

Review of Access to Mental Health Services for People with Intellectual Disabilities



Údarás Náisiúnta Míchumais
National Disability Authority

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Foreword

The National Disability Authority (NDA) was established by the National Disability Authority Act (1999), which states that the principle function of the Authority is "to act as a central, national body which will assist the Minister in the co-ordination and development of policy relating to persons with disabilities."

Furthermore, section 8e outlines the role of the Authority "to liaise with other bodies, both corporate and unincorporated, involved in the provision of services to persons with disabilities and to facilitate and support the development and implementation of appropriate standards for programmes and services for persons with disabilities."

The NDA Act defines disability as "a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment." (NDA Act 1999).

The first strategic plan of the NDA A Matter of Rights (2000- 2002) outlined our mission to secure and promote the rights of people with disabilities in Irish society. The rights based approach to disability essentially means "viewing persons with disabilities as subjects of law." It focuses on the human being, and aims to "empower disabled persons so as to ensure their active participation in political, economic, social and cultural life in a way that is respectful and accommodating of their difference. Finally, the human rights approach to disability puts an increased emphasis on the participation of person with disabilities and their representative in the formulation and implementation of plans and policy affecting them" (Sensi, 2003). The shift to this rights based approach has been authoritatively endorsed by the United Nations.

In April 2002, the issue of access and denial to appropriate mental health services for people with intellectual disability was raised as a matter of concern by members of the NDA Board. Anxiety was expressed that people who require a service may be being denied this service, specifically owing to their intellectual disability. The members of the Authority requested that the executive of the Authority establish the facts on this issue in line with section 14.1 of the NDA Act, which authorises the Authority to "seek information on any matter which concerns the provision of programmes or services for person with disabilities (including a public body) who has overall responsibility for provision of those programmes or services...with a view to ascertaining whether 'a programme or service is required to be provided...or is being provided in an inadequate manner or unsatisfactory manner in any regard".

Discussions with a range of stakeholders confirmed that the issue of access to appropriate services for this group was a matter of concern to families, professionals in the service, service providers and service funding bodies. The NDA sought to verify the extent and detailed nature of the problem and commissioned Secta Consulting to conduct a review of the service.

This report contains:

- A review (type and quantum) of currently available services for persons with intellectual disabilities and psychiatric illness and/or challenging behaviour in Ireland;
- A review of current/future service needs for this group;
- A review of resources and structures required to deliver an appropriate service to meet identified/anticipated need.
- A proposal for multi-disciplinary, mainstreamed service provision delivered primarily in the community, with specialist residential and forensic support.

The findings of this review were as follows:

- Circa 8,000 persons in Ireland with an intellectual disability also have a psychiatric condition, 4,500 of which may require some sort of specialist assessment and treatment
- Between 900-2,400 of those with intellectual disabilities will exhibit challenging behaviours - up to two thirds of whom will have a psychiatric condition.
- Nationally, there is incoherence in strategy in this area and a lack of clarity between the Department of Health and Children's Disabilities and Mental Health Sections as to which has lead responsibility for services to this group.
- Locally, there is confusion when a person with an intellectual disability seeks support from or access to mainstream mental health services and is often turned away.

In the course of this review case studies of a number of persons with intellectual disability and psychiatric illness were also investigated by Secta to enable the Board of the NDA to more fully appreciate the implications of the absence of this service. Two such case studies are appended and provide a picture of lives marked by isolation, lack of support, stress and confusion for this vulnerable population and their families. (See Appendix I).

The review concluded that:

- Persons registered with an intellectual disability service provider do not enjoy the same right to the range of mental health services available for the general

population - diagnosis, assessment, support from community mental health teams - and importantly, treatment and rehabilitation for acute episodes.

- Services appear largely non-existent for persons with intellectual disability and psychiatric illness living in the community
- There is no clear pathway to support for people with intellectual disabilities and their carers during an acute psychiatric episode
- There has been an absence of leadership in this area, despite numerous policy documents over the years which have identified this issue and made recommendations to resolve it.

The Board of the NDA is determined that the absence of service for this client group is discriminatory and in contravention of the Equal Status Act (2000) the International Covenant on Economic, Social and Cultural Rights and the U.N. Standard Rules for the Equalisation of Opportunities for People with Disabilities. The NDA strongly endorses the calls made by the Disability Legislation Consultation Group (DLCG) for ongoing, person centred, needs assessment and service co-ordination for people with disabilities to cover the full range of service needs, including independent assessment, treatment, rehabilitation and advocacy services. (Equal Citizens, 2003)

The forthcoming disabilities legislation and the establishment of the Expert Group on Mental Health Policy by the Department of Health and Children could deliver legislative and policy change in this area. The current Northern Ireland Mental Health and Learning Disability Review [2002-2005] presents opportunities to develop work on an all-Ireland basis.

We must act to protect and promote the rights of all citizens with mental health needs. The NDA believes a comprehensive mental health service for people with intellectual disabilities must be provided, underpinned by legislation as a matter of urgency. Such a service must be integrated into the mainstream mental health service, clarified in an agreed national strategy on this issue and resourced in line with international best practice.

The Board of the NDA is grateful to those who contributed to this review of services. In particular we are grateful to the families who took the time to share their experiences with us. Finally, we wish to thank the team of Researchers at Secta Consulting Limited: Grainne Stafford, Martin Spollen, Dr G. Johnston Calvert and Prof. Roy McConkey, for their work in shedding light in this important area.

Angela Kerins Chairperson
National Disability Authority

Executive Summary

Context

Ireland in recent years has enjoyed increased investment in its health and social care economy - helping to modernise services, raise standards and extend provision to more citizens in need. In generic mental health services, for example, the development of Community Area Mental Health teams is helping to support people with a range of mental health difficulties to live in the community where appropriate, as one alternative to traditional institutional based care. The value of early intervention, carer support and timely assessment and treatment is well recognised. In generic intellectual disability services, likewise, increased investment has extended provision of day centre places, respite places, and broadened options on residential services and supported living.

However, there is a significant number of people whose needs intersect both services - being those with a dual diagnosis of intellectual disability and psychiatric illness and/or challenging behaviour. The published epidemiological evidence suggests that in the State:

- Circa 8,000 persons with an intellectual disability also have a psychiatric condition, 4,500 of which may require some sort of specialist assessment and treatment; and
- 900-2,400 of the intellectually disabled population will exhibit challenging behaviours - up to two thirds of whom will have a psychiatric condition.
- Individuals with a dual diagnosis often have distinct mental health service needs from the general population. The Psychiatry of Learning Disability is a recognized subspecialty, for example, reflecting clinical and diagnostic aspects of difference.
- Additional considerations arise from variation in communication and comprehension impairment, vulnerability in mixed group settings, and the ability of individuals to give consent to assessment and treatment.

This report assesses the service needs of the dual diagnosis group, and asks whether their needs are being met consistent with Ireland's international obligations as regards the rights of people with disabilities. These obligations are that:

- All citizens should have acceptable levels of access to appropriate mental health services; and
- Such services should be suited to their needs, and be provided in a manner that respects their fundamental human rights and dignity; and

- Citizens with disabilities should enjoy equality of service access and provision, with measures taken to ensure that no direct or indirect discrimination arises owing to the nature or severity of disabilities.

Summary of findings

In summary, the findings of the research are as follows:

- The general population with mental health needs are catered for by the generic mental health services - offering assessment, treatment and continuing care in a range of settings including in hospitals, residential facilities and in the community. However, we note that generic mental health services are widely reported as underfunded in relation to service demand;
- By comparison, persons registered with a generic intellectual disability service provider find it even more difficult or impossible to gain access to appropriate mental health services for assessment, treatment or continuing care. In some areas, local informal arrangements do exist to provide emergency assessment and treatment - but a defined service appropriate to the needs of the dual diagnosis group does not exist nationally at present;
- The difference in experience arises mainly because of policy confusion in the sector, both at national level (in the Department of Health and Children) and 'in the field', as to which of the statutory services has lead responsibility for planning and/or delivering mental health services to the intellectually disabled population. Funding issues between the services also appear to influence attitudes;
- There are also outstanding issues to be addressed in ensuring that a comprehensive legislative base exists to support high quality services reflecting the rights of individuals with disabilities and mental health conditions. Progress is being made but, for example, many professionals dealing with mental health issues in dual diagnosis patients in residential settings continue to work outside the protection of current legislation;
- The health of persons with a dual diagnosis suffers as a result - conditions are left undiagnosed or untreated that are routinely addressed in the general population by the generic mental health services;
- This provides the basis for current inequality of treatment between the dual diagnosis group and the general population with mental health needs in Ireland.

To address the deficiencies noted, the research has explored the potential contribution of various therapeutic interventions, care models and settings and the views of a wide range of stakeholders.

Summary of recommendations

There is limited empirical evidence available on the comparative efficacy of models of care for the dual diagnosis group. Recommendations in this report are therefore based on a consensus of views from prior reports in this area in Ireland and the researchers' own findings during recent consultation with service commissioners, providers and users'/carers' representatives.

Formal recommendations are set out in detail in the body of the report. In summary, these are:

- Provision of services and development of new services for this group, which should be underpinned by legislation and clear statements on access, standards and inspection, etc;
- The Department of Health and Children (DoHC) should publish a national policy statement and service framework for mental health services appropriate to the needs of the dual diagnosis group (consistent with the above point). This should be accompanied by a strategy for the development of such services, their management and funding;
- Services should be planned by Regional Health Offices (RHOs) for their resident populations - with consistency at national level in standards of care and access criteria across all providers;
- Service delivery should largely focus on specialist multi-disciplinary teams who are dual trained in intellectual disability and mental health. Their aim should be to maintain people in their normal community setting through timely assessment and treatment, supporting informal and professional carers, providing social service input, and linking efficiently with specialist services when required;
- Four regional units, geographically distributed, must be available to support community teams by providing specialist acute assessment and treatment for the dual diagnosis group. These units, operated by the statutory and/or voluntary sectors, would themselves be supported by step-down capacity preferably in the community and by the active co-operation of referral agencies;

- Distinct forensic provision is made in four geographically distributed centers offering both semi-secure and low secure beds - lined to the Central Mental Hospital, Dundrum;
- Full consideration to staffing issues is required in order to ensure a stable and sustainable service, supporting the highest standards of care, and providing a rewarding career for those in the services.

Despite limited empirical evidence, the research found a high degree of consistency amongst stakeholders in their views about dual diagnosis service needs and current gaps in provision in Ireland.

This report recommends service development to ensure that the mental health needs of the dual diagnosis population in Ireland are adequately addressed. The need for these services is growing, and provision should be addressed as a matter of urgency.

Section I – Introduction

In December 2002, the National Disability Authority (NDA) commissioned Secta to undertake research on the health and social care requirements of persons with intellectual disabilities¹ in Ireland who present with mental health disabilities. Such people are referred in this document as having a 'dual diagnosis'.

This report presents the findings and recommendations of the research. It covers:

- A definition of the groups and conditions included in the study remit;
- An estimation of the prevalence of dual diagnosis in Ireland;
- A review of the rights of persons with a dual diagnosis under international law to access appropriate services, how those rights are currently enacted in Irish legislation, and issues arising;
- A review of service provision in Ireland, and commentary on current gaps in provision;
- A review of treatment approaches and models of care reported in the literature;
- Recommendation for the establishment and maintenance of appropriate services to meet the mental healthcare needs of persons with a dual diagnosis - based on agreed principles and contemporary evidence of effective interventions; and
- The costs of such provision and consequences of non-provision.

The research questions whether persons with a dual diagnosis in Ireland have equality of access to an appropriate range of mental health services compared to the general population with similar needs - and recommends change where warranted.

The aim of the research is to inform policy development in this area, consistent with the NDA's core values of a rights-based approach and quality services. This study is focussed entirely on the range of mental health and challenging behaviour

¹ The terms Intellectual Disability and Learning Disability are treated as equivalent and used interchangeably where appropriate in this report – although the former is now in more contemporary favour, Mental handicap is an older term less in use today. Mental Retardation is a term used in North America.

services required to meet the specific needs of the dual diagnosis group. This means that:

- Whilst recognising that full participation by this group in society requires intervention across a range of sectors (education, training and employment, social security, etc.), these interactions are beyond the terms of reference of this research;
- The need for, or supply of, generic intellectual disability services or mental health services is not addressed per se.

The research has involved:

- A review of published literature on the prevalence of dual diagnosis conditions, contemporary issues in assessment, care management and therapeutic interventions,
- A review of a wide range of policy and consultative documents that have emanated from Government, professional and advocacy groups over the past 20-25 years - many of which highlight consistent messages about gaps in provision and promote a similar range of solutions based on multi-disciplinary team-working across community and residential settings;
- A systematic review of legal and rights aspects, both nationally and internationally pertaining to persons with a disability and disability services;
- A postal survey of both statutory and voluntary sector providers of services to the relevant population - assessing views on current services, gaps in provision, priorities for change and perceived barriers going forward;
- Face-to-face interviews with a range of key stakeholders, representing inter alia patient advocacy, statutory and voluntary providers of care, representatives of health and care professionals, the Department of Health and Children (DoHC), and other health and social care agencies; and
- Visits with frontline services, staff and service users.

Acknowledgements

The researchers are grateful for the support and input to this review of a large number of individuals and organisations with interest in this client group. See Appendix 2 for a list of contributors.

Section 2 - Definition of Client Group & Contemporary Evidence on Prevalence

This section defines the population covered by this research, as agreed with the NDA. The section then presents contemporary evidence from the literature on the prevalence of dual diagnosis in Ireland and internationally.

Groups covered by the research

Those covered by this study include the following:

- People with intellectual disabilities including those considered to fall within the categories of 'mild' and 'borderline';

Who also have a diagnosis of

- Recurring psychiatric illnesses and/or severe challenging behaviours. People who have committed offences that may or may not have come before the courts are also included;

and

- Who may be children, adults and elderly persons (aged over 65 years).

The following group do not fall under the remit of this research:

- Teenagers and adults who have acquired brain injury which results in cognitive impairments, psychiatric illnesses and challenging behaviour. However children with acquired brain injury that occurs during the developmental period could be considered within the sub-population.

Description of terms used

Intellectual disability

Internationally the definition of an intellectual disability has broadened beyond the use of IQ scores. This applies also to the sub-groupings, such as mild, moderate and severe intellectual disability. Hence in the literature different criteria may be used in defining the population of people with learning disabilities. Moreover it has been suggested that social and intellectual disadvantage may be more meaningful than scores on intelligence tests in determining and meeting the needs of the subpopulation reviewed here (Simpson and Hogg, 2001).²

² Simpson, M.K. and Hogg, J. (2001) Patterns of offending among people with intellectual disability: A systematic review. Part I: Methodology and prevalence data. *Journal of Intellectual Disability Research*, 45, 384-398

Severe challenging behaviours

The term 'challenging behaviour' embraces a great variety of behaviours that also vary in terms of their frequency, severity and seriousness for the individual and other persons. Hence variations in prevalence rates across different studies may reflect variations in definitions used to define these behaviours.

A commonly accepted definition provided by Emerson (2001)³ is:

Severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities.

Psychiatric illness

Likewise the range and severity of mental illnesses is wide and past studies have not consistently used the same criteria. Moreover the number of people experiencing an acute episode will be less than those with a history of mental illness.

Co-occurrence of psychiatric illnesses and challenging behaviours

A proportion of people showing severe challenging behaviours will have psychiatric illnesses, but not all will. Conversely, a proportion of people with psychiatric illness will not show challenging behaviours.

The literature on occurrence and co-occurrence of such conditions is explored in the sections below.

Prevalence of intellectual disability in Ireland

The latest report of the National Intellectual Disability Database (NIDD) shows a total of 25,448 persons with intellectual disability known to service providers in 2002. This represents a national prevalence rate of around 6.49 persons per 1,000 population, comprising:

- 2.4 persons per 1,000 with a mild intellectual disability; and
- 3.7 persons per 1,000 with moderate/severe/profound disabilities (a figure commonly reported in other studies).

³ Emerson, E. (2001): Challenging Behaviour: Analysis and intervention in people with learning disabilities (2nd Edition). Cambridge: Cambridge University Press.

The prevalence of persons with mild disabilities is likely to be an undercount because a proportion of adults with mild or borderline intellectual disabilities will not be known to services until they present with a problem. For example, the prevalence rate of 15-19 years old with mild intellectual disability in Ireland is reported at 5.80 per 1,000 population.

Of particular note:

- Local and regional variations are commonly reported in the prevalence figures - there is not a uniform distribution of persons with intellectual disability across the country. For example, the range in overall prevalence across the Health Boards/Authority in Ireland for 15 - 19 years old (for those with moderate, severe and profound intellectual disability combined), is from 3.84 per 1,000 in ERHA area to 4.18 per 1,000 in WHB. Similarly in Northern Ireland, the prevalence rates varied within one Health and Social Services Board from 6 to 9 per 1,000 (McDonald and MacKay, 1996);⁴
- There appears to be a strong association between intellectual disability and social deprivation with higher prevalence found in areas with higher deprivation (see Morgan, Ahmed and Kerr, 2000).⁵ This may be particularly so for a sub-population of persons with mild/borderline intellectual disabilities and psychiatric illnesses and/or challenging behaviours.

This provides a baseline within which to look at prevalence of dual diagnosis with psychiatric illness and/or challenging behaviours.

Prevalence of challenging behaviours

Irish estimates

A number of unpublished studies have been undertaken of challenging behaviours found in clients using intellectual disabilities services in Ireland. The estimates range from 14% of clients in a Southern Health Board region (Connelly et al, 1995) through 29% in the Galway area (Walsh et al, 1995) and 37% in Dublin

⁴ McDonald, G. and MacKay, D. (1996) The prevalence of learning disability in one Health and Social Services Board in Northern Ireland. *Journal of Intellectual Disability Research*, 40, 550-556.

⁵ Morgan, C.L, Ahmed, Z. and Kerr, M.P. (2000) Healthcare provision for people with learning disability: Record-linkage study of epidemiology and factors contributing to hospital care uptake. *British Journal of Psychiatry*, 176 37-41.

(Mulrooney et al, 1997).

A survey in a large Cork service reported 50% of people with mild disabilities and 75% of those with profound intellectual disabilities had challenging behaviours (Desmond et al, 2000).⁶

This variation arises from differences in samples used in the different studies as well as definitions of challenging behaviours. However, if a median percentage across these studies of 30% is used, this would suggest that 22 people per 10,000 have intellectual disabilities and challenging behaviours. The severity of these behaviours is not reported.

Challenging behaviour is not currently a recognised medical diagnosis, therefore there are subjective definitional differences between studies into its prevalence.

British population estimates

Quershi (1994)⁷ screened a sample of over 4,200 people in seven administrative districts in the North-West of England. Further studies were then undertaken by Emerson (2001)⁸ using similar methods in the same areas. Using the precise definition noted earlier, these studies reported that for every 10,000 of the general population there are 2.4 people on average who had an intellectual disability and serious challenging behaviours. (The range in the seven areas studied was from 1.41 to 3.62 persons). This equates to an estimated rate of 1 in 13 persons (7.3%) with an intellectual disability also having serious challenging behaviours.

In these studies, physical aggression was present in 2.1% of the intellectually disabled population; 1.3% had frequent and severe self-injury and 1.3% were destructive of property. (Other behaviours were present in 3.4% of the population studies).

⁶ All these studies were cited in the Report by Eastern Regional Health Authority (2002) on "Proposed Specialist Service for Clients with Intellectual Disabilities presenting with severe challenging behaviour and/or psychiatric illness".

⁷ Qureshi, H. (1994). The size of the problem In E. Emerson, P. Mc Gill, and J.Mansell (eds.). Severe learning disabilities and challenging behaviours: Designing high quality services, Cheltenham: Stanley Thornes Publishers.

⁸ Emerson, E. (2001): Challenging Behaviour: Analysis and intervention in people with learning disabilities (2nd Edition). Cambridge: Cambridge University Press.

Within the child population (0-19 years) the estimation of children with severely challenging behaviours has been estimated at 1 per 10,000 of the population (Mental Health Foundation, 2001).⁹

United States

A survey of over 91,000 persons served by the California Department of Developmental Disabilities (Borthwick-Duffy, 1994)¹⁰ reported figures that were over twice as high as in Britain - 6.3 persons per 10,000 of the general population, or 14% of those with learning disabilities.

One reason is that these researchers included all people with self-injurious behaviours while the British studies had only included those with serious self-injurious behaviours.

Again 2.1% of the intellectually disabled population had aggressive behaviours; 2.2% had frequent and severe self-injury; 9.3% frequent self-injury and 7.1% were destructive of property (NB People could show more than one behaviour).

Applying prevalence rates to Ireland

The UK and US studies are among the best available to date on which to base estimates for other populations.

Thus if the rate of challenging behaviours is taken to fall between 2.4 and 6.3 per 10,000 of the general population and applied to the Republic of Ireland with a population of 3.8 million, then:

- There are likely to be between 912 and 2,400 intellectually disabled people with severe challenging behaviour
- Of which around 560 persons would show physically aggressive behaviour

The latest report of the National Intellectual Disability Database identifies a total of 284 persons who were resident intensive placements due to challenging behaviours in 2002 and indicates a shortage of 416 such places between 2003 and 2007.

⁹ Mental Health Foundation, (2001) Learning Disabilities: The Fundamental Facts. London-. Mental Health Foundation.

¹⁰ Borthwick-Duffy, S. (1994) Epidemiology and prevalence of psycho-pathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, 62, 17-27

However, the surveys conducted in Irish services would indicate that still more persons with intellectual disability - up to 8,000 - exhibit some form of challenging behaviour.

Variations in challenging behaviours

These overall figures are subject to variation as follows:

- In the British studies, the rates could be over twice as high in one administrative area (such as a county) than in another. It is not clear why this should be although it may be linked to the variations found in intellectual disability in general or to deprivation.
- The incidence of challenging behaviours is much higher in institutional settings (e.g. Kiernan and Moss, 1990¹¹ report a 40% incidence) than among people living in residential settings. For example, Mansell et al, 2002,¹² reported that 35% of 495 residents in 99 homes recently provided by a single voluntary agency throughout England had severe challenging behaviours. Of these 24% showed aggression. Likewise in the California study, 49% of those in institutional settings showed challenging behaviours compared to 24% of larger community based residences and 9% in smaller homes (1-6 places) or with family carers.
- Severely challenging behaviours are more common among people rated as being profoundly and severely disabled than those with moderate and mild disabilities. In particular people with impairments of vision or hearing, communication difficulties and poorer social skills were found to show more challenging behaviours. In the California study for example, the percentages of people showing one or more forms of challenging behaviours were: 7% mild intellectual disabilities; 14% moderate; 22% severe and 33% profound.
- Boys and men are more likely to show challenging behaviours than girls and women; especially for aggression and property destruction than for self-injury.
- Challenging behaviours appear to increase with age; reaching a peak between 15-34 years and then they start to decline.

¹¹ Kiernan, C. and Moss, S. (1990) Behaviour disorders and other characteristics of the population of a mental handicap hospital. *Mental Handicap Research*, 3, 3-20.

¹² Mansell, J., Ashman, B., Macdonald, S. and Beadle-Brown, J. (2002) Residential care in the community for adults with intellectual disability: needs, characteristics and services. *Journal of Intellectual Disability Research*, 46, 625-633

- People with particular syndrome are also more likely to show certain forms of challenging behaviours, for example those with autism, Fragile X, Prader-Willi.
- People with epilepsy tend to show more challenging behaviours.

Hence severe challenging behaviours are more likely to be found among males, aged 15 to 35 years with severe and profound intellectual disabilities and additional deficits who are in congregated residential accommodation.

Persistence of challenging behaviours

All of the above studies took a snap-shot of the numbers of people showing challenging behaviours. There have been relatively few studies that have explored the persistence of these behaviours over time. Kiernan et al (1997)¹³ reported that of the 179 people identified as showing 'more demanding' challenging behaviours when first seen; 63% still showed them when followed up some seven years later.

Likewise Turner and Sloper (1996)¹⁴ found that 80% of children with Down Syndrome still showed the same challenging behaviours over a ten year period.

Emerson (2001)¹⁵ reviewed a range of studies that followed up people with specific challenging behaviours across a range of settings such as institutions and also those who had been admitted for treatments to special centres or hospitals. He concluded:

The available evidence does suggest that severe challenging behaviour may be highly persistent despite discharge from specialized congregate care settings or significant changes in staffing resources and the quality of the physical environment (p.30).

This sub-population will have continuing care needs over extended periods of time. Hence generic intellectual disability services must be equipped to deal with

¹³ Kiernan, C., Reeves, D., Hatton, C. et al (1997) The HARC Challenging Behaviour Project. Report 1-. Persistence and change in the challenging behaviour of people with learning disabilities. Manchester: Hester Adrian Research Centre, University of Manchester.

¹⁴ Turner, S. and Sloper. P. (1996) Behavioural problems among children with Downs Syndrome: prevalence, persistence and parental appraisal. *Journal of Applied Research in Intellectual Disability*, 9 , 129-145

¹⁵ Emerson, E. (2001): *Challenging Behaviour: Analysis and intervention in people with learning disabilities* (2nd Edition). Cambridge: Cambridge University Press.

their needs beyond crisis periods. This is further explored in later sections on appropriate models of service.

Prevalence of psychiatric illnesses

Until recently this topic has received less attention than that of challenging behaviours, and is particularly beset by definitional and assessment criteria.

However a recent review of research studies for the World Health Organisation (WHO) estimated that 50% of people with severe and profound learning disabilities will have a mental health problem at some point in their lives as will 20-25% of those with mild and moderate learning disabilities (IASSID, 2000).¹⁶

Moreover these persons seem to experience the full range of psychiatric illnesses with affective disorders and psychoses the more common.

Cooper and Bailey (2001)¹⁷ undertook psychiatric examination of 207 persons randomly selected from a register of all persons with an intellectual disability in one English County. They report the percentages of people presently experiencing the following 'psychiatric disorders': behaviour disorder 15%; autism 6.7%; anxiety disorders 5.7%; dementia/possible dementia 5.5%; depression 4.2%; schizophrenia 2.7%. In all 30% of the people examined had an ongoing psychiatric condition. These results were broadly comparable to similar studies done in London and Denmark. The proportions are higher than the proportions of non-intellectually disabled people found in a large-scale survey of households in England (Meltzer et al, 1995).¹⁸

A study in Wales (Morgan, Ahmed and Kerr, 2000)¹⁹ which identified over 1,500 persons with an intellectual disability in one administrative area of 434,000 persons found that in one year 16.5% had a primary or secondary diagnosis of

¹⁶ International Association for the Scientific Study of Intellectual Disabilities (IASSID) 2000: Mental health and intellectual disabilities: Addressing the mental health needs of people with intellectual disabilities. Report by the Mental Health Special Interest Research Group of IASSID to the World Health Organisation.

¹⁷ Cooper, S. A. & Bailey, N. M. (2001): Psychiatric disorders amongst adults with learning disabilities: prevalence and relationship to ability. *Irish Journal of Psychiatric Medicine*, 18, 45-53

¹⁸ Meltzer, G., Gill, B., Petticrew, M. and Hinds, K. (1995): The prevalence of psychiatric morbidity among adults living in private households: OPCS survey of psychiatric morbidity in Great Britain, Report 1. HMSO: London.

¹⁹ Morgan, C.L, Ahmed, Z. and Kerr, M.P. (2000) Healthcare provision for people with learning disability: Record-linkage study of epidemiology and factors contributing to hospital care uptake. *British Journal of Psychiatry*, 176, 37-41.

psychiatric illness that brought them into contact with in-patient or out-patient services.

Emerson (2003)²⁰ reported around 2 in 5 of young people aged 11 to 15 years with learning disabilities had a diagnosable mental health problem compared to one in ten adolescents who do not have learning disabilities. (This was based on national sample of families in England). The two groups differed mainly in conduct disorders (ADHD), anxiety and depression.

Some caution must be exercised in extrapolating the results of small-scale surveys to whole populations. That said, this data suggest that among the intellectually disabled population of the Republic of Ireland there are in the region of around 8,000 persons with a psychiatric condition of whom some 4,500 may require some form of specialist assessment and treatment.

Variations in psychiatric disorders

These overall figures are subject to variation as follows:

- Psychiatric disorders appear to be more commonly reported among those with severe and profound disabilities than those with moderate and mild disabilities. (However people with mild disabilities are more likely to be admitted to in-patient facilities: see later section).
- Psychiatric disorders are three times more commonly reported among ex-institutional patients than those in community settings.

Prevalence of challenging behaviours and psychiatric illnesses

Emerson, Moss and Kiernan (1999)²¹ identified three possible ways in which psychiatric disorders may be associated with challenging behaviour:

- Challenging behaviours may represent the atypical presentation of the core symptoms of a psychiatric disorder in people with intellectual disabilities (.e.g. self-injurious behaviours may represent obsessive compulsive disorders).

²⁰ Emerson, E. (2003) The prevalence of psychiatric disorders in children and adolescents with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 47,51 -8.

²¹ Emerson, E. Moss, S. & Kiernan, C. (1999). The relationship between challenging behaviours and psychiatric disorders in people with severe developmental disabilities. In N. Bouras (Ed.) *Psychiatric and Behavioural disorders in development disabilities and mental retardation*. Cambridge: Cambridge University Press.

- Challenging behaviours may occur as the secondary feature of psychiatric disorders. (e.g. aggression may be linked with depression as a means of expression to those with poor verbal skills).
- Psychiatric disorders may establish a motivation base for the expression of challenging behaviours (e.g. a person who is depressed is unwilling to engage in social activities and learns that aggressive behaviours will terminate these events. Hence episodes of depression become linked with increases in challenging behaviours).

However there has been little application of this approach into population prevalence studies.

Recent studies in Northern Ireland (Cunningham et al, 2002)²² of people admitted to a specialist assessment and treatment facility (primarily because of aggressive behaviours) suggest that two-thirds of those demonstrating severely challenging behaviours had a mental health problem.

However, the community studies of challenging behaviours reported earlier suggest that around 50% of the intellectually disabled population show neither psychiatric problems or challenging behaviours; around 15% show behavioural disorders and the remaining 35% have psychiatric disorders that may present along with challenging behaviours.

Current data is not adequate on which to base population projections for the Republic of Ireland - suffice to say that of the estimated 900-2,400 persons with severely challenging behaviours given earlier it is likely that upwards of two-thirds (500 - 1,600) will have a psychiatric condition.

Prevalence of offending behaviours in ID population

The needs of people with intellectual disabilities who break the law are generally thought to be better met within health and social services than through the criminal justice system (Murphy and Fernando, 1999).²³ This means it can be very difficult to determine the numbers of people who commit offences as they may not come before the courts or the police may decide not to press charges.

²² Cunningham, M., Taggart, L., Marriot, C. and McConkey, R. (2002): The prevalence of psychiatric disorder in the acute in-patient population of a hospital for people with learning disabilities. Paper presented at the IASSID European Conference, Dublin

²³ Murphy, G and Fernando, S. (1999) Services for people, with challenging behaviour and mental health needs at risk of offending. *Tizard Learning Disability Review*, 4, 3, 31-39.

Simpson and Hogg (2001)²⁴ concluded after a systematic review of published studies internationally that "there is no compelling evidence that the prevalence of offending among people with ID is higher than for the wider population" (p.394).

There is some evidence to suggest that the relative prevalence of sexual offending (particularly against younger and male children), criminal damage and burglary (but not theft) are higher among people with borderline disabilities. Arson also seems to be more common (Day, 1993).²⁵ However there is little reliable data on which to base estimates of need for secure/semi-secure accommodation (Fraser, 2002).²⁶

An international working party (IASSID, 2000)²⁷ noted that additional mental health problems, drug and alcohol abuse, and social factors, such as homelessness and unemployment, may increase the risk of offending by a person with an intellectual disability and lead to further social exclusion. Preventive measures would include meaningful employment opportunities, and housing, together with assessment and treatment services, and that should be available to people with intellectual disabilities, including those with mild/borderline disabilities whose need are often ignored in present social care systems.

Persons who pose an ongoing danger to others may need to be detained against their will. Full legal safeguards need to be in place for recognised places of detention outside of the criminal justice system. More attention needs to be given to preventative social measures.

Characteristics of people admitted to specialist units

Another approach to the identification of people with additional needs is to examine the characteristics of those admitted to specialist units. The following

²⁴ Simpson, M.K. and Hogg, J. (2001) Patterns of offending among people with intellectual disability: A systematic review. Part I: Methodology and prevalence data. *Journal of Intellectual Disability Research*, 45, 384-398

²⁵ Day, K. (1993): Mental health services for people with mental retardation: a framework for the future. *Journal of Intellectual Disability Research*, 37 (Supplement, 1), 7-15.

²⁶ Fraser, W.I. (2002) Forensic learning difficulties - the evidence base: Executive Summary. *Journal of Intellectual Disability Research*, 46, Supplement 1, 1-5.

²⁷ International Association for the Scientific Study of Intellectual Disabilities (IASSID) 2000): Mental health and intellectual disabilities: Addressing the mental health needs of people with intellectual disabilities. Report by the Mental Health Special Interest Research Group of IASSID to the World Health Organisation

conclusions can be drawn from studies reported to date from England, Sweden, Finland and Northern Ireland.

- The majority of patients are classed as having mild/borderline intellectual disabilities.
- The majority will have a psychiatric illness or a history of such. Psychoses and depression are the most common reasons for admission.
- Aggression to others is a main trigger for admission.
- The mean age tends to be in mid-30s.
- Upwards of 25% of people were repeat admissions within a two-year period.
- People with a history of institutionalisation or residential care as children are more likely to be admitted.
- Only a minority live with family carers; most people are in some form of residential accommodation or they are homeless.
- A sizeable proportion of people - around two in five people - may need to be detained under Mental Health legislation.

The population of person admitted to specialised units form a particular subset of persons with intellectual disabilities; typically those with mild or borderline disabilities living in inappropriate accommodation and who have a history of psychiatric illnesses. It is likely that neither mainstream mental health services or intellectual disability services have responded adequately to the needs of this client group. However the level of repeat admissions suggests that special units must be linked with ongoing community support services which are often absent (Xenitidis et al, 1999),²⁸ and this is discussed further in later sections on appropriate models of service.

²⁸ Xenitidis, K. I., Henry, J., Russell, A. J., Ward, A. & Murphy, D. G. M. (1999): An inpatient treatment model for adults with mild intellectual disability and challenging behaviour, *Journal of Intellectual Disability Research*, 4 3 (2), 128-134

Section 3 - Rights and Legislation

International treaties & obligations

rights of disabled citizens to equality of access to services (including health and social care services), and the rights of the mentally ill to appropriate care in pursuance of quality of life and opportunity.

Under the United Nations (UN), the International Covenant on Economic, Social and Cultural Rights (ICESCR) obligates states party to the Covenant:

to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.

Furthermore, Article 12 of the ICESCR provides for:

the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

The UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (the UN MI Principles) spell out what is expected of signatory states in full compliance with ICESCR obligations. Principle I of the UN MI Principles states:

All persons have the right to the best available mental health care

In relation to the provision of mental health services, UN MI Principle 7(1) provides that:

Every patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives.

Principle 9(1) adds that:

Every patient shall have the right to be treated in the least restrictive environment.

Article 3 of the UN Declaration on the Rights of Disabled Persons sets out what is expected of states in their treatment of persons with mental illness:

Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizen.

Specifically in relation to children, Article 23.2 of the UN Convention of the Rights of the Child provides that:

State Parties recognise the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources...

The import of these measures is that:

- All citizens should have acceptable levels of access to appropriate mental health services; and
- That such services should be suited to their needs, and be provided in a manner that respects their fundamental human rights and dignity; and
- That citizens with disabilities should enjoy equality of service access and provision, with measures taken to ensure that no direct or indirect discrimination arises owing to the nature or severity of disabilities.

Despite ratifying these international treaties, the UN Committee on Economic, Cultural and Social Rights (CESCR) had cause to report in 2002 on:

persistence of discrimination against persons with physical and mental disabilities [in Ireland] especially in the fields of employment, social security benefits, education and health.

The Committee expressed concern that:

The principles of non-discrimination and equal access to health facilities and services was not embodied in the recently published National Health Strategy.

The Irish Government have legislated on equality for disabled citizens across a broad range of areas, and on action to combat discrimination. However, the CESCR comments indicate that further effort is required to discharge obligations more fully particularly with regard to disabled citizens and health services.

In the context of services considered in this study, ICESCR compliance would mean equality of access between disabled and non-disabled citizens to appropriate mental health and behavioural services. Later sections of this report address this issue directly and indicate that, at present, such equality of access does not exist.

Legislation in Ireland

At the time of writing this report, the Mental Treatment Act (1945) is still on the statute book. The Mental Health Act (2001) has only partly been implemented - so far to establish the Mental Health Commission.

The primary purpose of mental health legislation is to offer assessment and treatment to those suffering mental disorder who, due to their disorder and diminished capacity, are likely to cause harm to themselves or others and who are unable or unwilling to accept such treatment. Legislation must balance the interests of the individual with the protection of society.

There is no single legislative provision in Ireland for those persons with Intellectual Disability. For instance, while the Mental Health Act makes provision for most of the issues relating to such persons, the Mental Treatment Act applies in relation to compulsory admissions. The Child Care Act (2001) also overlaps with the Mental Health Act as does, to a lesser extent, the Criminal Law (Insanity) Bill (2002).

The Mental Health Act falls within the remit of the Department of Health & Children whereas the Child Care Act and the Criminal Law (Insanity) Bill are within the remit of the Department of Justice, Equality and Law Reform. Consequently this overlap is likely to cause problems. The Criminal Law (Insanity) Bill does not define the term 'Mental Disorder' as that contained in the Mental Health Act 2001. It has a separate Mental Health Review Board.

Main provisions of the Mental Health Act (2001)

The main provisions of the mental Health Act (2001) are:

- Establishment of Mental Health Commission
- Establish Mental Health Tribunal
- Appoint Inspector of Mental Health Services
- Develop Register of 'Approved' Centres
- Monitor consent to treatment for ECT and psychosurgery
- Admission Criteria specified in the definition of mental disorder

Terminology

"Mental Illness" means the state of mind of a person which affects the persons thinking, perceiving emotion or judgement to the extent that he/she requires care or medical treatment in his/her own interest or in the interest of another person or persons

"Mental Disorder" includes severe dementia and significant mental handicap

"Severe Mental Handicap" means a state of arrested or incomplete development of mind of a person, which includes significant impairment of intelligence and social functioning and abnormally aggressive or seriously irresponsible conduct on the part of the person.

Admissions and treatment:

Involuntary admissions are to 'Approved ' Centres only.

Application can be made by a spouse or relative of the person, an authorised officer or a member of the Garda Siochana.

Development of the Mental Health Act 2001

Consultation for the Mental Health Act began in 1992 with the issue of the Green Paper on Mental Health. This Paper was wide-ranging - reviewing International law and principles in relation to mental disorder with particular note taken of Human Rights and European law. The Paper was in two parts - Part 1 dealt with Mental Health Services and Part 2 with Mental Health Legislation. This Paper took cognisance of the need for services and standards especially for those patients deprived of their liberty for compulsory treatment by the State.

The publication of the White Paper - A New Mental Health Act - followed in 1995. Surprisingly, this Paper did not address Mental Health Services, dealing only with legislative issues. It did, however, refer to the development of psychiatric services included in the Mulcahy Report²⁹ which was published in 1996. Appendix 2 of this Paper summarised the European Convention of Human Rights and the U.N. Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care.

Limitations of the Mental Health Act (2001)

Mentally Disordered Offenders and Adult Care Orders are not addressed in this legislation. Other issues omitted include Reciprocity of Services, Guardianship, Court of Protection and the need for an Official Solicitor, the power of attorney

²⁹ Department of Health (1996). Discussion Document on the Mental Health Needs of Persons with Mental Handicap (Mulcahy Report). Department of Health, Dublin

extension to include health care decisions and a right to a minimal standard of service provision by statute.

Children must be afforded the same rights as adults. However, raising the age of consent from 16 years of age to 18 years of age would appear to preclude this age group from access to Mental Health Tribunals.

The Act also makes provision whereby children may be admitted to an 'approved' centre by order of the Court without any examination by a Consultant Psychiatrist.

This may be a serious infringement of children's civil rights. Furthermore, this provision is in conflict with the Child Care Act (2001).

In addition, there is no statutory provision for the separation of children and adults in 'approved' centres.

These areas are of particular importance to those with intellectual disability.

The remit of the Inspector of Mental Health Services and that of the Mental Health Commission is currently open to interpretation. It is important that their remit extends to include those who are both detained in 'approved' settings and those de-facto detained both in approved and non-approved centres.

At present only six beds provided by Stewarts Hospital Services Ltd in Dublin are classified as 'hospital beds' and therefore inspected by the current Inspector of Mental Hospitals.

Therefore, the vast majority of individuals with intellectual disability who reside in community accommodation, and who may also be receiving medication or other psychiatric treatment to which they have not had the capacity to consent, are 'de facto detained' and are not subjected to any formal independent monitoring.

Conclusion

Present mental health legislation is only applicable in practice to a small number of individuals with intellectual disabilities. The vast majority of those with intellectual disability who are receiving psychiatric treatment within the specialist services are outside the remit of the protective legislation. This matter needs to be addressed with a degree of urgency.

Section 4 - Interventions and Care Models

This chapter summarises current discourse and best practice with regard to treatment interventions and service models for people with intellectual disabilities and psychiatric illness and/or challenging behaviour. However, the authors found little consensus and limited evidence-based practice.

Therapeutic interventions

The literature is sparse on identifying efficacious treatment approaches with this client group. In part this is due to the neglect of their particular needs, the definitional difficulties noted earlier and the lack of suitable measurement tools to assess changes in mental health states and challenging behaviours.

Psycho-pharmacological interventions constitute the most common form of treatment. Studies undertaken in North America and UK suggest that in many localities approximately one in two people with intellectual disabilities with severe challenging behaviours are prescribed anti-psychotic medication. Moreover clients receiving a cocktail of drugs will require careful managing and regular review. Even so there is little empirical evidence to demonstrate the efficacy of drugs per se. However advances in identifying neuro-biological determinants of certain behaviours does hold out the hope of developing specific drug therapies.

The use of behavioural therapies also holds much promise. These consist of detailed behavioural analysis to determine the functions of the behaviour and the use of differential reinforcement schedules to modify existing behaviours and to build more purposeful behaviours. There is evidence that these approaches can bring about rapid, significant and widespread reductions in severely challenging behaviours although there is less empirical data that these are generalised to new situations and maintained over time.

'Talk therapies' such as psychotherapy and cognitive behaviour therapy have been largely under-used with this population on the basis that the population lacked the requisite communication and linguistics skills required to actively participate in such therapeutic approaches. Latterly this view has been challenged and case reports are appearing suggesting that these therapies can be successful with people who have intellectual disabilities and mental health problems.

In a recent report in the American Journal on Mental Retardation (Aman et al., 2000),³⁰ an expert panel of psychologists and psychiatrists developed guidelines on the 'treatment of psychiatric and behavioural problems' for people with a learning disability. The panel identified seven psychosocial interventions in addition to medication that they would possibly use to treat people with depression, schizophrenia and generalised anxiety disorders. The three most highly recommended in almost every situation were:

- Client / Family/Carer Education;
- Applied Behaviour Analysis; and
- Managing the Person's Environment.

This highlights the importance not only of the need for multi-methods of interventions but of ensuring that these treatments fully involve the persons and/or their carers and that they are rooted within the natural environment if they are to be fully effective.

The IASSID (2000)³¹ working party on this topic concluded that:

"the treatment of mental ill-health and behaviour disorders must be based on a thorough assessment and formulation that may require, and often benefits from, the expertise of more than one discipline. Treatment interventions must be based on this formulation and the effects of any intervention must be reviewed regularly to inform future intervention and management strategies".

Multi-disciplinary assessments and treatments need to feature at all levels of service delivery from community-based services through to specialist units.

Service models

There is widespread agreement that a continuum of service provision is required to meet the diverse needs of a sizeable proportion of the population with

³⁰ Aman, M. G., Alvarez, N., Benefield, W., Green, G., King, B. H., Reiss, S., Rojahn, J. & Szymanski, L. (2000). Special issue, Expert consensus guideline series: Treatment of psychiatric and behavioural problems in mental retardation. American Journal on Mental Retardation, Vol. 105.

³¹ International Association for the Scientific Study of Intellectual Disabilities (IASSID) 2000): Mental health and intellectual disabilities: Addressing the mental health needs of people with intellectual disabilities. Report by the Mental Health Special Interest Research Group of IASSID to the World Health Organisation.

intellectual disabilities. This has been conceptualised by Mansell et al (1994)³² as four interrelated sub-systems operating within the same service system or across different service systems.

1. Prevention
2. Early Detection
3. Crisis Management
4. Specialised long-term support

Each sub system serves a different function as the name implies and within each there are distinct procedures that services need to follow in order to make effective responses to the person's behaviours.

The first three subsystems should be present in generic intellectual disability services, with appropriate support from the mental health services.

According to Mansell, specialised support could be provided from another service such as a specialist support team or specialist centre. However it would be possible for larger intellectual disability services to create such a resource for themselves.

Although the main presumption is that this client population will be served by augmented intellectual disability services, this section concludes by exploring the contribution that generic mental health services could make in service provision.

Improving generic intellectual disability services

Four main themes recur in making generic intellectual disability services more responsive to the needs of people with challenging behaviours and mental health needs in the areas of prevention, early detection and crisis management, namely:

1. Appropriate staffing levels
2. Appropriate staff training
3. Defined procedures
4. Environmental considerations.

Many of these are 'good practices' that are commended for all service-users. Examples of specific initiatives include the following:

³² Mansell, J. Mc Gill, P. & Emerson, E. (1994). Conceptualising service provision. .In E. Emerson, P. McGill, J. Mansell (eds.) Severe learning disabilities and challenging behaviour, designing high quality services. London: Chapman & Hall Publishers.

New staff are properly inducted in managing the challenging behaviours and activity programmes of the clients with whom they work.

A range of in-service training courses are available to all service staff depending on the client groups with whom they work. Refresher courses are also provided.

Services are staffed and rotas drawn up so that clients can receive one-to-one attention at some points during the day; especially at times when challenging behaviours are more likely to be shown.

Records are kept of client's behaviour and actively shared with colleagues in the same services and other relevant services (e.g. Between day and residential services) so that changes are noted and acted upon.

Appropriate reactive strategies are in place so that any behaviours displayed are appropriately managed and defused. Ideally these should be documented for each individual person and made available to all staff working with that person, including 'bank' and relief staff.

Residents have their own bedrooms with at least two 'shared areas' such as sitting rooms so that people can be apart from others without going to their bedroom.

Modifications are made to the property such as sound-proofing, unbreakable glass.

Specialist staff are readily available for consultation about issues or concerns about a particular client - either by telephone or visits.

The use of a contingency budget to cover the costs of managing a crisis is useful because in practice a major obstacle to managing crisis situations can be the difficulties in obtaining appropriate resources.

Equally generic services need to be better equipped to deal with crises when they arise. Among the strategies that have been found to be effective are:

A contingency budget is set aside to cover the extra costs involved in managing the crisis.

Arrangements are in place to provide extra support staff to the facility in order to maintain the person in the service setting. These staff should be experienced and trained in managing people with challenging behaviours.

Arrangements are in place for the person (or other residents) to stay elsewhere on a short-stay basis. The staff or carers in any receiving service need to well

briefed about the person so that programmes and procedures for maintaining his or her behaviours are at least maintained.

An audit needs to be undertaken by each intellectual disability service provider of the recurrent and capital costs they anticipate incurring in meeting the above recommendations. These procedural standards could then be written into service contracts when funding is provided for 'augmented' services.

Mental health services

There is an argument that the needs of clients, particularly those with mild/borderline intellectual disabilities, should be met within the generic mental health services. There is experience internationally of doing this primarily by locating specialised beds in psychiatric or general hospitals with linked out-patient clinics.

Advantages of this model of service provision are identified in the literature as:

- Less stigmatising for service-users; they could be more accepting of the service;
- Avoids unnecessary duplication of resources;
- Nursing staff have the competence and confidence to deal with psychiatric illnesses;

There is evidence that this approach can be effective although empirical studies are sparse (Bouras et al., 1994;³³ Xenitidis et al. 1999;³⁴ Raitasuo et al. 1999a,³⁵ 1999b).³⁶

However the potential drawbacks which have been identified as:

³³ Bouras, N., Brooks, D. & Drummond, K. (1994): Community psychiatric services for people with mental retardation. In N. Bouras (Ed.) *Mental health in mental retardation: recent advances and practices*, Cambridge University Press: Cambridge

³⁴ Xenitidis, K. I., Henry, J., Russell, A. J., Ward, A. & Murphy, D. G. M. (1999): An inpatient treatment model for adults with mild intellectual disability and challenging behaviour, *Journal of Intellectual Disability Research*, 4 3 (2), 128-134.

³⁵ Raitasuo, S., Taiminen, T. & Salokangas, R. K. R. (1999a): Characteristics of people with intellectual disability admitted for psychiatric inpatient treatment. *Journal of Intellectual Disability Research*, 4 3 (2), 112-118.

³⁶ Raitasuo, S., Taiminen, T. & Salokangas, R. K. R. (1999b): Inpatient care and its outcome in a specialist psychiatric unit for people with intellectual disability: a prospective study. *Journal of Intellectual Disability Research*, 4 3 (2), 119-127

- Mainstream generic mental health services cannot provide the more comprehensive service packages that these clients need;
- The main therapeutic approaches used in mainstream psychiatric units may have limited applicability to people with intellectual disabilities;
- People with intellectual disabilities require longer admissions but given the pressures on in-patient psychiatric beds this is not possible;
- Nurses and psychiatrists with generic training have not been trained in general to deal with people who have intellectual disabilities;
- Where this approach has been tried nation-wide, e.g. In Norway, it was found that this population received less service than when they came under intellectual disability services (Nottestad & Linaker, 1999);³⁷ and
- Inpatient beds must be supported by community mental health services which are already over-stretched.

The disadvantages can be overcome through the promotion of dual specialisms in both intellectual disabilities and mental health. Dually qualified staff could be employed in specialist teams that serve both client groups as well as in specialist treatment units.

At present, Senior Registrar posts in psychiatry have been operating a system of dual training in intellectual disability and either child and adolescent psychiatry since the early 1990s. Dual training in nursing is available but additional resources here are needed to support service development.

Moreover specialised assessment and treatment units might be located alongside generic psychiatric facilities and while they may have some autonomy they could share some resources such as staffing and training.

Specialist challenging behaviour services

The need for specialist services to address the complex needs of a small but significant group of people with the most severe challenging behaviours and mental health needs is not questioned. However an ongoing debate in service provision is the merits of removing people to specialist assessment and treatment units for people with challenging behaviours against making available specialist support teams with the aim of maintaining people with challenging behaviours in community settings.

³⁷ Nottestad, J. A. & Linaker, O . M. (1999): Psychiatric health needs and services before and after complete deinstitutionalisation of people with intellectual disability. *Journal of Intellectual Disability Research*, 4 3 (6), .523-530.

At present we lack strong evidence to recommend one approach over the other, as so much depends on the clients, the staff in post and resources available to each. Professional opinion is also mixed. For example, the Irish Section of the Royal College of Psychiatrists (Learning Disability Section) has argued the need for 'in-patient mental treatment units' whereas the Psychological Society of Ireland has favoured the specialist team approach

There is evidence that both approaches can be effective and yet both have limitations.

Specialist units

The available literature suggest that Specialist Units serve a number of functions:

- They provide a place of safety to which people in crisis can be taken;
- They can be approved under Mental Health legislation as places where staff and clients can be provided with protection under legislation;
- They offer short-term assessment and treatments - typically around three months - with the person returning to their community placement. Ideally these should be multi-disciplinary in nature with psychiatric and psychological involvement;
- They provide longer-term treatment and support for people with more intractable problems and often, by default if not design, provide a holding place while suitable community facilities are planned for people admitted who are unable to return to their previous accommodation. This 'delayed discharge' group can take up a sizeable proportion of the beds; and
- They provide appropriate care for people who pose a major threat to themselves, fellow residents and society as a whole.

It is preferable that these different functions are fulfilled by different facilities rather than the one facility attempting to provide them all. This is sometimes done by having different buildings or 'wings' of buildings on the same site, or longer-stay facilities are established in different locations.

Under the Children's Acts or Orders in the United Kingdom and Ireland, children must be accommodated in separate buildings from adult persons. However, children's facilities can be provided on the same site.

Advantages of specialist units

The main arguments in favour of specialist units are:

- They provide a controlled environment suited to the management of challenging behaviours;

- They can contain high intensity episodes of challenging behaviours and those of high frequency of occurrence through access to a range of procedures that are harder to implement in community services such as restraint and isolation;
- The staff in specialist units become highly skilled in managing behaviours across a range of clients;
- The environment can be customised to meet the particular needs of these clients, such as the provision of specialist rooms and therapies;
- The unit can become a resource centre of skills and expertise with the opportunity to develop new approaches to assessing and treating clients;
- The costs per person are reduced when people with high support needs are brought together in the one setting; and
- The units fill a gap in current provision, particularly for those persons who fall between existing intellectual disability and mental health services. Out-patient clinics can provide an ongoing service post-discharge.

Shortcomings of specialist units

The following arguments have been used against the provision of specialist units.

- People are removed from their usual environments and any behaviour changes that occur in the specialist unit may not generalise. This leads to repeat admissions of the same clients.
- People may be removed from some distance from their homes, especially those living in rural areas.
- The grouping of different diagnostic groups together can create chaotic living environments and lead to inappropriate learnt behaviours.
- The presence of a specialist unit lowers the threshold of tolerance in community services to cope with these clients. The units become used as a first resort.
- The units de-skill staff in intellectual disability services as the resources are not made available to train and support community staff.
- The units 'silt-up' with clients who cannot be found a community place but the incentive to do this is much reduced as they already are placed in the Unit (Cumella and Roy, 1998).³⁸

³⁸ Cumella, S. & Roy, A. (1998): Bed blockage in an acute admission service for people with a learning disability. *British Journal of Learning Disabilities*, 26, 118-121.

- The costs per place in units can be high but the quality of life outcomes for the clients resident in them over longer periods are low.

Estimates of in-patient beds

Surveys undertaken by Bailey and Cooper (1997)³⁹ in England and Wales, and by Smiley et al (2002)⁴⁰ in Scotland have identified wide variation among Health services in their provision of 'short-stay' in-patient assessment and treatment beds for people with intellectual disabilities. These range from none to 21 places per 100,000 of ordinary population. The median number was around 3-4 beds per 100,000.

In Northern Ireland, recent studies of admissions to two specialist hospitals identified that around 4 beds per 100,000 of ordinary population were used for admissions of up to two years (McConkey et al, 2002;⁴¹ Slevin et al, 2002).⁴²

The median length of stay varies widely across Units for people admitted predominantly with a psychiatric condition. The range is from around one month to three months but it can extend beyond one year. Hence a planning ratio of 4 beds per 100,000 could in one year accommodate some 16 - 48 persons per 100,000 of a population.

The size of units also varies greatly although recent research reports have focussed on Units with around 12 beds, usually serving population units of circa 300,000 persons. These units include those located within intellectual disability services as well as those within generic psychiatric services.

Other health authorities promote the concept of day hospitals for both short-term and longer-term placements.

³⁹ Bailey, N. M. & Cooper, A. (1997): The current provision of specialist health services to people with learning disabilities in England and Wales. *Journal of Intellectual Disability Research*, 41, 52-59.

⁴⁰ Smiley, E., Cooper, S-A., Miller, S.M., Robertson, P. and Simpson, N. (2002) Specialist health services for people with intellectual disability in Scotland. *Journal of Intellectual Disability Research*, 46, 585-593.

⁴¹ McConkey, R., Marriott, C., Cunningham, M. et al. (2002). Specialist Assessment and Treatment Project for people with learning disabilities and additional needs: Summary of Final Report. Belfast: EHSSB.

⁴² Slevin, E., McConkey, R., Irwin, D. and Reaney, E. (2002) A census and investigation of admission trends to Longstone Hospital in Armagh: Information for a new core hospital. Armagh: Southern Health & Social Services Board, Armagh, NI

Some form of short-stay assessment and treatment units are likely to be required. They should be planned according to local needs and existing provision and most crucially as part of an overall service development plan of services for this client group within a catchment area.

Long-stay provision

Many of the foregoing arguments relating to the advantages and drawbacks of short-stay units apply equally to the concept of specialist long-stay units. There is not always agreement however that specialised long-stay provision is required.

In Scotland, for example, (Smiley et al, 2002)⁴³ the projected number of long-stay beds in small homes or hospitals varied from 0 to 17 per 100,000 across 15 health authorities. (It should be noted that this provision would include the needs of people with profound and multiple disabilities previously resident in long-stay hospitals, in addition to those with challenging behaviours).

Long-stay accommodation should be planned for as a component of existing intellectual disability services and should not be an adjunct to the specialist short-stay treatment units as it will compromise their primary functions.

Specialist teams

The concept of multi-disciplinary teams has been around for many years. Specialist teams are an extension of this concept but with the important difference that they focus exclusively on clients with challenging behaviours or other additional complex needs.

The teams are multi-disciplinary and usually consist of intellectual disability nursing, clinical psychology, and social work with psychiatric input. However, team members could include speech and language therapists and occupational therapists, alongside other specialists such as music or art therapists.

The teams are peripatetic in that they work with individuals in their present settings such as the family home, day centres or residences. However some teams function as the 'outreach' arm of a specialist unit. Typically they have small numbers of clients on their caseload at any one time. They strive to discharge clients as soon as appropriate in order to concentrate on an active caseload.

The teams have a number of functions:

⁴³ Smiley, E., Cooper, S-A., Miller, S.M., Robertson, P. and Simpson, N. (2002) Specialist health services for people with intellectual disability in Scotland. *Journal of Intellectual Disability Research*, 46, 585-593.

- Undertaking detailed assessments of the person and their environments;
- Drawing up treatment and intervention programmes;
- Training and supporting family carers and service staff in implementing the programme;
- Providing hands-on support to service staff at times of crisis and when introducing new management programmes; and
- Counselling and supporting staff under stress.

Advantages of teams

Emerson (2001)⁴⁴ reviewed the sizeable number of studies that were carried out in the 1990s into specialist teams. He noted the following:

- The teams were effective in providing behavioural support to clients in a variety of community setting with evident reduction in either their challenging behaviours and/or increased tolerance of community staff to the behaviours;
- Teams reduce the number of admissions/re-admissions to institutions and specialised units
- Enhancements in the persons' quality of life and adaptive skills are reported along with higher carer satisfaction and improvements in the carers' coping with these behaviours; and
- Teams are more cost-effective than institutional-based services.

Shortcomings of teams

However all teams are not uniformly successful. Allen and Felce (1999)⁴⁵ identified certain factors that are likely to enhance the effectiveness of specialist teams.

- The team needs to have a broad skill base that enables them to intervene with the diversity of clients who will present with challenging behaviours. Teams members require specialist training for their task that combines expertise from both mental health and intellectual disabilities;

⁴⁴ Emerson, E. (2001): *Challenging Behaviour: Analysis and intervention in people with learning disabilities* (2nd Edition). Cambridge: Cambridge University Press.

⁴⁵ Allen, D. & Felce, D. (1999): Service responses to challenging behaviour. In N. Bouras (Eds.) *Psychiatric and Behavioural disorders in development disabilities and mental retardation*, (pp. 279-294). Cambridge: Cambridge University Press.

- They need to be able to provide support over a long-term and not just when a crisis arises and is apparently resolved. They need sufficient resources for this to happen;
- They need to use a clear conceptual model for their intervention that is shared by all team members and which can be readily communicated to others;
- The ability to support carers and staff in reactive behavioural management strategies;
- An efficient and clear management structure for referrals, allocation of cases, emergency contacts and named liaison staff for different services; and
- The ability to deploy staff in services so that they can model and establish effective ways of working with people who present severe challenges.

Moreover, teams in themselves cannot provide the solution to people who have to be moved from their present residence because of the threat they pose to themselves or others. Some form of short-stay facility will be required. This could be planned as part of the overall short-break services.

Similar arrangements may be required to replace the person's usual day service arrangements with the person attending some form of specialist day service.

The team will also need access to a facility where people can be detained, possibly because of an offence they have committed.

Estimates of provision

Specialist teams are a relatively new phenomena and hence the literature gives sparse details on which to base estimates of the numbers of professionals needed. A survey of 46 teams in England and Wales (Emerson et al, 1996)⁴⁶ found the community intellectual disability nurses made up half the membership of all the teams.

Psychological input was also a feature of most teams. At any one time, a median of around 6 clients were served by the teams (range one to 25 persons).

⁴⁶ Emerson, E., Forrest, J., Cambridge, P. & Mansell, J. (1996): Community support teams for people with learning disabilities and challenging behaviours: results of a national survey. *Journal of Mental Health*, 5, 395-406

Conclusions

A number of conclusions emerge from this review:

- Although the total numbers of people are comparatively small, this group of clients has the potential to place great stress on their family carers and existing services.
- The numbers are likely to increase for the foreseeable future although they should level off by 2020 with the fall in the child population.
- The group is very diverse in terms of their characteristics and needs. Often individualised treatment and care programmes are required.
- An interdisciplinary team approach is required to meet their needs effectively.

A three-strand approach is required in developing services. In order of priority these would be:

First investing in existing community services so that they become more robust in the early diagnosis and management of crises and the prevention of placements breaking down.

Second the provision of specialist support teams to existing services who have a vital role to play in ensuring continuity in care across different settings.

Third, the provision of in-patient assessment and treatment units for people in crises.

Section 5 - Current Service Provision

Despite advancement in the provision and quality of both mental health and intellectual disability services in Ireland in recent years, the distinct needs of the dual diagnosis group have yet to be met satisfactorily. This is in spite of a number of reports in recent years that have catalogued the frustrations of dual diagnosis patients and carers in attempting to gain access to appropriate mental health services.

The Department of Health and Children's Mental Health policy document "The Psychiatric Services - Planning for the Future" (1984)⁴⁷ states that:

Disturbed mentally handicapped persons should be catered for in the mental handicap services.

The Needs and Abilities Report (1990)⁴⁸ contradicted this somewhat, indicating the DoHC's policy is that persons with a mild intellectual disability not in contact with intellectual disability services should normally access generic mental health services.

In 1996, the then Department of Health published a discussion paper on the Mental Health needs of persons with intellectual disability (the Mulcahy Report).⁴⁹ Again, the gaps in provision for this dual diagnosis group were clearly highlighted, and detailed proposals made for a multi-tiered service comprising community residential and specialist serviced delivered by dually trained professionals.

At the time of writing, the proposals of the Mulcahy Report have not been acted on by Government.

In 2001, the Eastern Regional Health Authority made similar and detailed proposals after extensive consultation for service development that have yet to be funded for implementation.

⁴⁷ Department of Health (1984). The Psychiatric Services - Planning for the Future. Dublin. Stationery Office

⁴⁸ Department of Health (1990). Needs and Abilities Report of the Review Group on Mental Handicap Services. Dublin. Stationery Office

⁴⁹ Department of Health (1996). Discussion Document on the Mental Health Needs of Persons with Mental Handicap (Mulcahy Report). Dublin. Stationery Office

Pressure from users and carers for service development is growing, and has been relayed to this study by NAMHI, and through the Board of the NDA that comprises both providers and service users/carers.

As part of this research, a postal survey about dual diagnosis services issues was undertaken across all Health Boards and relevant voluntary bodies - with a 58% response rate. Face-to-face interviews were also conducted with a range of people involved in managing services, patient care and advocacy from both statutory and voluntary services.

These sources have further reinforced this message of lack recognition, strategy, planning and delivery of appropriate services.

Leadership

This research has found:

- A lack of a national service strategy for this client group - for example the recent National Health Strategy⁵⁰ did not mention the needs of dual diagnosis patients in either the Intellectual Disability or Mental Health sections;
- A lack of 'leadership' from the Department of Health and Children (DoHC) in this area. The researchers found a lack of clarity between the Department's Disabilities and Mental Health Sections as to which has lead responsibility for mental health services the ID population; and
- An absence of joint planning by the DoHC across mental health and intellectual disability, which is historical and ongoing. For example, service plans for the current period for both sections make no reference to providing an integrated care package to persons in need of both services.

As regards funding, the DoHC is currently engaged in an exercise to establish the exact baseline funding for intellectual disability services by Health Board area. Currently only national figures are available. This has precluded this study from assessing the quantum of funding for population catchment areas across Ireland.

At Health Board level, there is insufficient managerial capacity to ensure the effective delivery of services meeting the needs of the dual diagnosis group - even though the Boards are the statutorily responsible body and notwithstanding that they may contract with third party voluntary bodies for care delivery. Health Boards, for example, could not readily provide the researchers with adequate

⁵⁰ Department of Health & Children (2001) Quality and Fairness - A Health System for You. Dublin. Stationery Office

information on their residents currently receiving dual diagnosis services funded through the Boards.

In line with Enhancing the Partnership,⁵¹ local Consultative and Development Committees have been convened bringing together statutory and voluntary providers. Whilst these committees may still be at an early stage in their work, there appears to be little systematic assessment as yet of needs of dual diagnosis citizens in the local population and consideration of appropriate service responses.

Services

Both intellectual disability and mental health services in Ireland have been reformed in recent years, with a stated policy objective of a provision of services in community based settings.

In mental health, for example, there has been a widespread move to build capacity in multi-disciplinary community mental health teams that are able to support people to live in community settings as appropriate, provide early intervention, and an access route when necessary to more specialised assessment and treatment services.

Persons with a dual diagnosis currently in the generic intellectual disability services, however, have great difficulty in accessing generic mental health services. This research found that:

- Mental health services to these persons are largely non-existent for persons living in the community with family carers or in their own accommodation. This results in persons reaching crisis before action may be taken to assess or treat their mental health problems.
- For persons in the residential services, psychiatric care is led by a relatively small number of psychiatrists with qualification in Learning Disability (see figures below). However, these psychiatrists often work in voluntary agencies that do not have the requisite range of facilities for comprehensive psychiatric assessment and/or treatment, nor do they necessarily have access to a range of professionals dual trained in intellectual disability and mental health, such as nursing and therapies, to support their work.

⁵¹ Department of Health (1997). Enhancing the Partnership Report of the Working Group in the Implementation of the Health Strategy in relation to Persons with a Mental Handicap. Dublin. Stationery Office

- There are only six inpatient hospital psychiatric beds provided by Stewarts Hospital Services Ltd dedicated to the inpatient care of intellectual disability patients with a mental illness. These are the only beds under the current remit of the Inspector of Mental Hospitals.
- The Irish College of Psychiatrists has indicated that the number of psychiatrists with specialism in intellectual disability for both adults and children is far below the levels recommended by international benchmark to provide an acceptable level of service to the dual diagnosis group. The table below shows a comparison of consultant numbers:

Comparison of consultant numbers

	Posts	Actual	Recommended
Children & Adults	30	24	35

This analysis is based on the number of approved consultant posts (per Comhairle na nOspideal Report 2003) and actual figures compiled by the Irish College of Psychiatrists (taking account of job-sharing, temporary posts and sessional commitments to generic psychiatry), Recommended numbers are per the Irish College of Psychiatry Guidelines.

Community Area Mental Health teams (operating under the generic mental health services) do not routinely provide a service to persons in the intellectual disability. It is assumed that the generic intellectual disability services provide for the entirety of the needs of their population - with only informal access to secondary psychiatric services;

Historically, voluntary bodies did not operate to defined catchment areas - and so there was no automatic assumption of access to the local voluntary services for people living in an area. This is changing in agreement with Boards, who have assumed a lead funder role in recent times.

The admission criteria applied by voluntary bodies varies substantially. This has contributed to difficulty in some areas of finding appropriate intellectual disability services for persons that may exhibit challenging behaviour or have mental health needs.

The practice of block funding voluntary agencies for generic intellectual disability services does not facilitate 'money to follow the patient' - and is acting to stifle the movement of individuals between services appropriate to their care across time. This practice results both in agencies not being compensated for the cost

burden of new admissions (particularly for high cost cases) and money not being released when individuals leave provider services.

The statutory services tend to know most about persons 'out-of-service', usually because they either do not meet the access criteria for local voluntary providers. Most of these clients are in crisis, and significant funds have been expended by Boards in recent years in inappropriate short-term placements (in hotels, for example) or by 'exporting the problem' to providers out of State.

An important factor to consider is that many persons with intellectual disability in care are not legally competent to give their consent to detention and treatment. As many are resident in generic intellectual disability centres (and not in approved psychiatric facilities), professionals involved in their care are not protected under the provisions of the Mental Treatment Act (1945) or Mental Health Act (2001). This is a serious concern stressed by professionals throughout the consultation phases of this study.

In relation to forensic mental health services, there are no secure centres providing specialist services specifically for people with intellectual disability. In addition, the Criminal Law (Insanity) Bill 2002 when effected is likely to draw an increased number of patients with intellectual disability who have not previously been recognised and are likely to be unfit to plead. The number of persons with an intellectual disability in the Irish justice system is generally unknown.

At present, the Central Mental Hospital in Dundrum treats patients in the criminal justice system with a mild and borderline intellectual disability. There is no specialist provision made for those with mild, moderate or profound intellectual disability. To date, there has also been a reluctance to charge offenders with an intellectual disability, owing to problems with providing for their appropriate disposal to places of detention. This is unsatisfactory from a Justice viewpoint, and does little to address the assessment and treatment needs of the offender.

Section 6 - Recommendations

There is limited empirical evidence available on the comparative efficacy of models of care for the dual diagnosis group. Recommendations in this report are therefore based on a consensus of views from prior reports in this area in Ireland and the researchers' own findings during recent consultation with service commissioners, providers and users'/carers' representatives.

Many of the potential models that could address the needs of the dual diagnosis group have been well aired in past reports - and indeed with a great degree of crossprofessional and user support. Seminal studies such as the Mulcahy Report and the more recent Eastern Regional Health Authority Report⁵² have led the way in this regard - and the gaps in provision and service development needs cited has resonated strongly with those in need and their carers.

This Report recommends as follows:

Leadership

1. After appropriate consultation with stakeholders, the Department of Health and Children (DoHC) should publish a national policy statement on mental health for the dual diagnosis group. This should be firmly rooted in their right of equality of access to services appropriate to needs, and incorporate a clear service framework covering inter alia issues of quality, accessibility and performance. A strategy statement setting out how the DoHC intends to deliver on this policy should also be published. The strategy should include information on planned development of services within a defined timescale, and management and funding arrangements. Stakeholders should include providers in the statutory, voluntary and private sectors, users and carers and advocacy groups, and other relevant government departments inter alia the Department of Enterprise, Trade and Employment, the Department of Education and Science, and the Department of Justice, Equality and Law Reform.
2. The DoHC should establish a standing committee drawn from both its Mental Health and Disability sections to oversee the implementation of the national policy and strategy, and to address ongoing issues of needs and resources, and service development.
3. Under the new health service reforms on structures, the proposed Regional Health Offices (RHOs) should have devolved responsibility for undertaking

⁵² Eastern Regional Health Authority (2002) Proposed specialist services for clients with intellectual disability presenting with severe challenging behaviour and/or psychiatric illness.

periodic population needs assessment, procuring services appropriate to that need, and making special provision so that potential users are signposted to services. RHOs should ensure that structures are in place to provide effective discharge of such responsibilities to plan for, procure and/or directly provide appropriate mental health to the dual diagnosis population resident in their geographical area. This should include a performance assessment mechanism to monitor local delivery against the service framework within the national policy.

4. Clear protocol and service level agreements should be in place in the instance where RHOs are discharging their responsibilities by procuring services from third party providers (i.e. private or voluntary bodies). These should as a minimum specify access criteria to services, state the quantum and type of service to be delivered, the cost per case agreed, and quality of provision to be maintained.
5. RHOs should liaise with local service providers, users' and carers' representatives, and professionals' representatives in determining how best to plan and operationalise local services - building on complementary services already in existence - and living with the reality of limited resources (both capital and revenue).
6. In line with the spirit of devolved responsibility, RHOs should have the latitude to assess what proportion of baseline funding is required to support services to the dual diagnosis group in their geographical area. Importantly, however, each RHO should be assessed periodically by the DoHC on their performance in delivering against the national policy service framework, and consideration given to making the results available across the service (for benchmarking) or to the public. Centrally imposed ring-fenced funding for dual diagnosis services should be considered for RHOs failing to deliver.
7. RHOs should maintain a contingency budget to cover the cost of managing crisis cases.
8. The Mental Health Commission and the National Disability Authority should publish, after appropriate consultation, clear guidelines for the quality of mental health services for the dual diagnosis group. This should deal with issues pertaining to detainment and consent. It should provide for inspection of all facilities and services where persons are detained or de-facto detained. These guidelines should be informed by the National Standards for Disability Services (NDA, draft 2003) and Guidelines and Good Practice and Quality Assurance in Mental Health Services (DoHC).
9. The DoHC should convene a working party comprising key stakeholders to explore the possibility of deriving an agreed definition of 'Challenging

Behaviour' to support a recognised diagnosis. This would further assist in streamlining access to services for individuals in need.

Recommended service delivery model

To those who have followed the debate on dual diagnosis service needs over the years in Ireland, this section will contain no surprises. Many of the solutions to the needs of the dual diagnosis population have been known and largely accepted for many years - thanks to the work of inter alia the Psychological Society of Ireland, the Irish College of Psychiatrists, NAMHI, the National Federation of Voluntary Bodies providing Services to Persons with Intellectual Disability, the Mulcahy Report - and laterally the ERHA report on dual diagnosis services.

What is required now is a commitment to action by Government.

1. The following model is recommended - but local variation in delivery arrangements should permit delivery responsive to local needs, delivery challenges and to integrate most effectively with whatever complementary services may already be in place.
 1. All services should be planned by RHOs - and delivered on a strictly catchment area basis by the statutory, voluntary and/or private sectors as appropriate to local circumstances. In some parts of the country, specialist services may be shared between a number of such administrative areas where utilisation volumes make this unfeasible or unwarranted. In a shared case, one RHO may take on a lead planning role.
2. In order to facilitate the effective management of dual diagnosis services on a regional basis, employment contracts of consultant psychiatrists should be held with the RHOs, on the same basis as consultant psychiatrists in the generic services. Their contracts and job descriptions should contain detailed descriptions of roles, responsibilities and reporting relationships. Employment contracts for other staff groups could be held by the lead service provider.

The focus of services should be on supporting people with dual diagnosis to live in an appropriate setting in the community - and to deliver prompt assessment and treatment where necessary to avoid or overcome crisis episodes and provide effective rehabilitation thereafter. Attention needs also to be paid to providing effective support for families' and carers' needs.

Services in the community

1. The cornerstone of the service should comprise multi-disciplinary community-based mental health teams dedicated to the dual diagnosis population. These teams would work as a specialist section of the already existing Community Area Mental Health Services. This will ensure that staff in the teams are fully integrated with colleagues in the generic mental health

service. These teams are referred to in the remainder of this report as the Community Area Mental Health (ID) Teams.

2. The teams should be professionally managed, with arrangements for such worked out to suit local circumstance. Clinical aspects of the services should be led by a consultant psychiatrist specialising in the psychiatry of learning disability, and accountable to the host RHO for clinical governance issues. The service would be delivered by a multi-disciplinary team including psychologists, occupational and other therapists and nurses dual trained in intellectual disability and mental health, and social workers with experience of the needs of this client group.
3. The role of the Community Area Mental Health (ID) Team would be to ensure a coordinated care function for each individual on the active caseload - covering assessment, treatment and review. Following initial assessment, the team (as specialists in the health and social care needs of the dual diagnosis group) will access a range of services as appropriate - to include specialist units (see below), continuing care facilities (see below), and the generic mental health services. They will also work closely in support of care professionals in the generic intellectual disability services.
4. As part of an integrated mental health service, the team would have full access to generic mental health services for assessment and/or admission where, in individual circumstances, access to specialist dual diagnosis units is not deemed necessary
5. The teams would have an active referral and discharge policy. Referrals would be made by primary care professionals or by staff in the generic intellectual disability services. For persons currently receiving residential services from generic intellectual disability agencies, such agencies should provide the long-term care function.
6. Teams would also be active in assessing the needs of family and other carers, family therapy, and supporting caring capacity (for example by providing education on effective interventions where appropriate and arranging periodic respite). Their role would extend to health promotion and protection for the dual diagnosis population.
7. The Community Area Mental Health (ID) Team would, in the discharge of their functions, liaise closely with providers of generic intellectual disability services. Also, the team would act to provide advice, education and support to providers' staff on a wide range of issues such as coping with challenging behaviours, identifying signs of mental health problems, environmental factors impacting on mental health, and other issues.
8. It is estimated that a minimum eight Community Area Mental Health (ID) Teams operating in defined population catchment areas would be sufficient to

meet needs across Ireland. An aggregate caseload of 500 may be expected (circa 60 per team on the active caseload at any one time). The capacity (and number) of teams should be periodically assessed by RHOs as part of normal service planning and development processes.

Inpatient services & specialist regional units

1. Patients may be assessed as needing inpatient admission for assessment and treatment. In these instances, the Community Area Mental Health (ID) Team will refer the patient to other parts of the mental health services. Depending on individual needs and circumstances, this may be referral to generic inpatient mental health services - or to proposed specialist dual diagnosis units operating on a regional basis.
2. Specialist Regional Assessment & Treatment Units would be established, comprising outpatient consultation space, assessment and treatment beds, and step down beds. This service would be available to deal with acute episodes that, in the opinion of the Community Team in liaison with colleagues in the referred services, cannot be managed successfully in the community or in the generic mental health service. Separate provision for children under 16 years shall be made within such units.
3. Following closure of inpatient episodes, arrangements need to be in place for the timely discharge of patients to appropriate settings. Where patients are referred from the generic intellectual disability services, protocols should be in place to secure patients' residential places and agencies should normally accept patients back into their service at the end of episode. This is essential to ensure that such inpatient assessment and treatment capacity does not become 'blocked' over time by patients who cannot be moved to more appropriate care settings.
4. Treatment in the specialist regional units would include a full range of contemporary therapies and interventions. Specialist day service provision will be associated with the above facility.
5. A study by the Eastern Regional Health Authority recommended circa 30 beds per one million population - a proposition that received widespread support from the sector. It is likely that demand in Ireland could support four such units (totalling 100 beds), to be allocated on a regional basis serving defined geographical areas.
6. Each Specialist Unit would comprise a mix of assessment, treatment and rehabilitation beds, determined to meet local demand. Rehabilitation beds on site should only be used to stabilise patients post treatment, pending their transfer back referring agency or onward to other services.

7. Catchment areas will need to be carefully defined, as it is unlikely that a unit under 10 beds would be cost effective or viable, mindful for the need to provide separately for children and adults - and so services may be shared by a number of administrative areas in some instances.
8. It is envisaged that staff in the Specialist Unit and in the Community teams would work closely in serving their catchment population. Strong professional and operational links need to be maintained also with the generic mental health services in order to provide an integrated service meeting the needs of the dual diagnosis population.

Continuing residential care

1. Some patients may not be discharged back to their admission address due to their diagnosis or behaviour, and will require either short or longer term continuing care.
2. Capacity to provide such care is essential to allow Community Teams to refer individuals into services meeting their ongoing requirements. Capacity is very important in the overall service model - without which evidence suggests that the efficiency and throughput of the specialist assessment and treatment units will be adversely affected.
3. Services should range from high-intensity staffed group homes to supported living arrangements - providing both time limited step-down and rehabilitation, and long term care. Such services should be closely linked with a range of complementary services -such as day services, training and employment services, etc. in order to provide a wide range of stimulating activities appropriate to the needs and capabilities of service users.
4. Elements of such a service spectrum already exist across the country - mostly provided by the voluntary sector. However, the services need to be specifically considered a locality level - and further development and investment committed where necessary as part of an integrated dual diagnosis service.
5. A proportion of persons who are chronically ill or exhibit severe challenging behaviours that cannot be managed in the community will require longer term residential support. These need to be provided back in their own locality - dispersed and community linked - otherwise there is a risk of recreating institutions. An example of a residential service for severe challenging behaviour is operated by the Hospitaller Order of St. John of God in Celbridge. Again, such services need to be specifically considered a locality level - and further development and investment committed where necessary as part of an integrated dual diagnosis service.

6. The provision of such a range of continuing care provision may best be achieved in partnership between the statutory sector and voluntary providers - to enhance existing residential provision in the generic intellectual disability services.

The diagram below shows graphically the central position of the Community Area Mental Health (ID) Teams in the proposed service model for the dual diagnosis population. The arrows represent the flow of service users, and of communication and support services between services and users/carers.

The structures to be established or enhanced sit firmly within the mainstream of Mental Health Services, whilst reflecting the specialised nature of the service to be provided.

Elements of the recommended service model are already being adopted. In 2002, the South West Area Health Board and the Sisters of Charity of Jesus and Mary, Moore Abbey announced plans to develop jointly a specific dual diagnosis service for persons with intellectual disability and psychiatric illness and/or challenging behaviour

The service is envisaged to comprise:

- From the statutory sector - an outreach team to offer support and interventions to clients with identified needs as well as training and support for staff in the referring agencies. The team would be led by a consultant psychiatrist, and include a registrar, community nurses, psychologists and social workers; and
- From the voluntary sector - a 17 bed stand-alone residential unit with facility to cater for patients with moderate, severe and profound intellectual disability.
- Muckamore Abbey Hospital - Vision for the Future.

Following consultation with local stakeholders, the Department of Health Social Services & Public Safety in Northern Ireland has approved a business plan to invest in modern specialist admission and treatment services for people with intellectual disability and psychiatric illness. An initial tranche of £7.5m has been awarded to enable the first phase of development to commence, comprising of:

- An admission and treatment unit of 35 beds; and
- A specialist forensic unit of 23 beds

This represents a considerable change in public policy, as consideration had been given in the past ten years to closure of such services. It underlines the increasing acceptance of the need to provide appropriate specialist services for this

population to support the community-based services, and to facilitate access to quality assessment and treatment in periods of acute need.

Forensic services

1. It would be advisable to plan forensic services for the learning disabled group on a national basis and linked to the national forensic services at the Central Mental Hospital, Dundrum. This is in view of the tertiary nature of services required.
2. Under the proposed model, the Central Mental Hospital would act as the secure centre supported by four regional units placed throughout the State offering a range of semi-secure and low secure places. The location of the four units to be determined in relation to population distribution.
3. As noted in Section 2, above, there is little evidence available at present on which to estimate accurately the quantum of need for forensic services for the dual diagnosis group (e.g. Fraser, 2002)⁵³ - particularly for semi-secure and low secure services. An indication is available from Northern Ireland, where existing services are being reorganised to provide for 23 beds (7 semi-secure, 16 low secure) in a region with a general population of 1.7 million. Translating this to the Republic infers a need for a total of circa 50 beds. This is indicative only - and primary epidemiological research within the population in the justice system should be undertaken in advance of more detailed planning of provision for this group.
4. Regional forensic units would provide a range of appropriate treatment interventions and therapies. The units may be linked or situated proximate to the specialist units proposed for the non-forensic group in order to take advantage of economies of scale in staffing and other overhead.
5. A consultant trained in intellectual disability and forensic psychiatry should lead the service. Each service will also require input of one or more forensic psychologists, dual trained nurses, and behavioural nurse therapists.
6. When the services envisaged above are in place, mechanisms should be developed to facilitate forensic outreach from regional units - in support particularly of professional colleagues working in the community. Outreach services may also liaise with probation, social security, education, and local authority services

⁵³ Fraser, W.I. (2002) Forensic learning difficulties - the evidence base: Executive Summary. *Journal of Intellectual Disability Research*, 46, Supplement 1, 1-5.

7. In May 2003, the NDA made a series of recommendations to Government on the Criminal Law (Insanity) Bill 2002, with a view to strengthening legislation on forensic mental health in Ireland.

Communication

1. Proactive steps should be taken by service planners and providers to ensure that potential users and carers are made aware of their rights to services - and to signpost them to services in place locally. All communications should be in a suitable format mindful of the client group concerned.
2. Service users and their carers should have access specialised and independent advocacy services.

Advocacy

It is important that service users and their carers have an effective means to voice their views on service provision, gaps in such provision, service quality, and other relevant issues - both at an operational and national level. This will require active facilitation, support and encouragement - and should act as a driver for positive change across the services.

An advocacy service independent of service commissioners or providers should be resourced to perform this role.

Investing in staff

It is vitally important that adequate planning and resources are dedicated to human resource and training issues, in order to attract and retain high quality staff in the proposed dual diagnosis services. Otherwise, the emergence and sustainability of such services will be compromised.

Strategies should be devised to address pertinent issues, agreed between staff representative/professional bodies and the employer side. These should include:

A policy commitment to national service delivery models that, in turn, provide long term sense of stability in these services. This should underpinned by a service framework that promotes best practice in clinical and professional standards of care and management;

The development of clearly defined career paths for entrants to the sector, with common job descriptions, terms and conditions, etc.

Ongoing training needs assessment and skills/capacity analysis across all professional groups. Increased dual training for all professional staff/disciplines working in this area, and liaison with training providers and accrediting bodies. Focussed investment in training and continued professional development is

essential, linked where appropriate to professional or academic accreditation in aspects of dual diagnosis services;

Disability and equality awareness training should be provided to all staff working in these services;

Ensuring that staff working in this specialist area are not isolated from the generic services, and a network established to promote staff support and mentoring;

A commitment to best practice health and safety standards - especially for staff working with patients exhibiting severe challenging behaviour; and

Leadership training should be provided to improve management capacity in the service.

Consideration should also be given to investing in research capacity in the area of dual diagnosis services - for example, by establishing a research unit or Chair within Irish academia. This would act to engender a sense of progression and modernisation in all aspects of the care of service users.

Section 7 - Indicative Costs

This section explores the likely physical and financial resources required to deliver on the model proposed in the last section. It also reflects on the costs on continued non-provision of services to the dual diagnosis group.

Community area mental health ID teams

The Irish College of Psychiatrists is currently debating a proposed model for the delivery of mental health services to people with intellectual disability. This envisages specialist multi-disciplinary community mental health teams, comprising:

- Consultant psychiatrist (x2)
- Psychologists (x4)
- Psychiatric nurses (x4)
- Social Workers (x4)
- Registrar (x4)
- Occupational therapist (x2)
- Speech & language therapist (x1)
- Administration officers (x4)

The team envisaged here would service BOTH adult and children. Two consultant psychiatrists in intellectual disability would lead the team - one specialising in children and adolescents, and one in adult and elderly patients.

Teams would operate from bases co-located with generic community mental health teams, or from facilities attached to specialist units, and would work across population units of circa 450,000.

Staffing costs per annum are estimated at €1.2m per team - totalling €9.6m across eight teams envisaged. This is based on mid-point salary bands for staff grades per the current pay scales in force at the time of writing.

Facility related revenue costs are more difficult to estimate as only marginal costs may accrue where teams co-locate.

Consultation by the Eastern Regional Health Authority suggested a capital cost of circa €635,000 for the proposals contained in the EHRA report, and this should be used as a planning figure in advance of more detailed costing.

Specialist regional units

Consultation by the Eastern Regional Health Authority suggests a capital cost per residential place of €160,000. This totals to €16m investment to provide a service across the four centres envisaged.

Revenue costs would accrue to cover staff in the following groups:

- Dual qualified nurses (x 15)
- Staff nurses (x 20)
- Care assistants (x15)
- Consultant on-call arrangements
- Administration (x4)

Annual staff costs of circa €1.6m per unit would accrue. Additional revenue costs would accrue from:

- Operation of the unit (heat, light, power, insurance, consumables, etc);
- Specialised vehicles / transport;
- Repair and maintenance costs;
- Security expenditure.

For planning purposes, total revenue costs of circa €2m per annum per unit should be used - pending a more detailed costing exercise.

Forensic services

It is difficult to be precise about the likely overall cost of providing forensic semi-secure and low-secure services because of:

- The difficulty in predicting total number of beds required in the absence of contemporary evidence in the Republic of Ireland; and
- The fact that costs will be influenced by organisational issues - such as the exact nature of service provided and the degree to which such services would share costs with other elements of the proposed service model for the dual diagnosis group.

Indicative revenue costs are available from the planned redevelopment of services at Muckamore Abbey Hospital in Northern Ireland. These costs range from circa:

- €170k per semi-secure bed per annum;
- €85k per low-secure bed per annum.

This implies a total of €6m for provision of 50 beds across the State (assuming an average of €120k per bed per year). Detailed demand and cost analysis should be undertaken by DoHC as part of a service planning process.

Capital costs are quoted above for specialist non-forensic units, and these may provide a conservative estimate given additional costs of security provision. Final costs will depend on the nature of development (new build or conversion) and the extent of site sharing with other elements of the service.

Phasing

An Implementation Group should be convened comprising key stakeholders in each locality to agree how best to operationalise the service model recommended. The Group should consider the quantum of additionally implied by the above costing in their own localities. Some of the structures to provide services envisaged may already exist in part, or could be developed in partnership with complementary services in the generic mental health or learning disability sectors.

However, it is expected that significant additional funding will be required to operationalise the recommended model fully. Where a phased approach is adopted for affordability or other reasons, specific attention will need to be given as to how the model will operate in the interim pending completion.

Funding mechanisms

An audit of statutory and voluntary providers should be carried out at a point in time to validate the number of people actively receiving services from the generic intellectual disability services. This should cover those in residential provision, high dependency units, day care, respite, supported housing, and supported to live at home. The audit could include those in hospital for reasons of intellectual disability (and/or dual diagnosis), whether in designated centres or not.

Evidence emerging should be evaluated by comparison to the quantum of funding provided to organisations providing such care.

Going forward, funding arrangements should, where possible, be linked to:

- The quantum and nature/type of services being provided;
- The provision of a quality of service meeting agreed standards; and
- Adherence to agreed service level agreements between RHOs and voluntary providers of care, including agreement on a protocol for access to services.

Cost implications of not providing adequate services

The enhancement of dual diagnosis service provision as proposed in this report will have real cost implications - both in capital and revenue terms. However, it is important to highlight in concluding this report that such costs will be defrayed by savings elsewhere. These include:

- A reduction in instances where persons with a dual diagnosis are placed in high cost emergency accommodation. This includes the cost of providing sufficient staff cover and cost of accommodating staff; and
- The additional costs of placements outside the State.

However, the principal 'costs' of non-provision are not financial in nature. They pertain to:

- Continued inequality in the provision of mental health services to persons with a dual diagnosis compared to the non-intellectually disabled population in similar need. This is incompatible with equality principles, and with Ireland's international legal obligations (see Section 3);
- Negative impact on the mental health of persons with dual diagnosis. Non-provision of adequate assessment, diagnosis and treatment services means that mental health problems can go untreated. This is particularly disturbing to find in any section of the community, but particularly so in a section traditionally marginalised, and with varying degrees of communication and comprehension difficulties arising from their intellectual disability.
- Negative impact on carers and caring capacity. Carers provide an invaluable role in enabling those they care for with dual diagnosis to live in the community. They provide a range of 'services' analogous to residential, domiciliary, social care, and aspects of nursing care such as medicines management for example. Many of these services would have to be provided by the State in the absence of such input. Those providing an informal caring role need adequate support covering respite, skills/knowledge, advice, or help to access to other public sector services. Such services would help build caring capacity, improve carers' lives, and help maintain persons with dual diagnosis in the community and out of costly residential settings.

Additional costs are likely to accrue as more people fall into the remit of the mental health services from proposed changes set out in the Criminal Law (Insanity) Bill. Other initiatives, such as action in support of carers described in Sustaining Progress, will add further to costs.

Section 8 - Conclusions

This report has explored the availability of mental health services to people with a dual diagnosis in Ireland. It concludes that, whilst generic mental health services exist to cater to the needs to the general population, persons with an intellectual disability find it difficult or impossible to access services appropriate to their needs. This is because they are routinely denied access to the range of generic services on account of their disability, and only limited mental health service provision is made within the generic intellectual disability sector.

For this reason, the report concludes that inequality in service provision exists between the dual diagnosis group and the general population with mental health service needs in Ireland.

The findings also place the Government of Ireland at odds with its legal obligation under a number of international treaties.

Summary of recommendations

Formal recommendations are set out in Section 6, above. In summary, these are:

- Provision of services and development of new services for this group, which should be underpinned by legislation and clear statements on access, standards and inspection, etc.;
- The Department of Health and Children (DoHC) should publish a national policy statement and service framework for mental health and appropriate to the needs of the dual diagnosis group (consistent with the above point). This should be accompanied by a strategy for the development of such services, their management and funding;
- Services should be planned by Regional Health Offices (RHOs) for their resident populations - with consistency at national level in standards of care and access criteria across all providers;
- Service delivery should largely focus on specialist multi-disciplinary teams who are dual trained in intellectual disability and mental health. Their aim should be to maintain people in their normal community setting through timely assessment and treatment, supporting informal and professional carers, providing social service input, and linking efficiently with specialist services when required;
- Four regional units, geographically distributed, must be available to support community teams by providing specialist acute assessment and treatment for the dual diagnosis group. These units, operated by the statutory and/or voluntary sectors, would themselves be supported by step-down capacity

preferably in the community and by the active co-operation of referral agencies;

- Distinct forensic provision is made in four geographically distributed centres offering both semi-secure and low secure beds - lined to the Central Mental Hospital, Dundrum;
- Full consideration to staffing issues is required in order to ensure a stable and sustainable service, supporting the highest standards of care, and providing a rewarding career for those in the services.
- Despite limited empirical evidence, the research found a high degree of consistency amongst stakeholders in their views about dual diagnosis service needs and current gaps in provision in Ireland.
- This report recommends service development to ensure that the mental health needs of the dual diagnosis population in Ireland are adequately addressed. The need for these services is growing, and provision should be addressed as a matter of urgency.

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Appendices

Appendix I - Case studies

Case Study - "Mary"

Mary is a young adult with who has exhibited persistent moderate to severe challenging behaviour since the age of 12. She was diagnosed with mild to moderate learning disability at that age, and subsequently diagnosed with high functioning autism at the age of 14.

Mary's family initially sought support from the local Health Board, who provided largely advisory services through their Child Guidance Clinic, and the family also at that time secured private psychiatric consultations. Despite that range of therapies, including medication, Mary's behavioural state remained disturbed.

She received primary-level education in the mainstream service, where she remained until 14 years old. During the last year, she received support for 2-3 days per week at school from classroom assistants trained to provide behavioural management.

Post primary, Mary had two brief periods in school - spending three months at a school for mild intellectual disabilities before moving for a similar period to a school for the moderate and upwards client group. However, her behaviour was very disturbed by this time and she was unable to remain in school.

For the next two years, Mary lived at home. Other than a brief period attending a day service, she received no mental health services to address her needs. During this period, Mary exhibited severe challenging behaviour on a daily basis, including swings of violence and remorse towards her principal carers.

Again the family sought private psychiatric help. Mary made limited progress on medication but, after a short period, suffered regression. Around this time, she began worsening bouts of self-injurious behaviour.

Mary was committed as an emergency during one episode to a regional generic psychiatric hospital. Her conditions had deteriorated to the extent that discharge to home was no longer possible - and she spent over one year in the facility. During this time, no therapeutic services were provided appropriate for her mental health needs or disability.

Despite appeals to the Health Board, no progress was apparent towards securing appropriate services for Mary - and her family commenced legal action against the Health Board to secure such services.

After protracted legal intervention, Mary was finally admitted to one of the only specialist centre in Ireland for persons with a learning behaviour and severe challenging behaviour. She has settled well, has returned to day services and her behaviour had moderated under therapy.

Case Study - "Sean"

Sean is a young adult from the Greater Dublin area who, until September last year (2002), was living at home with his mother and attending a nearby school for the intellectually disabled. He has a mild to moderate intellectual disability. His general health was good, though a history of acute episodes of epilepsy from the ages of 3-7 years old. Sean was progressing well at home and school, with occasional attention seeking behaviour and pseudo-seizures noted.

Last September his behaviour patterns changed dramatically over a few hours. Initially exhibiting severe agitation, this progressed over coming days into a pattern that included withdrawn communication, hand-biting, sleeplessness, bed/clothes wetting, pseudo-seizures, refusal to attend to personal hygiene, and threatening self-injurious behaviour.

Sean's mother contacted a voluntary organisation in the locality that provides services for persons with intellectual disability. Sean was initially placed in a group home but, without adequate structured day activities, became frustrated and he went missing from the home on a number of occasions. Six weeks after entering the home, the organization placed Sean into the care of the Area Health Board.

The Health Board had no prior contact with Sean and, after establishing his care record, lodged him with three care assistants in emergency accommodation in a local hotel. No therapy or other interventions were offered. Sean went missing from the hotel on several occasions, including an incident of threatening self-injurious behaviour.

A voluntary care order was obtained, and the Health Board changed Sean's carers to three Psychiatric Nurses - and another hotel.

Sean's mother has taken his case for to the District Court on five occasions - each time to secure services for her son. The court has now ordered the Health Board to provide a range of therapeutic interventions delivered by professional staff - including behavioural therapy.

Four months after the acute episode began, the Health Board moved Sean and his three carers into a privately-rented home. A significant improvement in Sean's functioning was noted - and ascribed to the interventions, provision of day services/activities, and the normalisation of his environment.

However, one year on, the Health Board moved Sean to long term care in an Acquired Brain Injury unit within a rurally-located Private Nursing Home. Initially, this was to be on a 'trial-basis', but the Board since conceded that no other option was being considered for Sean's care at that time. Sean was accommodated with a predominantly older adult and elderly population - none of whom have learning disabilities. The home offered no therapies, and its location and staff roistering provided little opportunity for spending time outside the institution. Sean's behaviour and mental health deteriorated markedly during this period, resulting in his day care place being withdrawn. He eventually absconded from the home.

At present Sean is homeless. He spends his days in local town centres near to where he grew up, and pseudo-seizures bring him into contact with a local casualty unit where he frequently spends the evening and night. His mother continues to fight to secure appropriate services for her son.

Appendix 2 – List of contributors

List of contributors

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