher HoNOS and HoNOS-LD scores would appear to indicate that they have more mental health issues and the higher LSP scores would indicate that they have greater impairment of functional skills than intellectually disabled patients in the designated long stay beds. This would suggest that this group continues to have demonstrable psychopathology, have high needs and are relatively more disturbed in their behaviour and that it is these factors that are preventing their transfer or discharge, presumably due to a lack of other facilities that can manage this degree of disturbance and dependency.

The data does not support the hypothesis that these patients have recovered and are waiting for an appropriate placement, although the survey responses suggest that this is the opinion of the staff. The average duration of the admission of 6 months suggests that they do not readily respond to standard interventions employed by acute in-patient units, which is again consistent with staff survey responses. It should also be noted that inpatients on acute units were only included if they had been there for more than 2 months, during the course of the project a significant number of units reported individuals with an ID who had been inpatients for less than 2 months.

C. Autistic Spectrum Disorder

Thirteen people were rated as above the threshold for Autistic Spectrum Disorder (ASD) when symptoms were measured using the Mini PAS-ADD. They are evenly distributed across settings, with a wide range of ages. There were significantly more males than females, which is consistent with the increased prevalence of ASD in males.

All 13 were diagnosed by the treating team with Axis I disorders (table), with the majority classed as undifferentiated schizophrenia. None were diagnosed with personality disorder. One person was diagnosed with catatonic schizophrenia. People with either schizophrenia or Autism can present with catatonic symptoms including stupor, muteness, and posturing and stereotypic or manneristic movements.

The relatively high number of people with a diagnosis of undifferentiated schizophrenia may reflect the difficulty differentiating between the symptoms of schizophrenia and autistic features. People with ASD may present with idiosyncratic and odd communication styles, poor interpersonal and social skills and blunted or inappropriate emotional expression. Many have intense preoccupations with bizarre ideas that may resemble delusions. Some features

associated with autism can appear to indicate a perceptual disturbance and sensory hypersensitivity along with concrete and literal thought processes, which can result in their statements being interpreted as indicating auditory hallucinations.

When compared with the total mean HoNOS scores, the scores for those who were rated above threshold for ASD on the Mini PAS-ADD showed a similar pattern. There were however, greater problems rated with several items including physical illness, anxiety related symptoms, relationships, ADLs and activities. Comparison of the LSP scores for this group with those not rated above the ASD threshold shows that the ASD group have greater problems with withdrawal, self care and antisocial behaviour. The data suggests that they are more difficult to manage and require greater input than the individuals who were not rated with ASD symptoms.

d. Patients not scoring above Mini-PAS-ADD thresholds

There were 8 patients that did not score above any of the thresholds on the mini-PASAD indicating a lack of current psychopathology. On further analysis of the data six had a clinical diagnosis of a psychotic disorder, one of a mood disorder and one did not have a clinical diagnosis.

Of note is that 3 of the 8 had an additional clinical diagnosis of a personality disorder, which would not be identified by the mini-PAS-ADD but may be a significant clinical issue. It may also suggest successful treatment of a mental disorder so that at the time of assessment there was no major psychopathology. Another possibility is that although the patients' mental state has improved they have other needs that prevent their discharge. Examination of their HoNOS scores for this group indicated that although the totals were very similar to the rest of the group, they scored highly on cognitive problems, problems with relationships, problems with ADL's and problems with occupations and activities. The LSP scores similarly indicate that they have difficulties on the self-care and anti-social dimensions. It appears that although these patients do not have evidence for acute symptoms of current mental illness as indicated by the mini-PASAD they have significant cognitive problems, difficulty in caring for themselves in conjunction with antisocial behaviours and difficulties in interpersonal relationships.

This pattern suggests that despite the lack of acute symptoms there are significant functional impairments that probably represent the combined effects of mental illness and

intellectual disability. In addition this group has difficulty in relating to other people that may limit the opportunities for alternative placements. In 3 cases, this pattern is associated with a clinical diagnosis of personality disorder.

3. Impact

a. Severity of mental health problems and level of disability

The life skills profile (table 5) indicates that this population has an average total LSP score of 23.8, with 8 people rated with a total score above 30. This is relatively high compared to other mental health samples and indicates significant impairment in functioning and the need for high levels of support. The average of the total HoNOS scores was 18.9 with the lowest being 3 and the highest being 36 (the highest possible score is 48). This falls into the top 15% of HoNOS scores across various mental health settings and is similar to scores of patients being admitted to acute inpatient units

b. Problem Behaviours

Problem behaviours are those that limit a person's opportunity to participate in normal community activities and require some form of intervention from services. They include aggressive behaviours but can also include other behaviours such as wandering, shouting, pica and self-injury. Problem behaviours are identified as a significant obstacle to community living and a frequent cause of admission or readmission to mental health units. The presentation of psychiatric illness in individuals with ID is usually one of a behavioural disturbance, which is causing management problems.

ICD-10-LD (Royal College of Psychiatrists 2001) classification scheme provides diagnostic criteria for problem behaviours. Based on these criteria, 28 patients (80%) were reported to display some form of problem behaviour, with 20 (71.4%) of these, exhibiting more than two problem behaviours. According to the HoNOS and HoNOS-LD about 80% had problems with aggression and in 25% of the group this was at a moderately severe or very severe level. This contrasts with an estimated prevalence of aggression in people with ID of 8% - 14% (Verhoeven & Tuinier 2001). The response difficulty checklist indicated that 62.9% of patients were considered violent and 70.1% would make repeated demands that could not be met, with 82.9% reported as exhibiting sudden changes in mood and behaviour. 51.4% had frequent crises.

On a positive note there were a number of other issues that were not identified as a problem. The HoNOS-LD identified that the majority do not having problems related to self-injury (82.9%), property damage (68.6) or personal behaviour (82.9%), problems that are reported in many studies as common in persons with ID (Dosen & Day 2001). The response difficulty checklist indicated that only 2.9% had a drug or alcohol problem, 2.9% were considered a suicide risk. The RDC results also demonstrated that only 34.3% were not cooperative, with 80% of the sample rated as being compliant with treatment.

It was not within the scope of this project to comment on the aetiology or long-term prognosis of problem behaviours although other research suggests that challenging behaviour is frequently associated with psychiatric illness. Irrespective of this consideration it has considerable implications for management and resources. Information from the United Kingdom exposes the high cost of problem behaviour to health and social services, with estimates of up to 140 million pounds per year based on a prevalence rate of 14% for challenging behaviour in people with ID (Xenitidis et al 1999).

3 Systemic issues

a. Legal status

Of the 35 patients, only 17 were detained under the Mental Health Act and 3 had a formal Guardian able to make health care decisions. The remainder were residing as inpatients under informal relationships that may have included family members providing consent on the patient's behalf. The majority of 68.6% had an administrator to manage their financial affairs.

The consequence of this is that patients are receiving treatment and are detained under different legal frameworks that have different reporting mechanisms and review processes. At a practical level, staff may be unclear about their roles and responsibilities to patients under the different legal mechanisms, and it raises the possibility that the patients are receiving different levels of protection in relation to their civil rights and reviews of the appropriateness of their treatment.

It is probable that many of these patients are cooperative with treatment but lack the capacity to understand the nature of the treatment and to provide valid consent. This perhaps reflects the tradition in psychiatry to avoid certification except as a last resort but

may not be appropriate in people with cognitive impairment who may lack capacity permanently rather than temporarily.

Although family members should be involved in treatment decision when appropriate, in these cases treatment is extremely complex and may require expert opinion to determine if it is appropriate and may involve decisions around restraint, seclusion and community access that a family member may not wish to be involved in. In addition, there is the possibility they may be influenced by factors that are not in the patient's best interests.

b. Other Services

Input from services other than mainstream Mental Health was reported as limited. 71% of the sample had not been seen by the VDDS. Excluding the patients seen as part of project work, the percentage of people with ID who are in the long stay component of AMHS in Victoria and have not been referred to the VDDS rises to 83%.

Of note most of the patients do not access other services with only 37.1% having a Disability Service case manager, and few receiving active input from behaviour intervention (BIST) or specialist services from Disability Client Services. The RDC data shows that 60% of patients had been referred to other services but have not been eligible. Where other services had been involved, they were not perceived by AMHS staff as having a positive impact.

c. Welfare, Health Recreation and Vocation.

This group has their long –term accommodation and other basic needs such as nutrition provided for by Mental Health Services. In this sense, many of the basic needs (food, shelter and income) are met in the current setting. Health does not appear to be a major issue with 74.3% being rated as having good to moderate health and this was supported by the HoNOS and HoNOS-LD scores which on average identified health problems as mild. Five (14.3%) had a diagnosis of epilepsy, with 2 suffering both generalised and partial seizures; however all but one was reported as well controlled.

Poor physical health and inadequate health care have been identified as major problems in studies of people with ID and of those with DD. The relatively low level of problems identified in this study suggests that either health needs are being adequately catered for in the person's current setting or alternatively it may indicate that health needs are not being identified. Given the high average age of the sample and also the high prevalence of physical illness and morbidity both in people with ID and people who have schizophrenia, it can be anticipated that this group will be at increased risk of physical health problems, as they get older.

The data indicates that although 50% attend a recreational service, this does not occupy much time as the patients spend 12 out of a possible 14 hours on the unit, and the vast majority (62.8%) had not left the unit unescorted at any time in the last three months. This is somewhat in contrast to the apparently voluntary nature of their admission and strongly suggests that they are thus very dependant on the unit for recreational and vocational activities.

The HoNOS and HoNOS –LD scores (the respective averages being 2.1 and 2.2) indicate that problems with occupations and activities were identified as significant and is likely to reflect the fact that this group is often unable to participate in unit activities that are often not tailored to cater for their conceptual and communication deficits. This is supported by the staff survey to some extent in which 74% agreed with the view that normal interventions are ineffective and around 50% agreeing with the statement that this group could not make use of the unit programme.

Occupations and activities are an important factor when considering the high reported prevalence of problem behaviours in this group. A lack of meaningful activity, sparse environment and limited engagement with the environment or others can result in increased aggression or other challenging behaviours. This can represent attempts to communicate needs or an adaptive means to increase stimulation.

d Social and adaptive functioning

Considerable problems are reported in all areas of self-care on the LSP and HoNOS with mean scores in the relative domains of 2.1 on the HoNOS and 9.0 on the LSP-16. These instruments also demonstrate that most patients would have difficulty in contributing to domestic chores and in accessing the community independently. This could be consistent with issues related to either mental illness or intellectual disability, and in this population, is likely to be a combination of the two. The implication is that these patients require significant support to simply survive on a day-to-day basis.

In addition, all measures indicated that difficulties with friendships and relationships are also significant problems. The main problem identified was that of forming and maintaining relationships with 32 (91.5%) patients rated as experiencing problems in this area. People with ID commonly face repeated disruption and change in their social conditions; they often have limited choice or determination and have impoverished social networks and opportunities. Additional problems are found with communication and understanding of their environment. Problems establishing and maintaining relationships may mean that they are unable to obtain the practical and emotional support needed to cope with everyday living.

Difficulties in this area may also influence the success of therapeutic interventions, it may require considerably more time to establish a relationship and interpersonal skills may need to be formally taught before interventions are attempted. Other items reported as problems in over 50% of cases were violent or threatening behaviour and difficulties in living with others. Despite these difficulties in relationships, all but one (who had no known family) had regular contact with their families and for 23 this was at least monthly.

e. Management issues.

People with a dual disability often present with a range of disturbed behaviour that is not seen in the normal population. These types of behaviour include head banging, skin picking,

wandering, incontinence and faecal smearing, and making repetitive requests to staff. They are also thought to be more vulnerable and may unintentionally put themselves at risk due to intrusive behaviours or be at increased risk of exploitation. The general psychiatric population is increasingly composed of patients with drug and alcohol problems or are very disturbed; meanwhile the average age of ID patients in the rehabilitation sector is steadily increasing. Many of the Unit Managers identified this as problematic; they expressed the perception that the level of vulnerability of patients with ID was increasing. The staff survey supported the existence of these issues with about 90% of nursing staff agreed with the statements that patients with an ID needed increased input to manage these specific issues. This may also explain why 78.5% thought that the in patient unit was detrimental to people with an intellectual disability.

Despite these perceived differences, 56% of staff also agreed with the statement that this group usually have a serious mental illness and that they are usually admitted for similar reasons as most other patients. However, in a contrary result, a substantial number of staff (72%) thought that this group was admitted with behavioural reasons related to their intellectual disability rather than a mental illness. Patients with a dual disability could be expected to require a different management approach due to the different behaviours in conjunction with their impaired communication and conceptual skills. This view is supported by the survey results with 75% of staff indicating that interventions that they would normally use were ineffective in this group and a similar number (76.8%) indicating that this group were perceived as being different from other patients.

More specifically, 89% agreed that there were significant problems in issues relating to consent and psychoeducation and 55% indicating that they lacked confidence in treating this group. In addition 70% did not think the inpatient unit was adequate for most people with an intellectual disability and 82% thought that these patients required a specialised unit with staff trained to manage their particular issues. In relation to the admission process, 77% of staff thought that this group remain in hospital significantly longer than other patients and 70% thought that this was longer than required for the treatment of their illness, with 85% indicating that accommodation was usually a problem on discharge.

Given the difficulties illustrated above, it is perhaps not surprising that 61% agreed with the statement that most nursing staff do not want to work with this group of patients

Conclusion

Prevalence

The point prevalence of patients with an intellectual disability in the long stay component of mental health services is estimated to be 8%. On average these patients had been in hospital care for 17 years. Of these 7 had been in acute inpatient units for an average of six months.

Nature.

The clinical diagnoses and Mini PAS-ADD indicate that the majority of patients have a psychotic illness. The Mini PAS-ADD results indicate that about 1/3 of the patients may have an Autistic spectrum disorder that had not been identified clinically. It also identified a number of high prevalence mental health problems that warrant further investigation.

Impact

The HoNOS, HoNOS-LD and LSP indicate that this group has significant difficulties in the areas of cognition, self-care, relationships and occupations and activities. The total scores are higher than those obtained on patients at the time of an acute admission to Victorian Public Mental Health facilities.

There is also a high rate of aggression, a finding consistent with other studies of people with ID receiving a psychiatric service (Bouras & Drummond 1993). These problems appeared relatively independent of psychopathology. Despite this the patients were reported as compliant and cooperative group with a low risk of self-harm, drug and alcohol use and property damage. Patients with ID are identified by staff as a different patient population; they take longer to respond to treatment and may continue to display problem behaviour in the absence of symptoms and often do not respond to standard mental health interventions. They are less likely to attend day programmes, don't respond to the same interpersonal interventions and require intensive support with ADL's and supervision due to their vulnerability.

This is consistent with findings from other studies of people with ID in generic treatment settings, which describe them as vulnerable and disadvantaged in general psychiatric settings (Day 2001, Kwok 2001). The process of rehabilitation is often slower for people

with ID and capacity may limit attainment. Mental health staff surveyed generally considered that they receive little support from Disability Services.

Lack of accommodation is reported as a significant problem and there is a perception that hospital admission and delayed discharge is used for social care rather than treatment of a mental illness. This group is likely to need life long care and supervision. The availability of trained and experienced staff is identified in the literature as crucial for effective care and management of people with ID and Mental Health Problems (Day 1994, 1988, Moss et al 1997, Naylor & Clifton 1993, Roy 1993).

However in the current system, given the small number of patients with ID in any one unit it is difficult for staff to develop the necessary skills and experience in the assessment and treatment of mental health problems in this population. The staff currently managing this group of patients have not accessed other services that are available such as the VDDS and Disability services. The reasons for this are not known but could include lack of awareness or that they have confidence in their current strategy and a belief that other services are unlikely to be of help.

Recommendations

1. An assessment unit for patients with intellectual disability admitted to acute inpatient units for longer than 2 months, or who have complex needs, or any individual with an ID being considered for placement at a CCU or SEC. This may be of value in relieving pressure on the system.
 - The service should offer an integrated service model incorporating Mental Health and Disability services and allowing cross system access. A specialised service can provide special expertise and experience in assessment and diagnosis of psychiatric disorder in people with ID in the face of atypical presentation and communication difficulties. It would also provide a secure environment for a people with ID who are vulnerable in general treatment settings. Therapeutic interventions can be designed and modified to account for particular cognitive, communication and social difficulties based. Underlying dependency levels can also be addressed. An additional benefit would be obtained by creating an environment where staff expertise in the assessment, care and management of this group can be developed. Strong links with community services would be required to promote normality with an aim to return the individual to community living with a comprehensive package of care.
 - A review of the international literature indicates that specialist services for dual disability seem to give better outcomes than general services. Evidence from a UK study in South London (Xenitidis et al 2004) identifies that there are increased costs associated with inpatient interventions for people with ID in general units. People with ID admitted to a specialist unit were compared with those admitted to general psychiatric units. The intensive and comprehensive assessment, treatment and rehabilitation required by people with dual disability are seen as unfeasible within general psychiatric services. It is reported that improved outcomes can be obtained when people with ID are admitted to a specialist unit for psychiatric care and management.
2. It can be anticipated that some of those admitted will require ongoing care and management in a secure setting. It is likely that a small-scale assessment unit would quickly become blocked unless there is facility for throughput. The project results illustrates that there are reasonably high number of people with an ID in the mental health system with a high level of both psychopathology and functional

/social needs that do not respond to existing service interventions. International opinion highlights the need for long term facilities for individuals with ID who have clear health needs but are unsuited to mainstream health services and whose health care needs cannot be met in standard disability accommodation settings (Vaughan 2003). The development of long stay capacity in community based long-term accommodation that can manage significant levels of disability associated with challenging behaviours may be needed. These should have the capacity to address problems using a combination of medical, psychological and behavioural frameworks and to provide on site recreational and vocational activities. A coordinated service structure that includes Mental Health and Disability Service input would provide a comprehensive array of services that are based on need and have an appropriate therapeutic and rehabilitation focus.

3. It would be important for staff managing these patients to be aware of available options and to make informed decisions about utilising the expertise available in the current service system. Education is required for staff from AMHS, Disability Services and other organisations providing direct care to people with ID, regarding recognition, assessment, treatment and management of psychiatric disorder in people with ID and the roles of other services within the system.
4. When a patient of the Mental Health Service is registered with Disability Services, there should be a greater emphasis on communication and collaborative working between services. Collaboration regarding provision of appropriate occupational and social activities is particularly relevant. The VDDS could play a role in facilitating these relationships.
5. The possibility of Autism should be considered in all patients who have an intellectual disability and mental health issues in the long stay component of mental health services. In relation to this group, an appropriate strategy would be for the VDDS to specifically target this component of the mental health service for an education and training package specifically relating to autism. The aim would be for staff to identify cases in their care that warrant further assessment and to introduce appropriate screening procedures at the point of referral for rehabilitation. Further recommendations would depend on the actual number of cases confirmed to have an autistic spectrum disorder.

6. Consideration could be given to a system for routine collection of data about patients with an ID should be established so that the department has ready access to this type of information.

7. It is recommended that the information in this report be distributed to AMHS area managers clinical directors and other stakeholders for their information.

References

- Bouras N & Drummond C (1993) Behaviour and psychiatric disorders of people with mental handicaps living in the community. *Journal of Intellectual Disability Research*. 36, 349-357
- Bouras N, Holt G & Gravestock S (1995) Community care for people with learning disabilities: deficits and future plans. *Psychiatric Bulletin*. 19, 134-137
- Bouras N & Holt G (2001) Psychiatric Treatment in Community Care. In A Dosen & K Day (Eds) *Treating Mental Illness and Behaviour Disorders in Children and Adults with Mental Retardation*. Washington DC: American Psychiatric Press.
- Davidson P, Cain N, Sloane-Reves J, Giesow V, Quijano L & Houser K (1996) Factors predicting re-referral following crisis intervention for community based persons with developmental disabilities and behavioural and psychiatric disorders. *Mental Retardation*. 101(2) 109-117.
- Davidson P, Cain N, Sloane-Reves J, Giesow V, Quijano L, Van Heyningen J & Shoham I (1995) Crisis intervention for community based individuals with developmental disabilities and behavioural and psychiatric disorders. *Mental Retardation*. 33(1) 21-30.
- Day K (2001) Service Provision and Staff Training. In A Dosen & K Day (Eds) *Treating Mental Illness and Behaviour Disorders in Children and Adults with Mental Retardation*. Washington DC: American Psychiatric Press.
- Day K (1994) psychiatric services in mental retardation generic or specialised provision. In N. Bouras (Ed) *Mental Health in Mental Retardation*. Cambridge: University Press.
- Day K (1988) Services for psychiatrically disordered mentally handicapped adults – a UK perspective. *Australia and New Zealand Journal of Developmental Disabilities*. 14, 19-25.
- Department of Health and Community Services, Victoria (1993) Needs for Care Study
- Hassiotis A, Ukoumunne O, Byford S, Tyrer P, Harvey K, Pichaud J, Gilvarry K & Fraser J (1999) Prevalence and characteristics of patients with severe mental illness and borderline intellectual functioning. *British Journal of Psychiatry*. 175, 135-140.

- Hassiotis A, Ukoumunne O, Byford S, Tyrer P, Harvey K, Pichaud J, Gilvarry K & Fraser J (2001) Intellectual functioning and outcome of patients with severe psychotic illness randomised to intensive case management. *British Journal of Psychiatry*. 178, 166-171
- Holt G, Costello H, Bouras N, Diareme S, Hillery J, Moss S, Rodriguez-Blazquet C, Salvador L, Tsiantis J, Weber G & Dimitrakaki C (2000) BIOMED-MEROPE project: service provision for adults with intellectual disability: a European comparison. *Journal of Intellectual Disability Research*. 44(6) 685-695.
- Jacobson J (1999) Dual diagnosis services: history, progress and perspectives. In N Bouras (Ed) *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation*. Cambridge: University Press.
- Moss S (2002) The Mini PAS-ADD Interview Pack. Brighton: Pavilion.
- Moss S, Prosser H, Costello H, Patel P, Rowe S, Turner S & Hatton C (1998) Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*. 42(2) 173-183
- Moss S, Emerson E, Bouras N & Holland A (1997) mental disorders and problematic behaviours in people with an intellectual disability: future directions for research. *Journal of Intellectual Disability Research* 41(6) 440-447.
- Naylor V & Clifton M (1993) People with learning disabilities – meeting complex needs. *Health & Social Care*. 1, 345-353
- Nottestad J & Linaker O (1999) Psychiatric health needs and services before and after complete deinstitutionalisation of people with intellectual disability. *Journal of Intellectual Disability Research*. 43(6) 523-530.
- Prosser H, Moss S, Costello C, Simpson N, Patel P & Rowe S (1998) reliability and validity of the Mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*. 42, 264-272
- Raitasuo S, Taiminen T & Salokangas R (1999) Inpatient care and its outcome in a specialist psychiatric unit for people with intellectual disability: a prospective study. *Journal of Intellectual Disability Research*. 43(2) 119-127.

- Roy A, Mathews H, Clifford P, Fowler V & martin D (2002) Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) *British Journal of Psychiatry*. 180, 67-70.
- Roy A (1993) Developing local services for people with a learning disability and a psychiatric disorder. *Psychiatric Bulletin*. 17, 215-217
- Royal College of Psychiatrists (2001) DC-LD (Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation) London: Gaskell.
- Royal College of Psychiatrists (1999) Meeting the health needs of people with learning disability: Adults with mild learning disability. London: Royal College of Psychiatrists.
- Trauer T (1998) A study of health perceptions in clients of a mobile support and treatment service for the severely mentally ill. *Evaluation and Programming Planning* 21. 297-305.
- Vaughan P (2003) Secure care and treatment needs of individuals with learning disability and severe challenging behaviour. *British Journal of Learning Disabilities*. 31, 113-117.
- Victorian Dual Disability Service (2002) Considerations for the assessment, treatment and management of residents with a known or suspected dual disability at Bunjil House. Unpublished report.
- Wing J (1994) Health of the Nation Outcome Scales: HoNOS field trials. London: Royal College of Psychiatrists.
- Xenitidis K, Gratsa A, Bouras N, Hammond R, Ditchfield H, Holt G, Martin J & Brooks D (2004) Psychiatric patient care for adults with intellectual disabilities: generic or specialist units? *Journal of Intellectual Disability Research*. 48(1) 11-18.

Appendices

Appendix I AMHS De-identified Case List

Victorian Dual Disability Service SEC/CCU/IPU Scoping Project

VDDS copy

Name and position of person

Completing this form: _____

AMHS: _____

Date of completion: _____

| VDDS ID Number To be completed by the VDDS | Regional ID number | Patient's primary contact | Phone number and email address of case manager |
|---|-------------------------------|--------------------------------------|---|
| | 1 | | Telephone: E-mail: |
| | 2 | | |
| | 3 | | |
| | 4 | | |
| | 5 | | |
| | 6 | | |
| | 7 | | |
| | 8 | | |
| | 9 | | |
| | 10 | | |
| | 11 | | |
| | 12 | | |
| | 13 | | |
| | 14 | | |
| | 15 | | |

Appendix II Inpatient Manager and Staff Survey

This questionnaire is part of a project commissioned by the Mental Health Branch and undertaken by the Victorian Dual Disability Service. The aim of the project is to determine the prevalence nature and impact of multiple mental disorders on the Mental Health Service system. The aim of this questionnaire is to assist the VDDS in determining if patients with an intellectual disability are different to patients without an intellectual disability. In other words do they present with a particular range of problems and difficulties that require a significantly different management approach for Mental Health Service staff.

Please complete the following questions and return the completed survey in the SAE provided.

If you have any questions please contact Andrew Pridding on 03 92882950.

1. Do you have a data collection that enables you to identify how many people with an ID have been admitted to the ward?

Yes No

2. How many patients with an ID have been admitted in the last year?
(Estimate if you do not collect data.)

| | | | | |
|---|--------|---------|----------|-----|
| 0 | 1 to 5 | 6 to 10 | 11 to 15 | >15 |
|---|--------|---------|----------|-----|

3. Have any of the people with an ID admitted totally lacked the ability to communicate or had a severe intellectual disability?

Yes No

| | Agree | | | Neutral | Disagree | | |
|---|-----------|----------|----------|---------|----------|----------|-----------|
| | Very much | Moderate | A little | Neutral | A little | Moderate | Very much |
| 4. In-patients with an ID usually have a serious mental illness | | | | | | | |
| 5. In-patients with an ID are usually admitted for the same reasons as most other patients | | | | | | | |
| 6. In-patients with an ID require more staff input with a range of behaviours that other patients do not normally have (incontinence, faecal smearing, repetitive questioning, head banging, pica or hair pulling and skin picking) | | | | | | | |
| 7. Nursing staff have to particularly monitor in-patients with an ID to prevent abuse or violence against them by other patients | | | | | | | |
| 8. In-patients with an ID are often admitted for behavioural reasons related to their ID rather than due to a mental illness | | | | | | | |
| 9. In-patients with an ID require the use of seclusion, restraint and high dependency more often than other patients | | | | | | | |
| 10. Most nursing staff do not want to work with people with an ID. | | | | | | | |
| 11. Interventions that are usually successful for most patients often do not work for in-patients with an ID. | | | | | | | |
| 12. In-patients with an ID remain in hospital significantly longer than other patients. | | | | | | | |
| 13. In-patients with an ID remain in hospital much longer than is necessary for treatment of their illness. | | | | | | | |
| 14. After discharge patients with an ID are re-admitted more often than other patients | | | | | | | |
| 15. In patients with an ID received significant input from the disability sector (case management, day placement, additional workers) | | | | | | | |

| | Agree | | | Neutral | Disagree | | |
|--|-----------|----------|----------|---------|----------|----------|-----------|
| | Very much | Moderate | A little | Neutral | A little | Moderate | Very much |
| 16. Staff on the ward are confident and competent to assess and manage this group | | | | | | | |
| 17. People with an intellectual disability often have medical problems that make their care more complex | | | | | | | |
| 18. This group of patients require care in a specialist unit with staff trained in this area. | | | | | | | |
| 19. The psychiatric ward environment is more detrimental to people with an ID than to other patients | | | | | | | |
| 20. Patients with an intellectual disability are not that different from patients without an intellectual disability | | | | | | | |
| 21. People with an ID are able to make use of the therapeutic programmes run on the ward | | | | | | | |
| 22. There are problems in providing advice and explanations about their illness and it's treatment to a patient with an ID | | | | | | | |
| 23. The in-patient facility is adequate for most people with an intellectual disability | | | | | | | |
| 24. In-patients with an ID have the same number of family and friends visiting as other patients. | | | | | | | |
| 25. When they are discharged patients with an ID usually return to their previous accommodation. | | | | | | | |
| 26. Finding accommodation is usually a problem when a in –patient with an ID needs to be discharged. | | | | | | | |

Multiple Mental Disorders in inpatient Secure Extended Care, Community Care and Inpatient Units of Area Mental Health Services within Victoria

This questionnaire is part of a project commissioned by the Mental Health Branch and undertaken by the Victorian Dual Disability Service. The aim of the project is to determine the prevalence nature and impact of multiple mental disorders on the Mental Health Service system. This survey aims to collect basic demographic data and details of service provision for patients identified as meeting the inclusion criteria for the project. The information obtain will be de-identified and used to inform future service provision.

**Please complete this questionnaire and return it in the attached envelope.
If you have any questions please contact Andrew Pridding on 9288 2950.**

Patient's Code _____
VDDS UR _____

Setting: SEC CCU IPU

AMHS Area _____

Legal Status:

Mental Health Act Formal Guardian Health Guardian Administrator Other

Severity of Intellectual Disability: Mild Moderate Severe

Cause of Intellectual Disability: Known Unknown

Specify if known: _____

Diagnosis (DSM-IV):

Incident reports in the past 3 months:

| Type | Number of deliberate | Number of non deliberate |
|----------------|----------------------|--------------------------|
| Harm to others | | |
| Harm to self | | |
| Absconding | | |
| Other | | |

Medication (include prn):

| Generic Name | Dose (max daily dose if prn) | Frequency | Route |
|--------------|------------------------------|-----------|-------|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Are other services involved?

Yes

No

If Yes, please specify:

Does the person have epilepsy?

Yes

No

**Specify type if
known:** _____

Are anticonvulsants prescribed for epilepsy? Yes No

Physical Health: Good Moderate Poor

List physical health problems or conditions:
(include chronic conditions)

Approximate number of hours spent on unit between 7am – 9pm:

Weekdays _____
Weekends _____

**During the last 3 months how many hours (approximately) has the person
left the ward unescorted?** _____

Does the person have any contact with family? Yes No

If yes, how often?

Daily or greater Weekly Monthly Less than monthly

Thank you for completing this survey.

Appendix IV Mini PAS-ADD

The Mini PAS-ADD is a reliable and valid assessment schedule for psychiatric disorders in people with an intellectual disability that has been widely used. It is a structured interview schedule that asks 86 questions concerning psychopathology and generates a series of sub-scores on anxiety, depression, hypo mania, psychosis, autism, OCD and unspecified disorders including dementia. It usually takes 30 to 40 minutes to complete

Appendix V Response Difficulty Survey

VDDS UR: _____
 Date Completed: _____
 Respondent: _____
 Relationship to patient: _____
 Administered by: _____

| Question | Yes | No |
|---|-----|----|
| Do the person's problems respond to interventions or treatment? | | |
| Does the person receive intensive input with limited gain? | | |
| Does the person have poor relationships with key workers? | | |
| Is the person unwilling to cooperate with most services? | | |
| Is the person unable to cooperate with most services? | | |
| Does the person disagree with service providers about the nature of their problems? | | |
| Does the person disagree with proposed solutions to problems? | | |
| Does the person make demands that cannot be met? | | |
| Does the person fail to comply with medical or psychological treatment? | | |
| Is the person prone to sudden changes in mood and behaviour? | | |
| Does the person have problems with illicit drug or alcohol use? | | |
| Is the person a persistent suicide risk? | | |
| Does the person either threaten violence or be violent? | | |
| Are there cultural barriers that limit a shared understanding with the person? | | |
| Are there communication barriers that limit a shared understanding of the person? | | |
| Are there communication barriers that limit successful interactions? | | |
| Does the person have any meaningful relationships? | | |
| Is the person geographically isolated? | | |
| Has the person suffered significant trauma or abuse? | | |
| Has the person suffered significant change or loss? | | |
| Does the person have difficulty in forming and maintaining relationships? | | |
| Does the person often refuse services? | | |
| Does the person have difficulty living with others? | | |
| Are the persons carers usually unwilling to cooperate? | | |
| Has the person been referred to other services but not be eligible to receive them? | | |
| Have any other services had a positive impact on the person? | | |
| When other services have been involved, it is easy to coordinate service delivery? Leave blank if NA | | |
| Does the person often have crises? | | |
| Does the person often need an after hours response? | | |
| TOTAL | | |

Appendix VI - Health of the Nation Outcome Survey – Learning Disabled

Scoring key

Not Known, 0 = No problem, 1 = sub clinical problem, 2 = mild, but definitely present, 3 = moderately severe, 4 = severe to very severe

VDDS UR: _____

Case Manager: _____

Date time one: _____

| HoNOS LD item number | Question | Score |
|----------------------|---|-------|
| 1 | Behaviour problem directed to others | |
| 2 | Behaviour problem directed to self | |
| 3a | Behaviour problem destructive to property | |
| 3b | Personal behaviour problem (spitting, smearing, eating rubbish, hoarding) | |
| 3c | Rocking, stereotyped or ritualistic behaviour | |
| 3d | Anxiety, phobias, OCD | |
| 3e | Other behaviour problems | |
| 4 | Attention and concentration | |
| 5 | Memory and orientation | |
| 6 | Communication (problems in understanding) | |
| 7 | Communication (problems with expression) | |
| 8 | Problems associated with hallucinations and delusions | |
| 9 | Problems associated with mood changes | |
| 10 | Problems with sleeping | |
| 11 | Problems with eating and drinking | |
| 12 | Physical problems | |
| 13 | Seizure | |
| 14 | Activities of daily living at home | |
| 15 | Activities of daily living outside of home | |
| 16 | Levels or self care | |
| 17 | Problems with relationships | |
| 18 | Occupations and activities | |
| TOTAL SCORE | | |

Appendix VII - Health of the Nation Outcome Survey

Scoring key

Not Known, 0 = No problem, 1 = minor problem requiring no formal action, 2 = mild problem, 3 = moderately severe, 4 = severe to very severe, 9 = not known or not applicable

VDDS UR: _____

Date: _____

| HoNOS item number | Question | Score |
|-------------------|--|-------|
| 1 | Overactive, aggressive, disruptive or agitated behaviour | |
| 2 | Non-accidental injury | |
| 3 | Problem drinking or drug taking | |
| 4 | Cognitive problems | |
| 5 | Physical illness or disability problems | |
| 6 | Problems associated with hallucinations and delusions | |
| 7 | Problems with depressed mood | |
| 8 | Other mental and behavioural problems | |
| | Specify Disorder (A,B,C,D,E,F,G,H,I,J) | |
| 9 | Problems with relationships | |
| 10 | Problems with ADLs | |
| 11 | Problems with living conditions | |
| 12 | Problems with Occupations and activities | |
| TOTAL SCORE | | |

- A Phobias
- B Anxiety and panics
- C Obsessional and compulsive problems
- D Reactions to severely stressful events and traumas
- E Dissociative (conversion) problems
- F Somatization
- G Problems with appetite
- H Sleep problems
- I Sexual problems
- J Problems not specified elsewhere

Appendix VIII - Life Skills Profile LSP-16

Key 0 = good functioning, 1 = slightly unreliable, 2 = moderately unreliable, 3 = extremely unreliable

| Subscale and brief item name | Item scores | Subscale scores |
|--|-------------|-----------------|
| A Withdrawal 1 Difficulty in conversation 2 Withdrawal from social contact 3 Shows warmth 8 Maintains friendships | | |
| B Self-care 4 Well groomed 5 Clean clothes 6 Neglect health 9 Adequate diet 16 Work capacity | | |
| C Compliance 10 Look after own prescribed medication 11 Willing to take prescribed medication 12 Co-operate with health services | | |
| D Anti-social 7 Violent 13 Problems with others 14 Offensive behaviour 15 Irresponsible behaviour | | |
| E Total score (1-16) | | |