Meeting the Challenge of Challenging Behaviour

The Policy and Vision for the Development and Delivery of Services for People with Intellectual Disabilities and Challenging Behaviour

Final Report
November 2004
South Eastern Health Board

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The steering group is responsible for overseeing the implementation of the Project and submitting the policy statement and strategic plan for the development and delivery of services for people with intellectual disabilities and challenging behaviour.

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TERMS OF REFERENCE

The terms of reference agreed by the Regional Behaviour Steering Group are:

1. To investigate the nature and prevalence of challenging behaviour within services for people with intellectual disabilities in the South Eastern Health Board and to assess the impact of challenging behaviour on families, staff and service users.

2. To provide an overview of the current service provision for people with intellectual disabilities and challenging behaviour, including those with a co-occurring mental disorder or ‘mental illness’.

3. To outline and recommend models of best practice on:
   - Delivery of services to meet the needs of people with intellectual disability and challenging behaviour.
   - How best to build staff capacity to support people with intellectual disabilities and challenging behaviour in the community.
   - The additional supports required for families in receipt of intellectual disability services to cope with challenging behaviour.

4. To identify the needs of individuals and their families whose community placements are at risk or who are in receipt of specialist services outside the region.

5. To specify sustainable service developments in the areas of assessment, prevention and crisis intervention and to prioritise services required for each area, including new services or facilities, having regard to best practice in meeting the needs of people with an intellectual disability, including those with a co-occurring mental disorder or ‘mental illness’ and challenging behaviours.

6. To examine the costs of any proposed developments and then to consider opportunities for the reinvestment and restructuring of existing resources deployed in the delivery of services for people with intellectual disabilities.

7. To identify clear timescales for the implementation of the project and the delivery of recommendations with an action plan for the implementation of the key priorities identified from both a regional and catchment area perspective.
EXECUTIVE SUMMARY

This report is based on the findings of a comprehensive review that was commissioned and undertaken by the South Eastern Health Board in 2003/2004. The report was sought in order to establish the strategic response to the growing and significant challenge faced by carers and staff in the South Eastern Health Board region in the management of people who exhibit behaviours that challenge. People with intellectual disabilities, for a variety of reasons, can display behaviours which are difficult to understand and difficult to relate to and place the person at a disadvantage in their relationships. Many individuals and agencies articulated their requirement to have a more comprehensive understanding of the issues surrounding challenging behaviour and a better awareness and available expertise in their approach to dealing with situations that arise as a result of challenging behaviours.

This report comprehensively documents feedback from the parents and carers of people with challenging behaviours, the staff who work with people with challenging behaviours, the managers and service planners involved in the care of people with intellectual disabilities.

The main findings of the report are that:

• Challenging behaviour is a significant problem across a number of different settings that provide services for people with disabilities. The majority of people with intellectual disabilities who are living in psychiatric hospitals have challenging behaviours (58%). Over half the people living in houses on campus have challenging behaviours (55%). Over one quarter of people with intellectual disabilities living in the community (31%) have challenging behaviours. 17% of children in special schools have challenging behaviours.

• Most people who present with serious challenges to service providers because of their behaviour are adults with a moderate or severe level of intellectual disability.

• For every 100,000 of the general population, there are likely to be between 24 and 63 people who have an intellectual disability and serious challenging behaviour.

• Challenging behaviour has a significant negative impact on the quality of life for the person themselves, their families and those who live or work with them. Challenging behaviour causes significant management difficulties and includes behaviours which cause risk of injury to the self or others and which results in the person being denied access to ordinary community facilities.

• This report highlights that staff who work with people with challenging behaviour are at risk of physical injury. There were a total of 241 incident reports of physical assault in the region over a four-week period.
• There is a reliance on pharmaceutical interventions to manage challenging behaviours. 74% of the people with challenging behaviour in sheltered work settings are on medication for their behaviour. Only 17% of all the placements have a behaviour management programme for people with challenging behaviour.

• Effective teamwork, experienced, trained staff, access to multi-disciplinary support, programme planning and a number of environmental conditions are factors identified by staff as contributing to the successful management of challenging behaviour.

• There are a number of people placed in services outside the region or with no service because of their challenging behaviour. The needs of these people are very diverse; there is no one model of service that would be appropriate to meet all of the needs identified.
  o 50% of the identified people with no service or placed outside the region have a mild level of intellectual disability.
  o Most of the people with no services or who are placed outside the region are over 18 and have been physically aggressive towards others. The majority of those identified have additional difficulties.

• Many of the people with challenging behaviours have additional mental health needs. Access to mental health services for people with intellectual disabilities and mental illness is inadequate and varies across the community care areas in the South Eastern Health Board region. There are an inadequate number of consultant psychiatrists and multidisciplinary mental health teams in intellectual disability in the region.

• The needs of people with challenging behaviour are so varied that a wide range of services and supports are required. The range of service options to support people with challenging behaviour include allocation of additional resources in existing services; establishment of specialised challenging behaviour units; establishment of challenging behaviour specialist teams.

• People with challenging behaviours require:
  o Person-centred planning
  o Intensive case management
  o Individualised support systems
  o Skilled personal assistance

• Planned relief and short breaks are required to give families and carers a break from the pressure of managing challenging behaviour at home. Emergency respite will be required for some families/carers in crisis situations.
• Familiarity, knowing the needs of service users and consistency in approach is essential in responding to behaviours that challenge. Ongoing supervision of practice and training is needed to ensure that carers and frontline staff have the required skill and technical competence to deal with challenging behaviour. Carers supporting people who display dangerous behaviours will require clearly defined strategies for managing these behaviours safely when they occur.

• Positive behavioural support has been identified as an effective means of addressing challenging behaviours and includes strategies to: 1) control the environmental conditions that lead to the challenging behaviours and 2) change the person’s repertoire to include more adaptive behaviours.

• Caring for people with challenging behaviour is inherently stressful. Throughout the review, the need for people to support each other and to share information became an integral feature of meeting the needs of staff who sometimes struggle to cope in a highly charged environment. During the process of this review a support network system was established for all staff and carers providing care to people with challenging behaviour in the region.

From this review of best practise and consultations with key stakeholders, this report has resulted in a strategic planning tool in the area of challenging behaviour, for use for all service providers, staff and carers. A wide number of recommendations have been made in the areas of training and support for families, carers and staff; respite and home support services, high support residential services, and the special multi-disciplinary expertise required, including behavioural support services and access to specialist mental health services.

This document will assist the health services in each area in formulating a local response to developing services for people who have challenging behaviours. The implementation of the recommendations in this document will significantly improve the quality of the services provided to people with intellectual disability and will make available the professional supports needed in order to sustain best practice.
Recommendations

The following recommendations are based on the data from the focus group research, consultations with key stakeholders, the data from the South Eastern Health Board Challenging Behaviour Survey; the work of the project sub-committees and best practise research in the area of challenging behaviour.

Challenging behaviour in young children with intellectual disabilities

1. The escalation of challenging behaviour should be prevented at an early stage. Specialist dedicated teams for early intervention services should provide a comprehensive multi-disciplinary assessment of need between the ages of 2-6 years and be responsible for the development and implementation of individualised care plans for children under 6 years (6.7.1).

2. A Behaviour Specialist should be available to the early intervention team to provide detailed assessments of challenging behaviour at home and at pre-school. The Behaviour Specialist should be responsible for training parents, family support workers and other key workers in current best practice in responding to behaviours that challenge and in the development of positive behavioural support programmes for children with challenging behaviour (6.7.2).

3. Each child should have a person-centred plan to facilitate the transfer from early intervention services to other services where ongoing multi-disciplinary support is required (6.7.3). Key professionals should work in partnership with families in co-coordinating service provision and in developing the plan to meet the child’s identified needs (6.7.4).

Challenging behaviour in schools

4. There should be a coordinated response between the Department of Education and Health to the recommendations outlined below in line with the Education for Persons with Special Needs Act 2004 and the Disability Bill 2004.

5. Additional support systems need to be developed in special education schools to support teachers and staff in responding to challenging behaviour within schools (6.7.33).

6. Counselling and support services should be available for staff who have been traumatised after an incident of assault in school (6.7.33).
7. Children in school with challenging behaviours and special education needs should have access to holistic assessment to be carried out by people with appropriate expertise (6.7.35).

8. There should be equitable and timely access to multi-disciplinary support in all schools that provide special education. A collaborative multi-intervention plan to address challenging behaviour should be developed between parents, teachers and the key multidisciplinary professionals involved (6.7.35).

9. Teachers and special needs assistants should have appropriate training, preferably as a team, in understanding challenging behaviour and current best practise in responding to behaviour that challenges and in the development of behavioural support programmes for students with challenging behaviour (6.7.36).

10. Protocols and procedures to facilitate communication and information sharing should be developed between school and health board staff and families (6.7.37).

11. School team meetings should be arranged to capitalise on teacher experience, to enable teachers and staff to work together in the development of proactive strategies, and to develop a planned crisis response strategy to manage challenging behaviour in school (6.7.38).

12. The school environment should be assessed and modified where possible to meet the needs of children with challenging behaviours (6.7.39).

13. Children with special needs in school should have a comprehensive needs assessment with an individualised care plan to meet their needs before they leave school. School principals and key professionals should work in partnership with families and school leavers in co-ordinating the care plan to meet their needs (6.7.40).

Challenging behaviour at home

14. Families with children and adults with intellectual disabilities and challenging behaviours should have regular short breaks (2-3 hours, 3 times per week) to be able to cope with behaviours that challenge. The current home support service should be reviewed to ensure that families are getting breaks when they need them, particularly in the evenings and at weekends (6.7.8).

15. Additional home support services should be provided during school, workshop or day centre holiday times. Holiday periods in Training/Day centres should be reviewed and where possible staggered over shorter time frames (6.7.9).
16. Planned relief and short-term breaks should be available to give families/carers a break from the pressure of managing challenging behaviour at home (7.8.7).

17. The respite service should be expanded and further developed to include alternative models (e.g. shared care) of providing respite and support to families (6.7.11).

18. Respite services should be provided in a flexible way, at the appropriate times and with the appropriate peer group to meet service users needs. Activities during respite should reflect service users likes and dislikes (6.7.12).

19. An emergency respite care service should be established in each community care area and made available to support families and carers in crisis situations (7.8.8).

20. A crisis after hours (5pm – 9am / week-end) telephone support service for families of children and adults with intellectual disabilities and challenging behaviour should be developed. This service should be linked to on-call family support workers and an emergency respite service (6.7.10).

21. An information desk with staff responsible for the provision of information should be developed in each region to assist families in accessing services available within the Health Board. Families should receive information on the services available to support people with intellectual disabilities (6.7.13).

22. Social / leisure activities in the community should be provided to meet the needs of people with intellectual disabilities and challenging behaviour, particular in the evenings and at weekends (6.7.14).

23. Practical skills training and work opportunities should be provided for people with intellectual disabilities and challenging behaviour (6.7.15).

24. Personal family support workers should be available to provide practical support to people with intellectual disabilities and behaviours that challenge in the home. Specialist training in the management of challenging behaviour and understanding challenging behaviour should be provided to family support workers (6.7.16).

25. Specialist challenging behaviour support services should be developed for assessment and management of challenging behaviour in the home. Training and support in the management of people with challenging behaviour should be available to parents (6.7.17).

26. Family therapy and counselling should be available to support families of children and adults with challenging behaviour (6.7.18).
Challenging behaviour in Residential/Day Services

27. Managers of services should promote a culture of supporting people with intellectual disabilities and challenging behaviours, in which they have a right to live as independently as possible, to develop and use their abilities and talents and, to live, learn and work in environments appropriate to their needs (6.7.19).

28. Service providers should ensure that people with challenging behaviour have opportunities for meaningful work, leisure and social activities in the community (4.4.1).

29. Service users should be fully informed about all services available to them, with information on how to access services (6.7.22).

30. Service providers should ensure that there is a structured programme of activity in place with enough flexibility to meet the person's needs. Multidisciplinary support should be available to service providers to support the development of a programme of activity which may include opportunities to learn functional daily living skills; communication skills, training and sensory integration programmes as needed (4.4.3).

31. Practical support needs to be incorporated into the person-centred plan to include training and support in independent living skills (such as, cooking, money management). Additional supports should be provided to empower service users to manage their own behaviours that challenge (e.g. counselling, anger management, assertive communication, stress management etc.) (6.7.21).

32. A person-centred planning system should be developed in each organisation to include a review of the person's environment to ensure that the person is living in a safe environment with adequate physical space (4.4.2).

33. The environment should be regularly assessed and adapted to ensure the safety of others. (6.7.23)

34. There should be regular reviews of the medication prescribed to individuals with challenging behaviour with monitoring systems in place to evaluate the effectiveness of medication to address challenging behaviours. These reviews should be incorporated into the person-centred planning system (4.4.6).

35. Service providers should ensure an appropriate staff: client ratio based on the needs of the service user with challenging behaviour. There should be continuity and consistency in approach to the management of challenging behaviour with staff trained in evidence-based methods in the assessment and management of challenging behaviour (4.4.4).
36. On-going supervision of practice and training programmes should be provided to ensure that frontline staff have the required skill and technical competence to deal with challenging behaviour to an agreed standard of practice (7.8.6).

37. Frontline staff should be supported to increase their understanding of how challenging behaviours develop in individuals with intellectual disabilities. The use of positive approaches to promote a healing environment to support people with challenging behaviour should be encouraged (6.7.25).

38. Managers of services should develop strategies to maintain staff consistency and reduce staff turnover (6.7.24).

39. Managers of services should develop systems to ensure communication between staff. These systems should be reviewed and evaluated on a regular basis (6.7.27).

40. Staff should work together as a team to support each other in the management of challenging behaviour. Team meetings should be scheduled on a regular basis to address challenging behaviours (6.7.26).

41. Employers and managers should ensure that their staff members receive training in responding to behaviour that challenges, including updates and refresher courses, appropriate to their role and responsibilities within the service (7.8.11).

42. Frontline training should be prioritised in the following areas:
   - Understanding how challenging behaviours develop in individuals with intellectual disabilities and how life experiences and the environment play a key role in the person's behaviour (4.4.10).
   - Training in behavioural assessment and multi-element behavioural support to promote the use of effective, non-aversive methods that work with individuals who have challenging behaviours so that they can enjoy community participation with dignity and respect (6.7.28).
   - Training in reactive strategies to manage crisis, including the appropriate use of physical intervention to manage physically aggressive behaviour. This training should be targeted specifically in services where there have been incidents of physical injury reported and where there is a need for staff members to physically intervene in order to manage physical aggression in a safe way (6.7.29).
   - Training and support in the management of sexualised behaviour (4.4.12).

43. The challenging behaviour support network should be formalised, facilitated and encouraged by management (6.7.32).

44. A Training Coordinator should be appointed to oversee, develop and coordinate training programmes for staff working within disability services in the South Eastern Health Board area (6.7.31).
45. Each organisation should have guidelines on responding to behaviours that challenge, which should include clearly defined crisis management strategies for responding to incidents of challenging behaviour when they occur and a policy on the use of restrictive physical intervention. These strategies should be used in conjunction with a long-term intervention plan based on positive programming (7.8.9). The policy should also include guidelines on providing counselling and support after incidents of challenging behaviour (6.7.30).

46. Interventions should be based on the least restrictive, non-aversive approaches to challenging behaviours. If an aversive procedure is used, a multi-disciplinary team must sanction this and its use should be recorded and evaluated on a regular basis. Relatives/advocates must be informed or consulted (7.8.10).

**Service options and specialist support for people with challenging behaviours**

47. A range of service options with a continuum of service provision should be available to support the wide range of people with intellectual disabilities and challenging behaviour (7.8.1). The needs of the individual should be matched with the appropriate model of care (7.8.2).

48. The system should be flexible to provide additional staffing and a range of supports as needed to maintain the person with challenging behaviours in their usual environment. People with challenging behaviours should have:
- Flexible person centred planning
- Intensive case management
- Individualised support systems
- Skilled personal assistance.
- Access to respite services (7.8.3).

49. Dedicated Challenging Behaviour Specialists should be available in each catchment area, to focus exclusively on children and adults with intellectual disabilities and challenging behaviours (4.4.6).

50. Challenging Behaviour Specialists should assist with the assessment of challenging behaviour and provide support to families and service providers in the implementation of effective behaviour support plans to address the challenging behaviour (6.7.5).

The challenging behaviour assessment should include a functional analysis of the behaviour. The interventions to address the challenging behaviours should be evidence-based and monitored and evaluated regularly (7.8.4).
51. Challenging Behaviour Specialists should provide families and direct care staff with the technical expertise to help the person with challenging behaviour acquire the skills and behaviours necessary for them to function with as much self determination and independence as possible in the community (4.4.7).

52. The Behaviour Specialists should provide training to frontline staff in the area of behavioural assessment and support (4.4.7).

53. The Behaviour Specialists should be part of a multidisciplinary team which should include a speech and language therapist, an occupational therapist and behaviour support workers. This team should:
   - Provide a comprehensive assessment and functional analysis of the challenging behaviour.
   - Develop a multi-element challenging behaviour intervention and support plan with service users, family carers and staff.
   - Train and support carers and staff in the implementation of the programme.
   - Provide hands-on support to families and staff in times of crisis (6.7.6).

54. Support should be prioritised in the areas with the highest levels of challenging behaviour and in locations where there have been incident reports of physical injury (4.4.8).

55. A multi-element behaviour support plan should be developed for all people with intellectual disabilities and challenging behaviours that significantly interfere with their quality of life and the quality of life of their carers (4.4.9).

56. Specialised high support housing will be needed for a proportion of people with severe challenging behaviour. The type of support required should be based on an individualised and comprehensive needs assessment (7.8.5).

57. People with mild intellectual disabilities and challenging behaviours should have access to a range of supports to live independently in the community. A case manager should coordinate the integration of mental health services, social services and disability specific services for individuals with mild intellectual disabilities and challenging behaviours (6.7.7).

58. A specialist sexuality assessment and therapeutic service should be developed for people with intellectual disabilities and problematic sexualised behaviour in the region. Service providers should have access to training and support in the appropriate management of sexualised behaviour (4.4.11).
People with challenging behaviour placed outside the region or with no service.

59. Placement outside the region should be seen as a last resort and the aim should be to develop services to support the person in their own community whenever possible (5.4.1).

60. There should be an annual review and needs assessment of the people placed outside the region to see if their circumstances have changed, if they can be brought back, and what needs to be put in place to allow this to happen. A needs assessment and person-centred plan should be developed for each person placed outside the region with challenging behaviour (5.4.2).

61. The Department of Education and Science should be involved in the placement and the monitoring of the educational input to children placed outside the region. Additionally if a placement breaks down the DES should be involved in the arrangements for an alternative placement (5.4.3).

62. The focus should be on how to prevent the necessity for placement outside the region in the future. A system to flag potential placement breakdowns should be developed. A comprehensive assessment of needs should be prioritised for those at risk of placement breakdown (5.4.4).

63. Service providers should have support from Challenging Behaviour Specialists to maintain the person with challenging behaviour in their current placement and to prevent placement breakdown. A behaviour assessment to include a functional analysis of the behaviour and behaviour support should be provided for any person with challenging behaviour in services that poses a risk to themselves or others (5.4.5).

64. People with intellectual disabilities and challenging behaviour should have access to a specialist mental health assessment and treatment as required to prevent placement breakdown and to support people in their current placement (5.4.6).

65. People with challenging behaviour should have individualised supports and a flexible care plan. The plan should be developed with the person, their parents and key people in the person's life. Individualised funding should follow the person rather than being linked to a service provider (5.4.7).

66. A working group should be established to consider the needs of people with mild intellectual disabilities and to make recommendations regarding the delivery of services and supports required for this group (5.4.10).
Home support services and behaviour support services should be prioritised for people with severe challenging behaviour living at home without a day service (5.4.8).

Emergency respite care and crisis short-term placements for people with challenging behaviours should be planned for and made available in crisis situations so as to give families, staff and the organisation an opportunity to arrange an appropriate response (5.4.9).

**Mental health assessment and treatment for people with intellectual disabilities**

There should be specific funding towards mental health services for people with intellectual disabilities (8.8.1).

Specialist multidisciplinary community based mental health teams dedicated to supporting people with dual diagnosis should be developed. The focus of the service should be on supporting people with a dual diagnosis to live in an appropriate setting within the community (8.8.2).

Geographical catchment areas should be established for the intellectual disability mental health service in order to provide an effective localised service (8.8.3).

Consultant Psychiatrists trained in the psychiatry of learning disability with multidisciplinary teams should be appointed to provide a mental health service for people with intellectual disabilities. The subcommittee of the faculty of Learning Disability Psychiatry of the Irish College of Psychiatrists (2004) recommends that 2 Consultant Psychiatrists with multidisciplinary teams are required per 100,000 population – one team for adults with intellectual disabilities and one team for children and adolescents with intellectual disabilities (8.8.4).

The other disciplines of the team should include psychologists, community mental health nurses, social workers, occupational therapists, speech and language therapists (8.8.5).

The team should provide:

- Multidisciplinary assessment and community based treatment programmes, including:
  - Pharmacotherapy, behavioural interventions and psychotherapy
  - Outreach consultation
  - Acute care with facilities for hospital admission
  - Cross training in local disability services and generic mental health services
  - An after hours crisis intervention service
  - Treatment plans and comprehensive aftercare planning (8.8.6).
75. The outreach service should provide support to service users and their families and organisations providing services in the community. The outreach service should include staff training, medication reviews with ongoing monitoring and re-assessment in the person's natural environment (8.8.7).

76. Appropriate in-patient assessment and acute treatment beds should be provided for people with intellectual disabilities who are mentally ill. The subcommittee of the faculty of Learning Disability Psychiatry of the Irish College of Psychiatrists (2004) recommends that 5 in-patient assessment and treatment beds are required per 100,000 population for people with intellectual disabilities and a mental disorder who present major risks to themselves and others (8.8.8).

77. Robust arrangements and explicit protocols should be in place for admission and discharge planning and liaison with local services. The goal should be for these individuals to return and live in their communities, with support packages that adequately meet their particular needs (8.9.10).

78. A 24 hour on-call emergency support system and an after hours crisis intervention service should be put in place that can respond rapidly to emergency situations, usually severe physical aggression or severe self-injury, with medical assistance if required (8.8.10).

79. A clear policy should be provided in relation to the admission of people with intellectual disabilities into psychiatric hospitals in the interim pending the development of specialist in-patient assessment and treatment units for people with intellectual disabilities (8.8.11).

80. There should be consultation and collaborative planning between disability and mental health services, to support people with a dual diagnosis (8.8.12).

81. People with intellectual disabilities and mental illness should have a comprehensive, co-ordinated plan of treatment and supports. A dual diagnosis and planning forum should be established in each geographical catchment area (8.8.13).
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CHAPTER 1:
INTRODUCTION

1.0 BACKGROUND TO THE CHALLENGING BEHAVIOUR PROJECT

There is a small number of people with intellectual disabilities whose behaviour at times is so challenging that services have extreme difficulty meeting their needs. Their behaviours may involve physical attacks on others, self-injury or serious property destruction. The behaviours may restrict a person's access to community activities and lead to isolation. Placing persons with challenging behaviours in community-based disability services can present a major problem Incapacity to cope with challenging behaviour at home and in the community has led to placement breakdown.

Challenging behaviours amongst people with intellectual disabilities can significantly interfere with their quality of life, the quality of life of other service users and of those who live and care for them. Those with intellectual disabilities and challenging behaviours may be excluded from schools or day services. They may be prescribed high levels of medication to control their behaviour. Their families may request respite care or crisis intervention or alternative residential provision.

Many people with intellectual disabilities and challenging behaviours have an additional mental illness or psychiatric disorder that requires specialist psychiatric interventions. There are some people with intellectual disabilities and challenging behaviours in psychiatric hospitals. These individuals are perceived as not fitting in to the general psychiatric services while the existing learning disability services have no tradition of providing a comprehensive mental health service. Appropriate accommodation and resources must be provided for these individuals.

Families and staff in the Boards area have identified challenging behaviour as contributing to increased stress. Often family members and staff may reach “breaking point”. Support for disability services has often been unavailable at the intensity required, and staff shortages in relevant fields e.g. clinical psychology and psychiatry have added to the problem. Challenging behaviour has led to an increased demand for specialist services. The "challenge" is to overcome service inadequacies by establishing a pattern of service that will respond effectively to the needs of people with intellectual disabilities and challenging behaviour. Failure to serve people whose behaviour has presented a challenge has far reaching consequences not only for the people themselves who may find themselves excluded from their local communities but also for the future of community-based services.

With these issues in mind, the South Eastern Health Board established a Regional Challenging Behaviour Project Steering Group. The function of the group was to develop over a defined period of time a comprehensive strategic and policy framework for the development of services to meet the needs of people with intellectual disabilities who present with challenging behaviour and to develop a comprehensive plan for implementation in the Boards area.
1.1 TERMINOLOGY

Language and labelling are sensitive issues. Considerable confusion exists over the appropriate use of terms such as ‘mental handicap’, ‘mental retardation’, ‘intellectual disability’ and ‘learning disability’. The Needs and Ability report (1990)¹ suggest the use of the term ‘intellectual disability’ for persons with a moderate or more severe mental handicap. Throughout this report, the term ‘intellectual disability’ will be used.

Intellectual Disability

The term ‘intellectual disability’ is based on the most widely accepted definition produced by the American Association of Mental Retardation (AAMR). A person with an intellectual disability, as defined by the AMMR, must have:

1. A significantly sub-average general IQ. The AMMR defines this as an IQ of 70 or less on a standard measure of intelligence.
2. Limitations in two or more of the following adaptive skills: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics and leisure and work.
3. Acquired their condition before 18 years old.

Challenging Behaviour

‘Challenging behaviour’ is a term (not a diagnosis) to describe severe problem behaviour that may include a variety of behaviours that vary in terms of their frequency, severity and seriousness for the individual and other person.

A commonly accepted definition provided by Emerson (2001)² is:

‘Severe challenging behaviour refers to culturally abnormal behaviour(s) of such 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 the use of, or result in the person being denied access to ordinary community facilities’.

Mental Disorder and Mental illness

The DSM IV defines mental disorder as:

‘A pattern of behaviour, or psychological features, occurring in an individual that are currently associated with any of the following: a subjective sense of distress, impairment in important areas of function, such as work, school, relationships; or a significantly increased risk of posing a danger to oneself or others, or of losing an important freedom’.

The range and severity of mental illnesses is wide. The Mental Health Act (2001) uses the following definition:

‘Mental illness’ means the state of mind of a person which affects the person’s thinking, perceiving emotion or judgment 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’.


1.2 AIMS AND OBJECTIVES OF THE CHALLENGING BEHAVIOUR PROJECT

The short-term objectives of the project are:

- To develop a clear statement of policy and vision for the development and delivery of services for people with intellectual disabilities and challenging behaviour in the Board’s area in the context of needs of service users, families, carers and staff.
- To develop a strategic plan to deliver such services in the context of the key principles, values and targets set down in the Health Strategy including full integration of services, equity, quality, accessibility, accountability and client centeredness.
- To deliver on the recommendations of the strategic plan and use the document as a framework for service development.

The long-term aims of the Challenging Behaviour Project are:

- To improve the capacity of services to respond to behaviour that challenges to enable individuals with intellectual disabilities to live everyday lives with maximum contact with the broader community.
- To establish an integrated pattern of service that will respond effectively to meet the needs of people with intellectual disabilities and challenging behaviour, including those with co-occurring mental disorder or mental illness.

1.3 OVERVIEW OF CHALLENGING BEHAVIOUR PROJECT

Stage 1: Gathering information

The first stage of the Project involved gathering information about the extent, nature and impact of challenging behaviour across the region.

- Consultation Meetings
  A number of consultation meetings were arranged with professionals working with in the South Eastern Health Board and with voluntary services to map out the pathways to services and to discuss issues around supporting people with challenging behaviour.

- Survey
  All settings that provide services to people with intellectual disabilities in the region were surveyed to find out the number of people with challenging behaviour in each setting and whether these behaviours can be effectively in that setting. The survey also provided additional information on multi-disciplinary supports available to people with challenging behaviour (Chapter 4).
• **Working groups**
A working group was established by the steering committee to specifically consider the needs of those who are placed outside the region in disability services or are without a service because of challenging behaviour. The findings and recommendations of this group are outlined in Chapter 5.

An additional working group was established to consider the needs of people with intellectual disabilities and challenging behaviour who have a co-occurring mental disorder or illness (dual diagnosis). The findings of this group and recommendations are outlined in Chapter 8.

• **Research**
As part of the project, a review of the literature was conducted and site visits were arranged to provide an analysis of treatment approaches and models of service to support people with intellectual disabilities and challenging behaviour, including those with a co-occurring mental disorder (Chapter 7).

• **Focus Groups with Key Stakeholders**
A series of role specific focus groups were arranged with key stakeholders to discuss their views of challenging behaviour, including the impact of challenging behaviour, the supports and resources required to deal with the behaviour, and the impact of aspects of the services on challenging behaviour (Chapter 6).

**Stage 2: Policy Development and Recommendations**

The second stage of the Project was to analyse the information collected, to highlight the key issues identified and to provide policy statements and recommendations.

**Stage 3: Action Planning**

The final stage in the Project is to formulate a plan of action to implement the recommendations at a regional and a local level.
OVERVIEW OF CHALLENGING BEHAVIOUR PROJECT

Fig. 1: Overview of Challenging Behaviour Project

Stage 1
Gather & interpret information

Overview of current services/gaps in service provision

Consultations with key stakeholders

Qualitative Research

Focus groups:
Parents
Staff/service managers
School Principals
Service users
Disability Coordinators & Liaison Counsellors

Overview of services for people with Dual Diagnosis

Sub Group

Quantitative Research

Stage 2
Provide policy statements and make recommendations

Stage 3
Formulate a plan of action

Stage 2
Analysis of treatment approaches/models of service

Needs of people placed outside the region/with no Service due to CB

Sub Group

Analysis of treatment approaches/models of service

Best practices in supporting staff, service users, & families

Stage 3
Formulate a plan of action

Literature review/site visits

Research evidenced based treatment approaches & models of service

Database of service providers with CB

Highlight strengths/weaknesses analyse issues
CHAPTER 2

SEHB VALUES AND KEY PRINCIPLES

2.0 SOCIAL AND HUMAN RIGHTS
MODEL OF DISABILITY

This document is based on the recognition of the human rights of people with intellectual disabilities and challenging behaviour. The human rights approach to disability 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 to their difference. The social model of disability locates disability within society and how society functions and adapts to disability. The aim of the social model is to create a society that recognises diversity and works towards inclusion and equality for all.

International Treaties and Obligations

The shift to a rights based approach has been authoritatively endorsed by a number of international conventions that enshrine the rights of disabled citizens to equality of access to service (including health and social care services) of which Ireland is a signatory.

Article 3 of the United Nations (1975) Declaration on the Rights of Disabled Persons states:

‘Disabled people, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full life as possible’.

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'.

The South Eastern Health Board Mission Statement is

"To help the people we serve to maximise their health and social well being using the resources at our disposal as effectively and efficiently as we can"

2.1 OUR BASIC VALUES

All people with an intellectual disability, including those with challenging behaviour should:

• Have the same value as everyone else
• Be treated with dignity and respect
• Be seen as individuals with individual needs like everyone else
• Be entitled to everyday lives
2.2 FOUR KEY PRINCIPLES

There are four key principles outlined in the Health Strategy (2002) that we have taken into account in all our considerations and recommendations.

1. Equity and Fairness
   All people with intellectual disabilities, including those with challenging behaviour should have fair access to services. The system must respond to people's needs rather than have access dependent on geographical location or ability to pay. No-one should be disadvantaged from achieving his or her full potential.

2. A Person-Centred Service
   A person-centred service is provided, organised and designed around what is important to the service user from their perspective. People with intellectual disabilities should be consulted about their needs; involved in decisions about services they receive and be able to exercise choice wherever possible.
   A person-centred approach looks at what is available in mainstream and community services rather than limiting services to what is available within specialised disability services. People with intellectual disabilities should receive help with communicating their needs, where required.

3. Quality of Care
   Services to support people with intellectual disabilities and challenging behaviours are to be delivered and improved based on current best practice and research. Service provision should be responsive to service user needs and based on providing the best personal outcome for the individual, which will eventually lead to an improvement in the person's quality of life.

   The Draft National Standards for Disability Services (April 2003) have been developed to ensure that services are provided to an agreed level of quality and that the level of quality is consistent on a national basis.

4. Clear Accountability
   All services for people with intellectual disabilities are accountable to their service users, family of service users, support workers and funding bodies. Financial, professional and organisational accountability must be demonstrated.

2.3 A POSITIVE APPROACH TO CHALLENGING BEHAVIOUR

The South Eastern Health Board aims to promote the use of effective positive, non-aversive approaches in responding to behaviours that challenge.

A person's behaviour usually changes for the better when they are supported to live in a manner that better meets their needs.
A positive approach aims to support people to grow and to develop, to make their own decisions to achieve their personal goals, to develop relationships and to enjoy life as a fully participating member of the community. The focus of a positive approach is on building competencies, creating opportunities and offering choices that help each person live a fulfilling life. It involves changes to the environment to achieve a better fit with the needs and characteristics of the person. This requires getting to know a person, their unique qualities, their personal history and their living environment.

The positive approach assumes that all behaviour has a meaning and that an individual’s behaviour can be a method to communicate needs and wants. We need to understand what the person is trying to communicate to us through their challenging behaviour, and then aim to teach the person more effective ways of communicating the message or alternative skills for achieving the purpose. Intervention strategies to manage challenging behaviour should include environmental accommodations and adaptations to meet the person’s needs. Strategies to reduce problematic behaviours that are difficult or potentially dangerous should incorporate the teaching of social and communication skills necessary to overcome challenging behaviour.
CHAPTER 3

UNDERSTANDING CHALLENGING BEHAVIOUR

3.0 INTRODUCTION

The term challenging behaviour has replaced terms such as maladaptive behaviour or disturbed behaviour and was originally adopted from The Association of Persons with Severe Handicaps (TASH). The term emphasises a shift in perspective away from seeing behaviour problems as inherent qualities of people towards a focus on how behaviours represent challenges to services. Challenging behaviour implies that the behaviour is a challenge to the environment in which the behaviour occurs.

The global term of challenging behaviour has led to problems of definition as the term challenging behaviour covers a wide range of behaviours.

Different people will have different ideas about what is meant by ‘challenging’. Identical behaviour may be seen as challenging by staff in one setting but not in another.

3.1 THE SOCIAL CONTEXT OF CHALLENGING BEHAVIOUR

Behaviour can only be defined as challenging in particular contexts. For example, physical aggression is encouraged in the boxing ring but not in a hospital setting.

Whether behaviour is defined as particularly challenging in a particular context will be dependent on such factors as:

- Social rules regarding what is appropriate behaviour in that setting.
- The ability of the person to give a plausible account of their behaviour.
- The beliefs held by other people in the setting about the nature of intellectual disabilities and the causes of the person’s challenging behaviour.
- The capacity of the setting to manage any disruption caused by the person’s behaviour.

3.2 DEFINITION OF CHALLENGING BEHAVIOUR

A number of attempts have been made to define the characteristics of challenging behaviour in people with intellectual disabilities more precisely. Emerson’s definition, revised in 1995 is the most commonly cited definition of challenging behaviour:

"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 a behaviour which is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities". (Emerson, 1995)³

This definition makes no reference to the form or type of the behaviour but rather emphasises the consequences to the individual or others of the behaviour occurring.

3.3 PREVALENCE OF CHALLENGING BEHAVIOUR

Relatively few studies have attempted to identify the prevalence of multiple forms of challenging behaviour among all people with intellectual disabilities in the total population living in a defined geographical area. More commonly, studies have determined the prevalence of specific forms of challenging behaviour (e.g. self-injurious behaviour: Hillery & Mulcahy\(^4\), 1997; aggression: Harris, 1993\(^5\)) or have restricted sampling to specific subpopulations of people with intellectual disabilities (Griffin et al., 1987\(^6\)). Different interpretations of the term challenging behaviour will have a major impact on prevalence figures. Chung et al (1996)\(^7\) found that the prevalence rate in reported studies usually fell between 8% and 38% of the surveyed population of people with intellectual disabilities.

**Irish Estimates**

A number of unpublished studies have been undertaken of challenging behaviours found in clients using disability services in Ireland. The estimates range from 14% of service users in the Southern Health Board region (Connolly et al. 1995) through 29% in the Galway area (Walshe et al, 1995) and 37% in Dublin (Mulrooney et al, 1997). The variation arises from differences in samples used in different studies as well as definitions of challenging behaviour.

The UK and US studies of prevalence rates of challenging behaviour (Quershi, 1994\(^8\), Emerson, 2001\(^9\) and Borthwick-Duffy, 1994\(^10\)) are the best available to date on which to base estimates for other populations. In these studies, for every 10,000 of the general population, there are between 2.4 and 6.3 people on average who had an intellectual disability and serious challenging behaviour.

If these rates are applied to the population within the South Eastern Health Board (approximately 400,000), there are likely to be approximately 96 – 252 people with intellectual disabilities and severe challenging behaviours.

The South Eastern Health Board conducted its own study to identify the extent of challenging behaviour within each organisation, and setting that provides services to people with intellectual disability in the region (Chapter 4).

---


Persistence of Challenging Behaviours

Emerson (2001) 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 specialised congregate care settings or significant changes in staffing resources and the quality of the physical environment.

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

3.4 RISK FACTORS

In a review of the literature, Emerson (1998) found that challenging behaviours are more common among:

- People in institutional settings
- Boys and men
- People between the ages of 15 – 35
- People with more severe intellectual disabilities
- People with additional sensory impairments, reduced mobility or specific impairment of communication
- People with some specific syndromes (e.g. autism, Fragile X)
- People with epilepsy tend to show more challenging behaviours

3.5 WHAT CAUSES CHALLENGING BEHAVIOUR?

It is appropriate to see challenging behaviour as the outcome of complex interactions amongst a range of factors, environmental, organic, physical, psychiatric, ecological, historical, some of which will be more important than others in individual cases.

A great deal of challenging behaviour occurs when people:

- Are in restrictive environments
- Have unmet needs
- Have needs met in inappropriate ways. (Psychology Society of Ireland 1998)

A person’s challenging behaviour may sometimes seem incomprehensible particularly when the person has limited communication skills and may not be able to describe their feelings, expectations or concerns. However, a considerable amount is known about the factors that influence challenging behaviour.

In many cases, a multiplicity of factors may be important when trying to understand the underlying causes of challenging behaviour.

---


• **Environmental Factors**
  Most of the time, when people exhibit challenging behaviours, a close look at a person's environment can show us why the person is having difficulties. A person's behaviour usually changes for the better when they are helped to live in a manner that better meets their needs. Often, altering the environment to meet the person's needs can alleviate the distress and the related maladaptive behaviour.
  For example, many people in group homes do not get along with their roommates. The daily irritation, sleep problems and experiences of personal space being violated will often lead to aggressive or self-abusive behaviour and general irritability. Changing roommates or arranging for individuals to have a room of their own are appropriate solutions rather than trying to force incompatible roommates to coexist.

  Environmental factors include:
  o The environment being crowded and hot
  o Mealtimes that don’t meet the person's needs
  o There being few structured activities in place (under-stimulation)
  o Too much noise or activity (over-stimulation)
  o Carers employing inconsistent approaches with service users
  o Limited transportation and access to friends and activities
  o Isolation from the community.

• **Communication Difficulties**
  Often a person who is presenting with challenging behaviours has communication difficulties and cannot articulate wants and needs. In order to meet a person’s needs, it is important to do whatever is possible to enable the individual to communicate. Those with a difficulty expressing themselves must be offered any tool available that might enable communication. It is important to ask how we know a person is communicating and to involve the people closest to the person, as these individuals are the ones who can most often read the person's body language enough to tell us what the person is trying to say.

• **Learned behaviour**
  Challenging behaviours may achieve outcomes that other behaviours do not. For example, a person who wants social interaction may have learned that aggressive behaviour leads to more social interaction with people than sitting quietly, doing nothing. Strategies for helping a person to develop more appropriate alternative behaviour that will be as effective, if not more effective, in achieving desired outcomes will be needed.
MEETING THE CHALLENGE OF CHALLENGING BEHAVIOUR

• Physical and Mental Health Factors

Physical and mental illnesses need to be accurately diagnosed and treated or ruled out. Physical factors, such as, constipation, stomach aches, headaches, addiction problems etc. can lead to physical discomfort and distress. A person may present with challenging behaviours as a result of physical discomfort and distress. For example, a person with limited verbal communication skills who has an earache may respond by hitting his ear, in order to communicate pain. A person with an intellectual disability and a mental illness may be distressed, confused and anxious and may respond by becoming verbally aggressive towards carers.

Many people cannot report their subjective experiences due to limitations in communication and therefore, symptoms of physical and mental illness are often misinterpreted. Medical personnel need to work closely with the people who know the person best (the person's family members, care givers) in order to gather information for medical assessment and treatment.

• Neurobiological Factors

Over the last decade, significant gains have been made in identifying neurobiological mechanisms that might underlie challenging behaviour. Most recent neurobiological theories have focused on the role of various classes of neurotransmitters in modulating behaviour. Some evidence suggests that abnormalities in dopamine receptors may be implicated in the development and maintenance of some forms of self-injurious behaviour. The serotoninergic system is closely linked with a number of processes including arousal, appetite control, anxiety and depression. Disturbances in the system have been linked with insomnia, depression, and disorders of appetite control and obsessive-compulsive disorders.

• Stressful Life events

Even with all of the needed supports, opportunities, and conditions in place, a person who has lived a life full of hardship, isolation, stigma and sorrow may have problems that continue for a long time. People with intellectual disabilities are vulnerable to abuse; many have experienced trauma, loss and bereavement. The person we are trying to help needs to have the opportunity to develop trust, often for the first time, needs to develop new ways of being in the world that can meet her/his needs, needs to experience the goodwill and positive regard of others. For those with the most serious challenges, finding someone to persevere with them has proven difficult. Once found, that person has more impact on their lives than any thing or any one else (Barol, 1996)13

3.6 THE IMPACT OF CHALLENGING BEHAVIOUR

Challenging behaviours may directly impair the health and/or quality of life of the person and their carers or those who live and work in close proximity. Within residential situations, the challenging behaviour of an individual also has an impact on other residents, Joyce et al (2001) found from contact with advocacy groups that they object to 'living with the threat of violence or with people whose behaviour interferes with their ability to relax in their own home'.

Challenging behaviour has been shown to increase the levels of stress in families and care staff (Jenkins et al., 1997). Episodes of challenging behaviour can provoke strong emotional reactions such as anger, frustration, despair, fear and disgust.

Escalation in challenging behaviour in adulthood usually results in a crisis residential care placement (Kiernan & Alborz, 1996, Joyce et al. 2001).

The difficulties involved in caring for people with challenging behaviours and the way in which the community, carers, and services respond to people with challenging behaviour, can have wide ranging personal and social consequences for the individual and in extreme cases can lead to abuse, inappropriate treatment, exclusion, deprivation and systematic neglect. Challenging behaviours may limit the development of social relationships and reduce opportunities to participate in community-based activities.

---

3.7 SUMMARY

- The global term of challenging behaviour has led to problems of definition as the term challenging behaviour covers a wide range of behaviours. Identical behaviour may be seen as challenging by staff in one setting but not in another.

- For every 10,000 of the general population, there are likely to be between 2.4 and 6.3 people who have an intellectual disability and serious challenging behaviour.

- People with intellectual disabilities and challenging behaviours will have continuing care needs over extended periods of time. Generic intellectual disability services must be equipped to deal with their needs beyond crisis periods.

- 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 congregated in residential accommodation.

- Challenging behaviour is the outcome of a range of factors; environmental, organic, physical, psychiatric, ecological, and historical, some of which will be more important than others in individual cases.

- Challenging behaviour has a significant negative impact on the quality of life of the person, their families and carers, and of those who live and work in close proximity.
MEETING THE CHALLENGE OF CHALLENGING BEHAVIOUR

CHAPTER 4

THE EXTENT OF CHALLENGING BEHAVIOUR IN DISABILITY SERVICES IN THE SOUTH EASTERN HEALTH BOARD AREA

4.0 INTRODUCTION

The South Eastern Health Board is unique in terms of the number of agencies and voluntary organisations that provide services for both adults and children with intellectual disabilities in the region. As part of the Challenging Behaviour Project research, a survey was conducted to determine the extent of challenging behaviour across a range of services for people with intellectual disabilities in the South Eastern Health Board area.

4.1 METHOD

a) Designing the questionnaire
   A multidisciplinary consultation meeting was held with a number of people providing services to people with intellectual disabilities and challenging behaviour. This included psychiatrists in learning disability, psychologists, school principals in special education, liaison nurse counsellors and managers of services. The purpose of the meeting was to establish the criteria for challenging behaviour and the format of the questionnaire. Criteria adapted from previous research on challenging behaviour were used (Quershi 1994) [17].

Challenging Behaviour:
It was agreed that a person is to be identified as having challenging behaviour if their behaviour meets one or more of the following:

- The behaviour causes repeated injury (bruising, bleeding, tissue damage) / repeated risk of injury to self or others or serious property damage.
- The behaviour seriously limits the use of or results in the person being denied access to ordinary community facilities.
- The behaviour causes significant management problems (Intervention requires more than 1 member of staff for control and/or the behaviour causes daily disruption of at least an hour disruption).

b) Pilot
   The questionnaire and covering letter was sent to the managers of two service providers for completion. The managers of the service in the pilot study were asked to copy and distribute the questionnaire to each setting within their organisation (e.g. residential home, day centre, pre-school etc). A supervisor/designated person who works directly with the clients in that setting was to be nominated by the manager to complete the questionnaire. Some minor changes were made to the questionnaire and covering letters after feedback and analysis of the data from the pilot study.

c) Survey
   All the residential services, rehabilitative training centres, day

centres, sheltered workshops, special schools, pre-schools, and psychiatric hospitals that provide services to people with intellectual disabilities in the South Eastern Health Board were included in the survey.

Service user confidentiality and anonymity was ensured, as no service user identifying information was required for the study. Each manager of the service was sent a letter explaining the study and a copy of the questionnaire (Appendix I). Managers were asked to distribute the questionnaires. Follow up telephone calls and reminder letters were sent to ensure a maximum response rate.

### Table 1: The number and percentage of people with an intellectual disability and challenging behaviour placed in each service category in the South Eastern Health Board Region.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>TOTAL NO. OF PEOPLE WITH INTELLECTUAL DISABILITIES IN EACH SERVICE IN THE SEHB REGION</th>
<th>THE NO. OF PEOPLE WITH INTELLECTUAL DISABILITIES WHO HAVE CHALLENGING BEHAVIOURS IN EACH SERVICE IN THE SEHB REGION</th>
<th>% OF PEOPLE IN EACH SERVICE WHO HAVE CHALLENGING BEHAVIOURS IN THE SEHB REGION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>493</td>
<td>119</td>
<td>24%</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>53</td>
<td>18</td>
<td>34%</td>
</tr>
<tr>
<td>Life Sharing Camphill Community</td>
<td>148</td>
<td>46</td>
<td>31%</td>
</tr>
<tr>
<td>Special Pre-school</td>
<td>149</td>
<td>28</td>
<td>19%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>99</td>
<td>57</td>
<td>58%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>270</td>
<td>13</td>
<td>5%</td>
</tr>
<tr>
<td>Residential Service on Campus</td>
<td>189</td>
<td>104</td>
<td>55%</td>
</tr>
<tr>
<td>Residential Service in the Community</td>
<td>393</td>
<td>121</td>
<td>31%</td>
</tr>
<tr>
<td>Special School</td>
<td>952</td>
<td>158</td>
<td>17%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>286</td>
<td>46</td>
<td>16%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>19</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>TOTAL NUMBER OF PLACEMENTS</strong></td>
<td><strong>3051</strong></td>
<td><strong>710</strong></td>
<td><strong>23%</strong></td>
</tr>
</tbody>
</table>
4.2.2 Challenging behaviour in services in the SEHB region

Respondents were asked to indicate the service type or setting in which the questionnaire was completed (i.e. day activation service for adults, school etc.) and to quantify the number of people attending that service. The respondents recorded the number of people attending the service that are presenting with challenging behaviour according to the criteria outlined above.

Table 1 shows the number of people with intellectual disabilities placed in different types of services in the South Eastern Health Board region and the number in each service category who have challenging behaviour. The table also shows the overall percentage of people with intellectual disabilities and challenging behaviour in each service category in the region.

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**Fig. 2. The number of people with intellectual disabilities placed in each service category in the SEHB region.**

- Supported Employment: 19
- Sheltered Work: 286
- School: 952
- Residential Community Home: 393
- Residential Campus Home: 189
- Rehabilitative Training Centre: 270
- Psychiatric Hospital: 99
- Pre-School: 149
- Life Sharing Community: 148
- Day Activation for Children: 53
- Day Activity for Adults: 493

Figure 2 gives a graphic presentation of the number of people with intellectual disabilities placed in different types of services in the SEHB region. As can be seen, school is the service category with the highest number of people with an intellectual disability. There are a total of 952 children attending schools providing special education for children with mild, moderate and severe intellectual disabilities in the South Eastern Health Board area. There are 149 children attending pre-schools for children with special needs.
There are a total of 493 adults and 53 children placed in the day activation centres that returned questionnaires. There are a large number of people with intellectual disabilities (393) living in the community in small group homes. There are a total of 189 people with intellectual disabilities living in houses on the campus or grounds of service provider organisations, such as Brothers of Charity, Waterford, Sisters of Bon Sauveur, Dungarvan or St. Patrick's in Kilkenny.

Fig 3: The percentage of people with an intellectual disability and challenging behaviour in each service category in the South Eastern Health Board region.

% people with CB in each service in the SEHB region

<table>
<thead>
<tr>
<th>Service Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supported Employment</td>
<td>0%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>16%</td>
</tr>
<tr>
<td>School</td>
<td>17%</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>31%</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>55%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>5%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>58%</td>
</tr>
<tr>
<td>Pre-School</td>
<td>19%</td>
</tr>
<tr>
<td>Life Sharing Community</td>
<td>31%</td>
</tr>
<tr>
<td>Day Activation for Children</td>
<td>34%</td>
</tr>
<tr>
<td>Day Activation for Adults</td>
<td>24%</td>
</tr>
</tbody>
</table>

There are 148 people living in life sharing communities, known as Camphill communities. There are 99 people with intellectual disabilities living in psychiatric hospitals in the South Eastern Health Board region. Most of the organisations in this study do not provide supported employment. The numbers of people in supported employment in the South Eastern Health Board is under represented as many are employed in the community and are not included in the survey. The overall percentage of people placed in each service category with an intellectual disability and challenging behaviours in the SEHB region is represented in Figure 3 below and shows that Psychiatric hospitals are the settings that have the highest percentage of people with intellectual disabilities and challenging behaviour. Residential houses on the campus grounds of services, such as Brothers of Charity, Sisters of Bon Sauveur, Dungarvan and St Patrick's in Kilkenny have a high percentage of people with challenging behaviour.

Surveys were returned for 21 residential homes on campus. There are 104 of the 189 people living in houses on campus presenting with challenging behaviours (55%). There are 3 organisations that provide day activation services for children with a total of 53 children attending, 18 have challenging behaviour (34%). There are no people in supported employment with intellectual disabilities presenting with challenging behaviour and very few people in rehabilitative training have challenging behaviours.
4.2.3 Challenging behaviour in services in each community care area

Table 2: The numbers of people with intellectual disabilities in each service category in the each of SEHB community care areas.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>NO. PLACED IN SERVICES IN CARLOW/KILKENNY AREA</th>
<th>NO. PLACED IN SERVICES IN WATERFORD AREA</th>
<th>NO. PLACED IN SERVICES IN WEXFORD AREA</th>
<th>NO. PLACED IN SERVICES IN SOUTH TIPP. AREA</th>
<th>TOTAL PLACEMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>212</td>
<td>121</td>
<td>126</td>
<td>34</td>
<td>493</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>24</td>
<td>0</td>
<td>29</td>
<td>0</td>
<td>53</td>
</tr>
<tr>
<td>Life Sharing Camphill Community</td>
<td>71</td>
<td>0</td>
<td>37</td>
<td>40</td>
<td>148</td>
</tr>
<tr>
<td>Special Pre-school</td>
<td>76</td>
<td>19</td>
<td>21</td>
<td>33</td>
<td>149</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>No returns</td>
<td>0</td>
<td>26</td>
<td>73</td>
<td>99</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>38</td>
<td>77</td>
<td>58</td>
<td>97</td>
<td>270</td>
</tr>
<tr>
<td>Residential Service on Campus</td>
<td>93</td>
<td>84</td>
<td>12</td>
<td>0</td>
<td>189</td>
</tr>
<tr>
<td>Residential Service in the Community</td>
<td>165</td>
<td>101</td>
<td>76</td>
<td>51</td>
<td>393</td>
</tr>
<tr>
<td>Special School</td>
<td>313</td>
<td>239</td>
<td>210</td>
<td>190</td>
<td>952</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>0</td>
<td>149</td>
<td>99</td>
<td>38</td>
<td>286</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>19</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td><strong>TOTAL NUMBER OF PLACEMENTS</strong></td>
<td><strong>1011</strong></td>
<td><strong>790</strong></td>
<td><strong>694</strong></td>
<td><strong>556</strong></td>
<td><strong>3051</strong></td>
</tr>
</tbody>
</table>

Table 2 shows the number of people with intellectual disabilities placed in each type of service in each of the community care areas in the South Eastern Health Board region. The Carlow/Kilkenny area has the highest number of adult placements in Day Activation services and also the highest number of people with intellectual disabilities placed in residential services in the community. The Waterford area has the largest number of people placed in sheltered work settings. The number of people attending Day Activation services in South Tipperary is under represented as all of the surveys from the Moorehaven centre in South Tipperary were not returned. There are no separate day activation services for children in Waterford or South Tipperary. There is no Camphill Community based in Waterford. All of the people with intellectual disabilities that had been living in St. Canice's psychiatric hospital in Kilkenny are now living in residential services in the Community.

No survey was returned from St. Dympna's hospital in Carlow. There are no people with intellectual disabilities in St Otteran's psychiatric hospital in Waterford. There are no residential services on the campus or grounds of service providers in South Tipperary. Most services included in the survey do not provide supported employment, apart from the Camphill Watergarden restaurant, in Co. Kilkenny, which employs 19 people with intellectual disabilities.
Table 3: The numbers of people with an intellectual disability who have challenging behaviour in each service category in each of the community care areas.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE PROVIDED</th>
<th>No. placed in services with challenging behaviour in CARLOW/KILKENNY</th>
<th>No. placed in services with challenging behaviour in WATERFORD</th>
<th>No. placed in services with challenging behaviour in WEXFORD</th>
<th>No. placed in services with challenging behaviour in SOUTH TIPPERARY</th>
<th>TOTAL NO. IN THE REGION IN EACH TYPE OF SERVICE WITH CHALLENGING BEHAVIOUR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>39</td>
<td>45</td>
<td>19</td>
<td>16</td>
<td>119</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>8</td>
<td>0</td>
<td>10</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>Life Sharing Camphill Community</td>
<td>34</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>46</td>
</tr>
<tr>
<td>Special Pre-school</td>
<td>14</td>
<td>0</td>
<td>5</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>No returns</td>
<td>0</td>
<td>26</td>
<td>31</td>
<td>57</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>6</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Residential Service on Campus</td>
<td>58</td>
<td>46</td>
<td>0</td>
<td>0</td>
<td>104</td>
</tr>
<tr>
<td>Residential Service in the Community</td>
<td>46</td>
<td>25</td>
<td>30</td>
<td>20</td>
<td>121</td>
</tr>
<tr>
<td>Special School</td>
<td>44</td>
<td>44</td>
<td>46</td>
<td>24</td>
<td>158</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>0</td>
<td>29</td>
<td>15</td>
<td>2</td>
<td>46</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL NUMBER OF PLACEMENTS</td>
<td>249</td>
<td>191</td>
<td>161</td>
<td>556</td>
<td>710</td>
</tr>
</tbody>
</table>

Table 3 shows the number of people with intellectual disabilities in each type of service and in each community care area with challenging behaviours according to the criteria outlined above. The Waterford area has the highest number of people with challenging behaviour in Day Activation centers (45). There are more people with challenging behaviour living in life sharing Camphill communities in Co. Kilkenny than in Wexford or South Tipperary. There are a large number of people with an intellectual disability and challenging behaviour (31) living in the Psychiatric Hospital in South Tipperary (St. Luke's Hospital). The residential services in the community and on campus in Kilkenny have the highest number of people with challenging behaviour. The South Tipperary area has the lowest number of children with challenging behaviour attending special school (46).
Table 4: The percentage of school, day or residential places with people with an intellectual disability and challenging behaviour in each of the community care areas.

<table>
<thead>
<tr>
<th>Community Care Area</th>
<th>The total number of school, day or residential placements that are attended by people with an intellectual disability in each community care area</th>
<th>The total number of those places that have people with challenging behaviours.</th>
<th>The percentage of places that have people with challenging behaviours in each community care area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carlow/Kilkenny</td>
<td>1011</td>
<td>249</td>
<td>25%</td>
</tr>
<tr>
<td>South Tipperary</td>
<td>556</td>
<td>109</td>
<td>19%</td>
</tr>
<tr>
<td>Waterford</td>
<td>790</td>
<td>191</td>
<td>24%</td>
</tr>
<tr>
<td>Wexford</td>
<td>694</td>
<td>161</td>
<td>23%</td>
</tr>
<tr>
<td>Region</td>
<td>3051</td>
<td>710</td>
<td>23%</td>
</tr>
</tbody>
</table>

Table 5. shows the total number of placements in each community care area and the percentage of those placements that have people with challenging behaviours. These figures represent places in each community care area as opposed to the number of people in each community care area with challenging behaviours, as the same person may be placed in both a residential service and a day service.

The percentage of people with challenging behaviour placed in services in each community care area ranges from 19% to 25%. The overall percentage is slightly lower in the South Tipperary area which may be due to a number of different factors such as, there are no large residential services in South Tipperary. Services in South Tipperary may be responding to people’s needs and there may be less people presenting with challenging behaviours.
4.2.4 Reports of Physical injury in services

Fig. 4. The number of incidents of physical injury reported in services over a four-week period in each community care area in the SEHB region.

As shown in Figure 4 most of the incidents occurred in the Carlow/Kilkenny community care area. Respondents quantified the number of incident reports of physical injury to others made in the last four weeks. Fig. 4 represents the number of incidents of physical injury reported over a four-week period in the South Eastern Health Board region. There were a total of 241 incidents of physical injury to others recorded over a 4-week period in the South Eastern Health Board region.

Table 5. The number of incident reports of physical injury to others in a 4-week period in each service category in each community care area.

<table>
<thead>
<tr>
<th>Service</th>
<th>Carlow/KK</th>
<th>Service</th>
<th>Sth.Tipp</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation for Adults</td>
<td>4</td>
<td>Day Activation for Adults</td>
<td>2</td>
</tr>
<tr>
<td>Pre-School</td>
<td>1</td>
<td>Life Sharing Community</td>
<td>6</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>0</td>
<td>Pre-School</td>
<td>0</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>0</td>
<td>Psychiatric Hospital</td>
<td>15</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>34</td>
<td>Rehabilitative Training Centre</td>
<td>0</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>25</td>
<td>Residential Community Home</td>
<td>6</td>
</tr>
<tr>
<td>School</td>
<td>42</td>
<td>School</td>
<td>5</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>Sheltered Work</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>135</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service</th>
<th>Waterford</th>
<th>Service</th>
<th>Wexford</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation for Adults</td>
<td>4</td>
<td>Day Activation for Adults</td>
<td>10</td>
</tr>
<tr>
<td>Pre-School</td>
<td>0</td>
<td>Day Activation for Children</td>
<td>1</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>0</td>
<td>Life Sharing Community</td>
<td>0</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>0</td>
<td>Pre-School</td>
<td>2</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>9</td>
<td>Psychiatric Hospital</td>
<td>2</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>8</td>
<td>Rehabilitative Training Centre</td>
<td>2</td>
</tr>
<tr>
<td>School</td>
<td>15</td>
<td>Residential Campus Home</td>
<td>0</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>3</td>
<td>Residential Community Home</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>39</td>
<td>School</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sheltered Work</td>
<td>33</td>
</tr>
</tbody>
</table>
Table 5 shows the number of incident reports of physical injury to others made within each category of service and in each of the four community care areas.

The majority of the incidents of physical injury in the Carlow/Kilkenny community care area occurred in schools providing special education (42). A high number of incidents also occurred in houses on the campus grounds of services in Kilkenny. In the South Tipperary area, the majority of incidents of physical injury (15) occurred in the psychiatric hospital.

As shown in Figure 5, the highest number of physical injuries reported came from schools providing special education. There were a total of 66 incidents of physical assault in special schools. There were also a high number of physical assaults in residential homes in the community. There were relatively few incidents of physical assaults in pre-schools, day activation centres for children, sheltered work and rehabilitative training settings.

Fig. 5: The number of physical assaults reported over a four-week period by service category in the SEHB region.

There were 39 incidents of physical injury over a four-week period in Waterford, the majority of these incidents occurred in schools providing special education (15) and homes on campus (9).

In Wexford, there were a total of 33 incidents in a 4 week period, the majority of these incidents occurred in residential homes in the community (12) and Day
4.2.5 Sexualised assaultive behaviour

Fig. 6. The number of people in each setting presenting with sexualised assaultive behaviour in the SEHB region.

Respondents quantified the number of service users in the setting in which the questionnaire was completed that have presented with sexualised assaultive behaviour. Sexualised behaviour was categorised separately as sexualised behaviour presents different challenges for service providers in regard to relationship and sexuality education and training, risk management and treatment.

Fig. 6 shows the number of people that have presented with sexualised assaultive behaviour in each service category. The above figures do not represent the total number of people with sexualised assaultive behaviour in the region as the same person may be living in a residential house in the community and attending sheltered work or rehabilitative training. There are a small number of children in schools providing special education (6 out of 902) with problematic sexualised behaviour.
4.2.6 Age Profile and Level of Intellectual Disability

**Table 6: The percentage of people with intellectual disabilities and challenging behaviour in each age category in the SEHB region.**

<table>
<thead>
<tr>
<th>Age range:</th>
<th>2 – 6 years</th>
<th>7 – 18 years</th>
<th>19 – 65 years</th>
<th>Over 65 years</th>
<th>Total No. in the region with Challenging Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of people in the region with ID and Challenging Behaviour</td>
<td>58</td>
<td>184</td>
<td>461</td>
<td>7</td>
<td>710</td>
</tr>
<tr>
<td>% of people with CB in each age group in the region</td>
<td>8%</td>
<td>26%</td>
<td>65%</td>
<td>1%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The majority of people in services presenting with challenging behaviour, according to the criteria, are adults over the age of 18 (65%) as shown in Table 6. The overall percentage of pre-school children with challenging behaviour is low (8%).

- **Level of intellectual disability:**
  Most people presenting with challenging behaviours in the South Eastern Health Board area fall within the moderate (36%) or severe (30%) range of intellectual disability as seen in Table 7. There are few people whose level of intellectual disability has not yet been assessed by a psychologist (don’t know 9%).

**Table 7: The percentage of people within each level of intellectual disability who have challenging behaviour in the SEHB region.**

<table>
<thead>
<tr>
<th>Level of Intellectual Disability</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Profound</th>
<th>Don’t Know</th>
<th>Total No. in the region with Challenging Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. CB in the region</td>
<td>153</td>
<td>253</td>
<td>213</td>
<td>42</td>
<td>49</td>
<td>710</td>
</tr>
<tr>
<td>% with CB</td>
<td>21%</td>
<td>36%</td>
<td>30%</td>
<td>6%</td>
<td>7%</td>
<td>100%</td>
</tr>
</tbody>
</table>


4.2.7 **Key factors contributing to challenging behaviour**

Respondents were asked to outline what they thought were the key factors or main reasons for the challenging behaviours. The key factors identified were:

- **Inappropriate environment:** Overcrowding and lack of space were repeatedly identified as key factors contributing to challenging behaviour. Other environmental factors suggested were 'lack of privacy for residents who do not have their own bedrooms' and 'over-stimulating noisy environments'. Some respondents indicated that a few individuals were 'wrongly placed' or that there was 'an inappropriate client mix'.

- **Staffing issues:** Change of familiar staff and insufficient numbers of staff were identified as key factors contributing to challenging behaviour. In some residential homes, the staff: client ratio is 7:1, which can make the management of challenging behaviour difficult. Some respondents indicated that there is not enough time to give 1:1 attention when needed.

- **Individual factors:** Many of those who responded to the survey indicated that some of the people identified with challenging behaviour have difficulties with communicating their needs or expressing their feelings, making it difficult for staff to understand and respond to them. Service users may become frustrated when they are not understood which in turn can lead to challenging behaviour. Psychiatric related disorders, particularly obsessive-compulsive disorders, and autism were identified as contributing to challenging behaviour. Other individual characteristics were suggested, such as, 'she is attention seeking', 'he has no control over his temper', 'he likes to control everything and becomes disruptive if not allowed'. Psychological factors such as 'poor self-esteem', 'emotional disturbance', and physical and/or sexual abuse and neglect in the past were identified as key factors. Physical disabilities, hearing impairments, and sensory impairments were also included as factors contributing to challenging behaviour.

- **Lack of meaningful activities** Respondents suggested that boredom, and the lack of day activation services contribute to challenging behaviour.
4.2.8 The extent of the difficulties in managing challenging behaviour

Table 8: The percentage of people in each service category in the SEHB region with challenging behaviour that causes significant management difficulties.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>The no. of people in the region in each service who have challenging behaviours</th>
<th>The no. of people in the region whose challenging behaviour causes significant management problems in each service category</th>
<th>The % of people in the region with challenging behaviour that causes significant management problems in each service category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>119</td>
<td>74</td>
<td>62%</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>18</td>
<td>11</td>
<td>61%</td>
</tr>
<tr>
<td>Life Sharing Community</td>
<td>46</td>
<td>20</td>
<td>43%</td>
</tr>
<tr>
<td>Pre-school</td>
<td>28</td>
<td>6</td>
<td>21%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>57</td>
<td>39</td>
<td>68%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>13</td>
<td>10</td>
<td>77%</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>104</td>
<td>73</td>
<td>70%</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>121</td>
<td>77</td>
<td>64%</td>
</tr>
<tr>
<td>School</td>
<td>158</td>
<td>61</td>
<td>39%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>46</td>
<td>21</td>
<td>46%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>710</strong></td>
<td><strong>392</strong></td>
<td><strong>62%</strong></td>
</tr>
</tbody>
</table>

Although there are a number of people in different services presenting with challenging behaviours, some of those identified do not cause significant management problems for the organisation and others are significantly difficult to manage.

From this table, it is clear the majority of people with intellectual disabilities and challenging behaviour living on the campus grounds of services (70%) 'cause significant management problems' for the services i.e. 'their behaviour requires more than one member of staff for control and causes daily disruption of at least an hour to normal activities'.

Although, there are very few people with challenging behaviour in Rehabilitative Training, most of those that are presenting with challenging behaviour cause significant management problems in that service (77%). The majority of the people with challenging behaviour in psychiatric hospitals (68%) are significantly difficult to manage. The majority of children with challenging behaviour in pre-schools do not cause significant management problems; only 21% of those with challenging behaviour in pre-schools are difficult to manage. This is probably because children are smaller, less threatening and less capable of doing serious physical harm than adults.
4.2.9 Factors contributing to successful management

Respondents were asked to identify what are the key factors contributing to the successful management of challenging behaviour in their setting.

- **Environmental factors:**
  There were a number of environmental factors identified. These included having a 'peaceful, homely, safe, warm accepting environment'; having 'space' and 'a diversification of meaningful work activities'. Other environmental factors included were; 'a small group home', 'a nice building', 'routine and structure' and 'suitable equipment'.

- **Staff / co-workers factors:**
  'Teamwork' and 'working with experienced people who have a good understanding of the needs of service users' and; 'staff with the skills to diffuse the challenging behaviour' were the key factors identified in the successful management of challenging behaviour. Other staff related issues included, the 'availability of 1:1 staff intervention when required'; a 'good staff: client ratio'; 'continuity and consistency in approach'; 'agreed guidelines on the management of challenging behaviour'; and having staff trained in effective 'behavioural technologies'.

- **Programme Planning**
  The importance of having 'structured teaching' was highlighted in a number of schools. Other key programme planning factors suggested were 'having a routine where the person with challenging behaviour knows what to expect'; person-centred plans, programme reviews; sensory integration programmes; flexibility; varied activities; a positive approach and good support from the multi-disciplinary team in developing programmes (behaviour programmes, sensory integration programme etc.) were all identified as key factors.

- **Individual factors**
  There were a number of respondents who indicated that the challenging behaviour is managed effectively with medication, including PRN medication. In other cases, the behaviours are less severe than they had been, or clients have got older and/or are more settled in their current environments. In some situations, the behaviours are more predictable.

4.2.10 Factors contributing to the difficulties in managing challenging behaviour

- **Staff / co-worker issues**
  The lack of staff with expertise and experience in the management of challenging behaviour was one of the most frequently identified factors that contribute to the difficulties in managing challenging behaviour. Staffing issues such as an inadequate staff: client ratio and staff shortages are highlighted. In some areas, there is only one staff on duty that can make the management of challenging behaviour very difficult. The lack of support staff in crisis was also a difficulty in some areas.

- **Environmental factors**
  Environmental factors such as overcrowding, lack of space, inappropriate client mix, lack of resources such as quiet rooms, multi-sensory rooms, lack of transport and no day activation services were identified.

- **Individual factors**
  Individual factors such as 'this client is a very strong determined man', 'the severity and frequency of the behaviour', the 'unpredictability of the behaviour', and
'mental illness' all contributes to difficulties in managing challenging behaviour.

- **Lack of multidisciplinary support**
The lack of available support from behavioural therapists, psychologists, psychiatrists, occupational therapists, and speech therapists was identified as contributing to problems with the management of challenging behaviour.

- **Medication**
Traditionally, psychotropic medications have been used with people with intellectual disabilities and challenging behaviour even though there is little empirical support in terms of their specific effect on challenging behaviour. The respondents in the survey were asked to indicate how many of the people identified with challenging behaviour in their service are on medication for their challenging behaviour.

### 4.2.11 Treatment and Interventions

Table 9 shows the percentage of people with challenging behaviours in services in the SEHB region who are on psychotropic medication because of their challenging behaviour.

53% of the placements have people with challenging behaviour who are on psychotropic medication because of their behaviour. The majority of people with intellectual disabilities and challenging behaviours in psychiatric hospitals (98%) are on psychotropic medication as might be expected. 34 of the 46 people in sheltered workshops with challenging behaviours are on medication because of their challenging behaviour (74%). 76 of the 104 people living on campus with challenging behaviours are on medication for their behaviour (73%). As might be expected, few children (11%) with challenging behaviours in special schools are on medication because of their behaviour.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>The no. of people in each service category in the region who have challenging behaviours</th>
<th>The no. of people with CB in services in the region who are on psychotropic medication because of their behaviour</th>
<th>The % of people in services in the region with CB who are on psychotropic medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>119</td>
<td>71</td>
<td>60%</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>18</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>Life Sharing Community</td>
<td>46</td>
<td>29</td>
<td>63%</td>
</tr>
<tr>
<td>Pre-school</td>
<td>28</td>
<td>3</td>
<td>11%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>57</td>
<td>56</td>
<td>98%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>13</td>
<td>5</td>
<td>38%</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>104</td>
<td>76</td>
<td>73%</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>121</td>
<td>76</td>
<td>63%</td>
</tr>
<tr>
<td>School</td>
<td>158</td>
<td>19</td>
<td>12%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>46</td>
<td>34</td>
<td>74%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>TOTAL NUMBER OF PLACEMENTS</strong></td>
<td><strong>710</strong></td>
<td><strong>378</strong></td>
<td><strong>53%</strong></td>
</tr>
</tbody>
</table>
Table 10. The percentage of people with challenging behaviour in each service category in the SEHB region who were assessed/reviewed by a psychiatrist in the last 3 months.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>The no. of people in the region in each service category who have challenging behaviours</th>
<th>The no. of people with CB in each service in the region who were assessed/reviewed by a psychiatrist in the last 3 months</th>
<th>The % of people with CB in each service in the region who were assessed/reviewed by a psychiatrist in the last 3 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>119</td>
<td>26</td>
<td>22%</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>18</td>
<td>8</td>
<td>44%</td>
</tr>
<tr>
<td>Life Sharing Community</td>
<td>46</td>
<td>12</td>
<td>26%</td>
</tr>
<tr>
<td>Pre-School</td>
<td>28</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>57</td>
<td>41</td>
<td>72%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>13</td>
<td>2</td>
<td>15%</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>104</td>
<td>68</td>
<td>65%</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>121</td>
<td>44</td>
<td>36%</td>
</tr>
<tr>
<td>School</td>
<td>158</td>
<td>10</td>
<td>6%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>46</td>
<td>22</td>
<td>48%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>TOTAL IN THE REGION</strong></td>
<td><strong>710</strong></td>
<td><strong>234</strong></td>
<td><strong>33%</strong></td>
</tr>
</tbody>
</table>

**Psychiatric intervention**

Challenging behaviour is a component of psychiatric disorder although not all people with challenging behaviour have a mental health problem. Table 10 shows the number of people with intellectual disabilities and challenging behaviour in services in the region that were assessed or reviewed by a psychiatrist in the last 3 months in which the questionnaire was completed. Most people with intellectual disabilities and challenging behaviour in psychiatric hospitals (72%) were reviewed recently (i.e. in the last 3 months) by a psychiatrist. 65% of the people with challenging behaviour in residential services (68 people) on the campus grounds of service providers were reviewed in the last 3 months by a psychiatrist.
• Behavioural intervention

Table 11. The percentage of people with intellectual disabilities and challenging behaviour in each service category in the SEHB region who have a Behaviour Management Programme.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>The no. of people in each service in the region who have Challenging behaviour</th>
<th>The No. of people in the region with CB in services who have a Behaviour Management Programme</th>
<th>The % of people in the region in services with CB who have a Behaviour Management Programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>119</td>
<td>29</td>
<td>24%</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>18</td>
<td>3</td>
<td>17%</td>
</tr>
<tr>
<td>Life Sharing Community</td>
<td>46</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Pre-School</td>
<td>28</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>57</td>
<td>4</td>
<td>7%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>13</td>
<td>3</td>
<td>23%</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>104</td>
<td>31</td>
<td>30%</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>121</td>
<td>37</td>
<td>31%</td>
</tr>
<tr>
<td>School</td>
<td>158</td>
<td>6</td>
<td>4%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>46</td>
<td>4</td>
<td>9%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>TOTAL NO. OF PLACEMENTS</strong></td>
<td><strong>710</strong></td>
<td><strong>118</strong></td>
<td><strong>17%</strong></td>
</tr>
</tbody>
</table>

Table 11 illustrates that there are relatively few people with challenging behaviour that have a current behaviour management programme. Only 17% of all placements have behaviour management programmes for people with challenging behaviour. The data above does not reflect the interventions and supports that may have been provided to support people with challenging behaviour. There may have been a number of meetings / case reviews arranged for people with challenging behaviour. However, it is clear that many service users with challenging behaviours do not have access to behavioural assessment and interventions. The highest proportion of people with behaviour management programmes are living in either group homes in the community or on campus. 37 people out of the total of 121 people with challenging behaviour living in group homes in the community (31%) have a current behaviour programme. 30% of the people living on campus with challenging behaviour have a current behaviour programme.
**Psychological assessment/review**

Table 12. The % of people with challenging behaviour in services in the SEHB region that have had a psychological assessment/review in the last 3 months.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE BEING PROVIDED</th>
<th>The no. of people in the region in each service category who have challenging behaviours</th>
<th>The no. of people with CB in the region who were assessed / reviewed by a psychologist in the last 3 months</th>
<th>The % of people with CB in services in the SEHB region who were assessed / reviewed by a psychologist in the last 3 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Activation Services for Adults</td>
<td>119</td>
<td>21</td>
<td>18%</td>
</tr>
<tr>
<td>Day Activation Services for Children</td>
<td>18</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>Life Sharing Community</td>
<td>46</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Pre-School</td>
<td>28</td>
<td>6</td>
<td>21%</td>
</tr>
<tr>
<td>Psychiatric Hospital</td>
<td>57</td>
<td>3</td>
<td>5%</td>
</tr>
<tr>
<td>Rehabilitative Training Centre</td>
<td>13</td>
<td>4</td>
<td>31%</td>
</tr>
<tr>
<td>Residential Campus Home</td>
<td>104</td>
<td>13</td>
<td>13%</td>
</tr>
<tr>
<td>Residential Community Home</td>
<td>121</td>
<td>16</td>
<td>13%</td>
</tr>
<tr>
<td>School</td>
<td>158</td>
<td>7</td>
<td>4%</td>
</tr>
<tr>
<td>Sheltered Work</td>
<td>46</td>
<td>9</td>
<td>20%</td>
</tr>
<tr>
<td>Supported Employment</td>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>TOTAL NO. OF PLACEMENTS</strong></td>
<td><strong>710</strong></td>
<td><strong>80</strong></td>
<td><strong>11%</strong></td>
</tr>
</tbody>
</table>

Very few services have access to a psychologist on a regular basis. Only 11% of all placements have people with challenging behaviour who have had a psychological assessment or review in the last 3 months as shown in Table 12. This figure may be an underestimation of the input provided by Psychologists as the psychologist may have attended team meetings or case conferences that may not have been documented as a psychological review.

As shown in Table 12, 21 of the 119 adults attending day activation centres with challenging behaviours have had a recent psychological assessment or review (i.e. within the last 3 months). 16 of the 121 people living in houses in the community have had a recent psychological assessment or review. Most services have had limited psychological input.

Relatively few people in services with challenging behaviour have access to psychological intervention. While the figure for people in rehabilitative training that have had a psychological assessment appears to be relatively higher (31%). This figure only represents a total of 4 out of 13 people with challenging behaviour in Rehabilitative training that have had a recent psychological review or assessment.

**Other interventions**

Respondents were asked to describe other interventions that have been used to address challenging behaviour. A wide variety of interventions were included such as sensory integration therapy, speech, drama and play therapy, massage and aromatherapy, counselling, TEACCH programme, PECS, eurhythmy therapy, creative writing, relaxation, and anger management courses.
4.3 SUMMARY AND CONCLUSIONS

- 710 of the 3051 residential or day placements surveyed have people with intellectual disabilities, and challenging behaviour (23% of placements).

- 58% of people with intellectual disabilities living in psychiatric hospitals have challenging behaviour. 55% of the people with intellectual disabilities living in houses on the grounds of disability service providers are presenting with challenging behaviours.

- The Kilkenny/Carlow community care area has the highest number of day/residential places with people with intellectual disabilities and challenging behaviour (25%).

- There were a total of 241 incident reports of physical assault in the region over a four-week period. The majority of these incidents occurred in schools providing special education.

- There are a small number of people in services that present with sexually aggressive behaviour that poses a risk to others.

- Most people with challenging behaviour in services are over age 18 and have a moderate or severe level of intellectual disability.

- The key factors contributing to challenging behaviour according to the respondents of the survey are: inappropriate or inadequate environments, insufficient numbers of experienced staff, lack of opportunities for meaningful activities during the day and a range of individual physical, psychiatric, and psychological factors.

- 38% of all the placements surveyed are successfully managing people with challenging behaviour. Effective teamwork, experienced trained staff, access to multi-disciplinary support, programme planning and a number of environmental conditions are factors identified as contributing to the successful management of challenging behaviour.

- There is a reliance on pharmaceutical interventions to manage challenging behaviours. 74% of the people in sheltered work settings are on medication for their behaviour. Only 17% of all placements have a behaviour management programme for people in their services with challenging behaviour.

- Very few services have access to a psychologist. Only 11% of the placements have people with challenging behaviour who have been assessed/reviewed by a psychologist recently.

- A wide variety of therapies have been introduced to address challenging behaviours, which include massage, sensory integration, speech therapy and communication training.
4.4 RECOMMENDATIONS

4.4.1 Service providers should ensure that people with challenging behaviour have opportunities for meaningful work, leisure and social activities in the community.

4.4.2 A person centred planning system should be developed in each organisation to include a review of the person's environment to ensure that the person is living in a safe environment with adequate physical space.

4.4.3 Service providers should ensure that there is a structured programme of activity in place with enough flexibility to meet the person's needs. Multidisciplinary support should be available to service providers to support the development of a programme of activity which may include opportunities to learn functional daily living skills; communication skills, training and sensory integration programmes as needed.

4.4.4 Service providers should ensure an appropriate staff: client ratio based on the needs of the service user with challenging behaviour. There should be continuity and consistency in approach to the management of challenging behaviour with staff trained in evidence-based methods in the assessment and management of challenging behaviour.

4.4.5 There should be regular reviews of the medication prescribed to individuals with challenging behaviour with monitoring systems in place to evaluate the effectiveness of medication to address challenging behaviours. These reviews should be incorporated into the person-centred planning system.

4.4.6 Dedicated Challenging Behaviour Specialists should be available in each catchment area, to focus exclusively on children and adults with intellectual disabilities and challenging behaviour.

4.4.7 The Challenging Behaviour Specialists should provide families and direct care staff with technical expertise to help the person with challenging behaviour acquire the skills and behaviours necessary for them to function with as much self determination and independence as possible in the community. The Behaviour Specialists should provide training to frontline staff in the area of behavioural assessment and support.

4.4.8 Support should be prioritised in the areas with the highest levels of challenging behaviour and in locations where there have been incident reports of physical injury.
4.4.9 A multi-element behaviour support plan should be developed for all people with challenging behaviours. The behaviour support plan should incorporate changes to the environment to achieve a better fit with the needs and characteristics of the person. It may involve the teaching of the social and communication skills necessary to overcome challenging behaviours. It may involve psychiatric assessment, medication reviews and the introduction of additional therapies to address challenging behaviour. Behaviour support plans may also include effective reactive strategies to manage crises.

4.4.10 Resources should be allocated to staff training and development in responding to behaviours that challenge. Training should be prioritised in the following area:
- Understanding how challenging behaviours develop in individuals with intellectual disabilities and how life experiences and the environment play a key role in the person's behaviour.
- Training in behavioural assessment and multi-element behavioural support to promote the use of effective, non-aversive methods that work with individuals who have challenging behaviours so that they can enjoy community participation with dignity and respect.
- Training in reactive strategies to manage crises, including the appropriate use of physical intervention to manage physically aggressive behaviour.

4.4.11 A specialist sexuality assessment and therapeutic service should be developed for people with intellectual disabilities and problematic sexualised behaviour in the region. The specialist service is needed to provide a risk assessment of the sexualised behaviour; relationship and sexuality education and training, and psychosexual therapy. Service users should have access to relationships and sexuality education.

4.4.12 Frontline staff should have access to training and support in the appropriate management of sexualised behaviour.
CHAPTER 5

PLACEMENT OUTSIDE THE REGION

5.0 INTRODUCTION

There are some people with intellectual disabilities in the region that are unable to access services because of challenging behaviour or who are placed outside the region for services. A working group (Appendix III) was established to:

- Quantify the number of service users whose placements are at risk or who are out of service due to challenging behaviour.
- Analyse the reasons why service users are placed outside the region for services and to identify if these services could be developed within the South Eastern Health Board region.

The subgroup met on 4 occasions between April and September 2003.

5.1 SURVEY

It was agreed that because of the small number of service users involved, that each of the Area Disability Coordinators would complete a detailed questionnaire on each service user (Appendix IV) in respect of:

- People placed and funded by disability services outside the region because of challenging behaviour
- People who currently have no service or who are at risk of discharge from a service because of challenging behaviour.

5.2 RESULTS

- No of Questionnaires returned: 26

26 people of the group above were identified in the region. There are some people with intellectual disabilities and challenging behaviour living at home who choose not to avail of the services offered to them and choose not to engage with any disability service providers. These people are not included in the results.

- Placement

The current placement of the people for whom questionnaires were completed is as follows:

<table>
<thead>
<tr>
<th>Placement</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.K.</td>
<td>2</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>4</td>
</tr>
<tr>
<td>Dept. of Psychiatry</td>
<td>3</td>
</tr>
<tr>
<td>Central Mental Hospital</td>
<td>1</td>
</tr>
<tr>
<td>At risk of discharge</td>
<td>4</td>
</tr>
<tr>
<td>In day service but requires residential service</td>
<td>4</td>
</tr>
<tr>
<td>In children's service but requires adult service</td>
<td>2</td>
</tr>
<tr>
<td>At Home with CB and without a Day Service</td>
<td>6</td>
</tr>
</tbody>
</table>
• Cost

The placements in Northern Ireland and the U.K. range in cost from €33,000 to €170,000. For people who are currently at home there is, in some cases, a cost associated with the provision of home support and this ranges from €8,000 to €14,000.

• Profile

There are 26 people who are either placed outside the region or at home without a service because of challenging behaviour. 11 of those identified have a moderate level of intellectual disability; 11 people have a mild level of intellectual disability and in 4 cases the level of intellectual disability is unknown. The needs of people with mild intellectual disabilities and challenging behaviour are diverse; they do not easily fit into existing Disability Services. The majority of the people identified are aged between 18 and 30 years.

• Nature of Challenging Behaviour

24 of the 26 questionnaires indicated some form of violence or aggression either physical or verbal. One indicated non-compliance and one indicated self-harm and suicidal tendencies.

Of those 24 people who are aggressive the following behaviours were also included:

- Absconding: 3
- Sexualised Behaviour: 4
- Criminal Behaviour: 1
- Self harm: 1

• Additional Difficulties

17 of the 26 people identified had additional difficulties such as autism spectrum disorder, attention deficit disorder, epilepsy and psychiatric disorder.

5.3 SUMMARY

• There are a total of 26 people identified in the region with intellectual disabilities and challenging behaviour either at home with no service or placed outside the region because of challenging behaviour.

• There are some people with intellectual disabilities and challenging behaviour living at home with parents who choose not to avail of the services offered to them. They are not included in the group above but may require residential and additional supports in the future.

• People are placed outside the region for a number of different reasons. The needs of the group are very diverse; there is no one model of service that would be appropriate to meet all of the needs identified. There may always be people for whom placement outside the region is the best option.
• 50% of the identified people with no service or placed outside the region have a mild level of intellectual disability. These people do not fit in easily to existing disability services, as many of the existing disability services primarily cater for people with moderate/severe intellectual disabilities.

• Most of the people with no services or who are placed outside the region are over 18 and have been physically aggressive towards others. The majority of those identified have additional difficulties.

5.4 RECOMMENDATIONS

5.4.1 Placement outside the region should be seen as a last resort and the aim should be to develop services to support the person in their own community whenever possible.

5.4.2 There should be an annual review and needs assessment of the people placed outside the region to see if their circumstances have changed, if they can be brought back, and what needs to be put in place to allow this to happen. A needs assessment and person-centred plan needs to be developed for each person placed outside the region with challenging behaviour.

5.4.3 The Department of Education and Science should be involved in the placement and the monitoring of the educational input to children placed outside the region. This is particularly relevant to children who currently are placed in Northern Ireland or the U.K. Additionally, if a placement breaks down the DES should be involved in the arrangements for an alternative placement.

5.4.4 The focus should be on how to prevent the necessity for placement outside the region in the future. A system to flag potential placement breakdowns should be developed. A comprehensive assessment of needs should be prioritised for those at risk of placement breakdown.

5.4.5 Service providers should have support from Challenging Behaviour Specialists to maintain the person with challenging behaviour in their current placement and to prevent placement breakdown. A behaviour assessment to include a functional analysis of the behaviour and behaviour support plan should be provided for any person with challenging behaviour in services that poses a risk to themselves and others.

5.4.6 People with intellectual disabilities and challenging behaviour should have access to a specialist mental health assessment and treatment as required to prevent placement breakdown and to support people in their current placement.
5.4.7 People with challenging behaviour should have individualised supports and a flexible care plan. The plan needs to be developed with the person, their parents and key people in the person’s life. The plan may involve a number of different providers for different aspects of the service proposed. It is considered that for this group individualised funding should follow the person rather than being linked to a service provider.

5.4.8 Home support services and behaviour support services should be provided in the home for people with severe challenging behaviour at home.

5.4.9 Emergency respite care and crisis short-term placements for people with challenging behaviours should be planned for and made available in crisis situations so as to give families, staff and the organisation an opportunity to arrange an appropriate response.

5.4.10 A working group should be established to consider the needs of people with mild intellectual disabilities and to make recommendations regarding the delivery of services and supports required for this group.
CHAPTER 6

CONSULTATIONS WITH KEY STAKEHOLDERS

6.0  AIM OF CONSULTATION

The aim of this programme of consultation was to examine key issues related to challenging behaviour among those groups that are directly involved in or impacted by challenging behaviours.

6.1  APPROACH AND METHODOLOGY

Central to this consultation is the need for discussions with as many groups as possible. As such five groups were targeted, service users, parents, staff, school principals, and disability co-ordinators / disability liaison counsellors. In identifying groups to target it was decided to sample both parents of children and parents of adult service users. The selection of participants, and in particular the inclusion of service users, reflects the need to consider every level of involvement in services.

Once the key stakeholders were identified, the next step was to select the most appropriate methodology for accessing their views. While there is a large body of literature available on the topic of challenging behaviour it was felt that it was important to be open to both the issues previously identified in the literature, and also the unique experiences of the groups involved. As such it was felt that the most appropriate methodological approach would be a qualitative one. Qualitative research allows the researcher to consider the experiences and views of the participants, rather than predetermining the issues to be considered.

Within the qualitative approach to research a number of research methods are available. The most commonly used method in qualitative research is the interview format, and semi-structured interviews which allow the researcher to explore participants' views on both predetermined issues and topics that arise over the course of the interview. While a semi structured approach was favoured, focus groups rather than interviews were chosen as the method of data collection. The reasons for this choice are detailed below.

A focus group consists of between five and eight individuals brought together to discuss key issues of interest to them. The group is led by a moderator who introduces the topics to be discussed and guides the discussion, drawing the group's attention to key issues. Focus groups were chosen over individual interviews for a number of reasons. Firstly the group format allows individuals to contribute as much or as little to the discussion as they wish. This may be particularly important where the participants may feel intimidated by the setting or the moderator, as may occur with service users or their parents. In addition, the dynamics of a group discussion can lead to both a greater range of issues and more in-depth discussions as members of the group 'feed-off' each other. On a more practical note, focus groups allow the researcher to access the views of more people in less time, as individual interviews with the same number of participants would take longer to complete.
Analysis of focus groups
For the purpose of this piece, all focus groups will be transcribed and content analysis will be used to explore the main themes identified by the participants in each group. Content analysis involves reviewing the group's discussion and identifying common themes that occur during the course of the discussion. In order to highlight these themes, quotes are selected and included to reflect the nature of the discussion around each theme. As it is not possible to include all quotes relating to a specific theme, samples are selected to offer the reader an insight into the groups' discussions.

In order to ensure the objective analysis of the information collected an independent researcher was invited to carry out the analysis. Dr. Suzanne Guerin, of the Department of Psychology, U.C.D, carried out all analyses reported in this chapter.

6.2 PARENTS PERSPECTIVES
Staff working directly with families were asked to make contact with families who were currently dealing with challenging behaviour in the home. These families were invited to put their names forward to take part in the focus groups. A list was then generated representing those families who were interested in taking part and participants were selected based on their availability. Two separate focus groups were held. One group consisted of parents of adults with various levels of disability, who ranged in age from 20 years to 31 years of age, while the second group consisted of parents of children also with various levels of disability between the ages of 6 years and 16 years of age. Overall 14 parents contributed to the focus groups. The aim of the groups were to discuss their views on challenging behaviour, including the impact of challenging behaviours on the family, and their perceptions of related services.

6.2.1 Types of challenging behaviour
Following on from a question from the facilitator a number of parents described incidents of challenging behaviour by their son or daughter. These descriptions appeared to fall into four main categories, with the first two being more prevalent in the older group and the second two described more often by parents of younger children.

The first category is referred to as refusal and covers behaviours such as refusing to get out of bed, go to work etc. As one parent described "when she is not in the workshop she goes down hill altogether on us, stays in bed, won't get out of bed, problems from Friday night to Monday morning", while another parent said "the lad I have is sitting there all day, won't get out of bed, up in bed shouting orders". The second type of behaviour is described as destruction and includes damage to property etc. One parent described her son in the following way, "when he gets them he breaks it, even down to glasses and things, he gets into a temper he just snaps them". Another parent described similar behaviour, "with radios, TV, videos, he has had the lot, he has broke the lot and had the lot again and broke them, and then he will try the same thing with ours as well". The next category referred to physical aggression, with one mother describing how her son, "hits me and bruises me." The final category was tantrums, with a number of incidents described by the parents of younger children.
These tantrums could also involve self-harm, for example one mother described, "when he doesn't get exactly what he wants at the time that he wants it, in a split second into a tantrum and that tantrum manifests itself by banging his head on the ground, punching himself in the head, pulling his hair, biting his hand."

In discussing their son or daughter's behaviour, a number of parents in the older group commented on the way in which challenging behaviour seemed to be context linked, i.e. that while challenging behaviours were common at home, their child would not behave in the same way when in the workshop or service. One parent described how her son "wants to be the goody goody in the workshop", while another felt that the staff in the workshop did not see this side of her son "they wouldn't know what I would be talking about in the workshop, perfect angel, street angel'. A third parent added "they all seem to be far worse when they are on their own and when they are in the workshop they are far far better".

6.2.2 Impact of challenging behaviour on others

One issue, which came up in both groups is the impact of challenging behaviour on members of the family. One sub-theme that emerged in the older group very clearly was the frustration felt by the parents. One parent described how "we get to a stage either she goes or we go", while another reported "I look at her and say how could I want to get rid of that girl but then when she is bad I say get rid of her". Another parent in the younger group reported, "it can just wear you down." One theme that appeared very clearly in the younger group was a sense of isolation.

One issue that arose in the second group (parents of younger children) was reports of their children (with intellectual disabilities) experiencing bullying and physical harm. One parent described how other children teased her son, while another parent reported; "some of the children had taken a chunk out of his face and the same on his arm when I stripped him off for a bath."
Another parent talked about other people's perceptions of her family, "If I wanted to go for a walk outside the door I can't go, we would have the horror of a wedding invitation dropped into us because we couldn't go to that, and people think we are odd." Reflecting this, a mother in the younger group described her feelings if her son acted out in a public place, "its tough, too much pressure, you would feel the sweat running down your head and you would be looking around at everyone else, and in that situation you would be better off avoiding the situation."

Aside from the impact on members of the family, parents also mentioned ways in which their children's behaviour impacts on staff in the various services they attend. As one parent described "he challenges the staff in the place". Another parent felt that her son's behaviour had made care workers hesitant to return, "they all leave after a week or two because he won't get up for them in the first place".

### 6.2.3 Factors influencing challenging behaviour

During the course of the groups' discussions the parents referred to a number of factors that they felt were linked to their son or daughter's challenging behaviour, or functions that they felt the behaviour served. For example a number of parents felt that their son or daughter used challenging behaviour to get attention, with one parent reporting "It's [the behaviour] not temper its to get attention" and another describing how "he takes all the attention as he is very demanding the whole time". A parent of a younger child described how her son "would wet the bed or something, it's a form of attention seeking." Another theme evident was the role of boredom in challenging behaviour. As one parent reported, "he seems to be bored and that is his main problem", while another parent, talking about her child in general, reported "he is bored and frustrated".

On another level the parents of adult children talked about the role of medication and medical conditions in their son or daughter's challenging behaviour. One condition that was discussed by a number of the parents was epilepsy. One parent asked the question "I often wonder if she could take her convulsions would she be better off, would some of the aggression come out in these convulsions?" while another parent said "I can relate to what you are saying ... you watch it building up, you can see the anger building up in him until he has a seizure and its all gone in that seizure". Another mother then linked this back to medication, saying "I have often wondered if they took away the medication what would actually be there at the end of the day, what are these tablets doing, you know what one is doing but you don't know what they all combined are doing and what reaction they are having".

Finally on a related note, parents of younger children talked about some of the strategies they used to manage their children's behaviour. Strategies included distraction, listening to tapes and activities.
6.2.4 Support from family and friends
In describing their children's needs a number of parents referred to the support they receive from family and friends. One parent from the adult group described how a neighbour regularly takes her daughter out and that “it works and no bother at all with her, [the neighbour] gets on very well with her,” while a parent in the child group reported, “we are lucky in that we have a good neighbour that takes her [daughter], and she is very good with her.” However, some did comment on a lack of support within the community, as one parent reported, “they all help for so long and all of a sudden they don’t want to know”.

6.2.5 Perceptions of services
One of the predominant themes discussed was the issue of services, from the perspective of commenting on services currently received and discussing future needs. One of the specific services that were discussed was home support. While the members of the group were very positive about this service a number of them felt that the current nature of the service (which appears to be approximately three to four hours a week) is not sufficient. One parent from the younger group described the importance of home support, “our son ... could be up 20 times a night and then when you have other children as well, you are trying to juggle everything. You would be exhausted. Sometimes you are just worn out and you rely on the home support to carry you through.” When asked what they would like to see parents discussed a more regular service. While one parent suggested “2-3 hours everyday”, another parent commented on the times the service is available, “everything just doesn’t happen between 9:30 and 4:30 in the day, you want someone that you can pick up the phone at 6pm or 8pm”. A parent in the younger group reported, “even if there was a help line that you could ring if things got on top of you.”

Aside from the availability of services, parents of adult service users made some suggestions around the content of training that their sons/daughters received, with a particular emphasis on practical skills. A number of parents talked about job coaches, and training in areas of work that they may be interested in, “now our lady has a fascination with babies and small children and she is absolutely brilliant with them, and if she was taken into a situation where she would even think she was working, she would spend all day playing with children and she would be very kind to them and wouldn’t hurt them.”

Parents of older service users discussed some of the workshop settings their children had attended. Discussions around this aspect of services were mixed with parents reporting good and bad experiences in the past. One difficulty that was discussed was the difficulty of care while centres/workshops were closed during the holidays. One parent reported “We approached the Health Board as he has three weeks holidays now from the workshop and for those three weeks he is going nowhere, he is at home, and we went to the Health Board and asked them could we get someone to come and take him out for a few hours, and were told maybe in September they would have someone.” Another parent responded, “I have often wondered in relation to the workshop or centre, instead of closing down the centre if they could be staggered, everything is closing down at the same time and then they are sent home.” One parent described a more positive experience, “The workshop my son goes to used to have three weeks but they have split it up now to 2 weeks and 1 week. And this is the first time they have done it and I find it great.”
The parents of younger children would not have had any experience of workshop settings, however they did discuss their child's attendance at school. Just as parents of adult service users described the challenges that arose during holidays, parents of younger children talked about the difficulties they had during the summer holidays. One parent reported, "I find it good when he is at school, but the summer holidays its [home support] not enough, they don't have anything to do," while another parent echoed this saying "there is nothing for the child all summer, if there was music sessions or something like that organised, it gives the child a break and gives the child some sort of purpose to get up in the morning." One parent pointed out that summer activities are available for children who do not have special needs, but not for those with special needs, "my other lad can go to class during the summer and join in with football, but there is nothing for our children, they should have something for children with disabilities, they need something as well."

Another service that was discussed in some detail was respite care. One parent of a young child described how she had been concerned about her daughter attending respite, but had been relieved when she settled in, "she goes off now and she is delighted ... when she gets there she is fine and she is very good." A parent of an adult child reported "we are very happy with respite, there's lots of help, but to have it available when you need it." Other parents talked about the difficulties that their child's attitude towards respite had caused, particularly where there had been previous bad experiences.

One parent of an adult service user described a situation where the respite service not being able to meet her son's needs. Her son had initially been placed in respite with others of similar level of disability, however due to a medical condition she was asked to take him home, "she [staff member] said you will have to come and take him away as we have no night cover ... I had to go down to that house that day and take him away and he didn't want to come as he was enjoying himself." When her son was next given respite care he was placed with a group of profoundly disabled adults where his medical needs could be met but this raised new issues, "I don't think the respite is geared properly because our lad went down and was in with profoundly handicapped kids, now all he wanted was someone to go out and kick the ball with him." A parent of a younger child had similar feelings, "I would like my son to go for a weekend, but he is not handicapped and he is put in with kids that are handicapped and in wheelchairs. I would prefer to put him with kids like himself, more able and independent." Another parent in this group described how her son no longer attended respite because of this issue, "he says now that there is nothing there for him."

Parents also saw integration as important and the topic was discussed among parents of young children. One parent reported, "Integration when they are young is very important," while another parent supported this saying, "we need to be able to integrate the kids into local clubs with the support of parents -- some children are afraid of our children." Developing this idea of the perceptions of other children, one parent suggested that other children needed to be educated around disability issues, "kids need to be made aware from an early age that there is children that have a disability and they needed to be treated properly."
Another other issue that arose was the lack of information around the services and benefits available to families, as stated by one parent “the thing is you are not told about what is on offer, everything we got we discovered it by accident”. A parent in the young service user group when talking about home support reported, “we knew nothing about that until it came out at a meeting we were at, and we followed it through, it took us about a year before we eventually got it.”

The parents also discussed their concerns for the future, with one parent expressing concerns around who would care for her son, “we are not going to live forever, somewhere suitable for him to suit his needs to live. I don’t want him a burden on my daughter”. Other concerns focused on their son or daughter’s abilities particularly in relation to money, work and other aspects of independent living.

One issue that was more evident in the group or parents of younger children was the concern expressed by parents that some professionals did not understand their children’s needs. One parent felt, “I don’t think they [psychologists/psychiatrists] understand much about it, they have text book stuff about previous cases,” while another parent reported, “I find with psychologists and psychiatrists, there is not a great understanding of behaviour problems.” One problem which parents felt related to this lack of knowledge was the fact that their children often did not act out in front of the psychiatrist/psychologist. One parent suggested filming outbursts so that professionals could witness the extent of a child’s difficulties and went on to say, “he [son] doesn’t kick up when he goes into the [psychiatrist]. You are trying to explain then and the [psychiatrist] is looking at the child saying ‘no way is he that bad’ and the minute you are gone out the door the child would tear the head off you.

6.2.6 Training for staff and parents
The final issue to be examined relates to parents views on training, both for themselves and for staff. One feeling among the group was that staff and parents needed to understand their children as individuals and the background to any challenging behaviour. As one parent described, “if we could establish their strengths and weaknesses, their likes and dislikes, what they are good and what they are not”. Another parent, who’s son’s key worker had been on a behaviour course, reported that this person had developed a better understanding of her son’s behaviour, “it’s helped and give him [key worker] more of an understanding of why he [son] is doing what he is doing”. Finally parents discussed the benefits of training for themselves, and while some in the older group felt that they would not benefit, as “there are so many different needs it would be very hard to train,” some of the parents in the younger group were more positive, “I went on the parents plus and I found that absolutely brilliant.”

6.2.7 Summary
- In discussing challenging behaviour, parents described a wide variety of behaviours, which included non-compliance, physical aggression, and tantrums.
- Attention seeking and boredom are associated with challenging behaviour.
- Parents described challenging behaviour as having a negative impact on the whole family; including restricted social activities, less attention for siblings, and a sense of frustration and isolation among parents.
Measuring the Challenge of Challenging Behaviour

- Parents have mixed experiences of support from family and friends.
- Parents feel that home support hours need to be increased, and in particular extended beyond 9am to 5pm.
- Parents described the difficulties of looking after their children during extended school or work shop holidays.
- Parents have concerns around their children being placed in respite with children of different ability levels, but also see the importance of integration.
- Parents feel they need more information on the services available to their children.

6.3 Staff and Frontline Managers Perspectives

Prior to carrying out the focus group a more informal discussion took place with a group of staff around the issue of challenging behaviour. This session was not recorded, however notes were taken and from these a number of positive and negative aspects of challenging behaviour were highlighted. The negative aspects of challenging behaviour included consideration of the impact on clients and staff. Topics included the impact on staff and clients' quality of life and the emotional impact on staff (e.g. frustration, fear, guilt, stress and burnout). Aspects of the job were also considered as negative consequences, including lack of resources and support, and the lack of clarity on dealing with challenging behaviour. Other consequences included low morale and a sense that challenging behaviour distracts them from their main responsibilities. However more positive consequences were also discussed. These included the rewards of small achievements, the lessons they learn from clients about themselves, and the admiration they felt for clients with challenging behaviours. In addition, staff felt that working in this area meant that work was never boring and that dealing with clients can bring teams together and make them stronger.

Following this informal discussion, a focus group was held with staff members working directly with clients. The staff were all members of the regional challenging behaviour support network and were selected from across a number of organisations. Six staff members from a variety of organisations took part. The aim of the group was to discuss in more depth, their views on challenging behaviour, including the impact of challenging behaviour, the support and resources required to deal with the behaviours, and the impact of aspects of their service on client's challenging behaviour. At the opening of this group the themes identified during the informal discussion were presented to the group.

6.3.1 Overview of themes

In reviewing the themes evident in the staff discussion two central themes emerged, which appeared to go beyond the issue of challenging behaviours in some ways and relate generally to service provision for clients. The first theme related to the way in which clients are viewed, in some ways referring to a model of service, while the second theme referred to more structural aspects of the service. These themes were linked back to challenging behaviour specifically, and a number of additional themes also emerged.
6.3.2 Models of Service
In discussing models of service provision
staff members discussed both the 'medical
model' and what they saw as alternative
models of service. Challenging behaviour
was linked to a more medical model, in that
"the more challenging people are the more
we give an artificial life model and then it
becomes a more sterile situation and the
person is looked after, medicated, cared for,
restricted". A number of participants spoke
about the difficulties of using a medical
model and in particular seeing clients as ill.
One staff member reported "I don’t have
any patients, they are not sick, they might
get the flu now and again, they might get
infections but they are like me they are not
sick". Developing this view of 'patients,'
one participant felt that a more personal or
person-focused approach was necessary
asking asked “are we using too much of a
patient approach as opposed to the
personal approach”. Another participant
criticised the medical model directly saying
"we are saying the medical model is fine,
but honestly I don’t think it is fine".

In discussing alternative models,
participants talked about taking a more
personal approach. One staff member
referred to a life model, “a life model does
contain some of the answers more than a
medical model". This participant went on to
describe an example of this model whereby,
"smaller units where the nurse is not
known from the carer or you don’t know
who is the person in care and who is the
carer, that is great.”

Looking at models of service on a more
practical level, a number of participants
talked about including clients more, in
some ways moving towards a participation
model. The group talked about involving
clients in preparing meals and other daily
activities. One participant described how
"this thing of having a bed made as they
get out of it does my head in, I think that
you can go down, bring them and if they
only hand you a pillow, if its participation
as far as I’m concerned and its involving
them on a one to one and its giving them
the time”.

6.3.3 Structural issues within the
service
A second theme that was discussed in both
general way and specifically related to
challenging behaviour considered structural
aspects of the service. In discussing how
stress and burnout related to challenging
behaviour, participants talked about staff
overtime and the challenges of dealing
with clients when staff have been on for
longer than a normal shift. The focus of this
point was that staff would take extra shifts
for financial reasons and that this would
increase the levels of stress experienced. As
one participant described “we’ve had to
stop a lot of overtime ... (staff) would
complain and write notes to me that they
were tired”. The group also discussed how
overtime can result in staff building up
extra leave and that this can put pressure
on other staff when people start to take
leave.

The group went on to talk about this issue
in relation to challenging behaviour
specifically. The main point made was that
if staff are tired from overtime or long
shifts their ability to deal with challenging
behaviour is effected. One participant said
“if you haven’t done all this overtime,
coming in fresh you would be ready for the
job”, while another reported “if you are
going back again after finishing a dreadful
morning ... feeling awful and the client can
pick that up".
6.3.4 Factors involved in dealing with challenging behaviour

In discussing challenging behaviour a number of other factors emerged, the two most prominent being the need for consistency and the importance of communication between staff. In discussing consistency, participants talked about the benefits of having consistent cover, as staff will be familiar with the clients and their behaviours. As one staff member described “I find and think consistency of staff in a challenging behaviour is essential as you know your clients and you know what to expect, you can anticipate things”. Another issue that was discussed referred to differences in how staff perceive and interact with clients and how this can impact on the clients. One staff reported “you could walk in one week and its done one way ... and you could walk in the next week and its done differently ... I would be saying to the staff its wrong for the clients to have to try and change”, and went on to say “if you break their week ... I'm going to have problems then because the clients are going to be confused”.

In discussing communication, participants stressed the need for clear communication. As one staff member put it “there needs to be a lot of input into how staff work together and time to talk together”. The group went on to discuss the difficulties of planning meetings. One participant explained “there was never one time at all when staff were together for a meeting with no clients” and went on to identify the impact of this by saying “all our differences started to build and separate and suddenly the three people that were working so well together were not working together at all”. Another staff member described communication as “absolutely essential”.

A related theme addressed the importance of staff working together as a team to tackle challenging behaviour. One staff member described, “it is the key thing having the staff working as a team whatever shift they are on,” while another talked about “coming together as a team.” Another factor that can impact on challenging behaviour that was discussed was staff training. One participant reported, “working with staff who have had no foundation in challenging behaviour at all you can see a huge difference, when they have some sort of a background in challenging behaviour they work with you so much better.” In the discussions that followed participants talked in more detail about the benefits of training. One staff member described how training gave staff “an understanding of where the clients are coming from,” while another participant talked about changes in attitudes towards challenging behaviour, “they [the staff] don’t see it as they’re the ones causing the problem, its looking underneath them for solutions.” Suggestions around further training included making it available to more staff and other techniques such as physical management.

6.3.5 Supports available to staff

Another topic that resulted in more in-depth discussion was the types of supports required by staff to effectively tackle challenging behaviour. One of the most widely discussed issues related to support was the availability of back-up from other services, including psychological services, speech and language therapy, and occupational therapy. However participants also talked about ways to capitalise on access to other services as well as expertise and experience within the group.
One participant described how they had set up a form of support group, "we set up a group for all the nurses ... and every so often there would be a half day assigned, every single RMHN and nurses and physios and there would be various people giving talks. "Another participant talked about the benefits of having an external person talk to the staff, "staff tend to listen to someone from outside where they mightn't always listen to other staff", a comment which was echoed by another member of the group who described input from a physiotherapist on a particular client, "staff took that on board because the physio said it. They felt that this person knows exactly what they are doing."

As well as discussing ways of support staff in dealing more effectively with the challenging behaviours exhibited by clients, the group also briefly discussed the impact that challenging behaviour can have on them personally and support needs in this area. One staff member described feeling vulnerable after an incident where she was physically harmed by a client, but was not able to take a break to recover from the incident.

6.3.6 Summary
- Staff members felt that the model of service provision is central to how challenging behaviour is managed and were critical of a primarily medical approach to challenging behaviour.
- Structural issues such as working a lot of overtime can affect staff members' ability to cope with challenging behaviour.
- Staff felt that knowing the clients as individuals and a consistent approach to interactions with them was essential to tackling challenging behaviour.
- Communication was also described as important, with staff describing the negative impact of failing to meet regularly to discuss work.
- In addition to communication, the group felt that staff had to work effectively as a team to deal with challenging behaviour.
- Experience and training in challenging behaviour were seen as essential for staff to understand clients and the nature of their individual behaviours.

6.4 SCHOOL PRINCIPALS PERSPECTIVES

In order to explore the perspectives of school principals, principals from the six schools providing special education in the health board area were invited to take part in a focus group. These schools provide services to service users from across the full spectrum of disability. Five principals and one representative took part in the group. A representative from the Department of Education was also invited to attend and take part in the focus group but was unavailable to attend.

6.4.1 Types of challenging behaviour
In discussing challenging behaviour the group described a range of behaviours and situations that they would classify in this way. Many behaviours were described, including physical behaviours, "Hitting. Biting. I saw her drawing blood with a pinch." Another participant described several types of situation; "You can have a child who is explosive one day and calm the next day. But actually a child that could hit out injure themselves or other children – they are like time bombs... Then there is other children who could have, for want of a better word, a corrupting influence on other children, and this is more ongoing there."
One principal commented further on the types of behaviours involved, "it's not so much the physical aggression I would find, it's the continual verbal aggression all the time," while another participant described "a child that would throw themselves on the ground ... it may not be the physical aggression towards someone else."

6.4.2 Impact of challenging behaviour

The group discussed the impact of challenging behaviour on the student exhibiting the behaviour, the other students in the class, and finally the staff. The group discussed a number of ways in which students exhibiting challenging behaviours are negatively affected by their own behaviour. One speaker reported, "It effects their ability to learn," while another talked about the impact the behaviour can have on their involvement in activities, "unless you have another adult, unless you have one to one you couldn't bring them out." Finally, (while not describing directly the effects of challenging behaviour), one principal described the students who exhibit these behaviours in the following way, "they come with an absolute sense of failure, no self esteem they are at the bottom, very angry and very frustrated children."

The group also talked about the impact of challenging behaviours on other students in the class and these ranged from the harm caused and the educational impact. One principal described the physical and psychological impact, "when violence occurs especially if they are older students, the younger ones are traumatised and the younger ones often get injured too." On an educational level, the group talked about the effect on students' ability to learn ("it effects others' ability to learn") and the staff's ability to deliver the curriculum, "Curriculum is irrelevant when you think of all the behaviour problems."

Finally, the group spent some time discussing the impact of challenging behaviour on staff. The group talked about the stress caused by having to deal with these behaviours, as well as the frustration that it can cause. As one participant described, "sometimes they [the students] can be seriously challenging and again for our staff causes quite a bit of stress." One discussion focused on the effect that challenging behaviour can have on staff members' confidence in their skills. One principal described how "you often feel your own resources are insufficient," and another added "you will try and try different programmes and they may fail and where to turn to next and that's the problem. A third participant continued this point, reporting "it's the level of frustration that creeps in when all your strategies have been exhausted and that's what causes the most stress, and it does happen on a regular basis."

One thing that appears to add to this frustration is perceptions of their role in the school, as one principal reported, "teachers feel frustrated as they feel that they are housekeepers, social workers, cleaner uppers along with special needs assistants as sometimes they can become very frustrated as they think 'what am I here for' as everything else gets in the way." Another commented, "your function in the school is to teach the formal curriculum, in fact by the time you have the child, he's dirty, he's hungry, he's frustrated, he's angry coming into school and by the time you have ironed out all those little/big problems you are exhausted before you begin to teach the formal curriculum."
Finally members of the group talked about health and related issues for staff. One participant talked about the possible health implications of being bitten by students, while another talked about the threat of harm staff experience, "just the other day I had a child who is twice as tall as me who threatened me with his fist, right up against me, but didn't connect, but someday he is going to, maybe another pupil." One participant talked about leaving special education, saying, "I'm very frustrated and intend only spending the next year or two in special Ed and then getting out."

6.4.3 Factors influencing challenging behaviour

Another theme to be touched upon by the group was the factors that influenced the development of behaviour problems. Two issues discussed were the influence of parents and the home environment and the importance of early intervention. One participant touched on both these issues, "I think what we are finding is that younger children coming in because of the parenting skills and sense of somewhat structure and discipline is lacking in homes. We are having what is not exactly challenging behaviour at a serious level, its there because children are not used to being disciplined. If it could be addressed at a younger age, if you had time to work with the parents more." One participant referred to the need for early intervention, "we are getting them at 13 and 14 when they should have come in earlier, it's not the schools fault but sometimes the parents as well, if we got them at 8 or 9, we can't iron out all the chips on their shoulders when they come and so you spend the first year or two actually not teaching at all your building up all sorts of other things."

6.4.4 Supports required for tackling challenging behaviour

The group discussed a number of issues around supporting staff, including what is available to them, as well as what is needed. The group noted the role that they as principals play in supporting staff, with one participant reporting, "[it is] very difficult to support staff, how much should staff take as regard to physical aggression and it does come back to the principal at the end of the day as regards supporting staff members that have been injured and picking up the pieces and getting back in there and continuing on – that's difficult." Another principal also reported, "I think as a principal that's difficult too as sometimes you can't really give the support that's needed to the other person."

One support system that was considered from both positive and negative angles was the Special Need's Assistant (SNA) role. One principal reported, "I would say the biggest advantage we have is the number of special needs assistants." However the absence/presence of SNA's in and of itself was not necessarily a positive influence, central to the impact of this group was their experience. The principal quoted above went on to say, "I'm particularly lucky in our school as they have experience, they have come from other places where they have had experience of challenging behaviour. However another participant commented on the difficulty of SNA's who had not received appropriate training, "a lot of them are coming in without any training, any specific training. So again if you are putting them in with someone with challenging behaviour that's not fair, you have to sit down and try and train this person and give them hands on experience with an experienced teacher."
It should also be noted that training was limited to SNA'a, as one participant reported, "we do need more training." This was echoed by another participant who said, "I think it’s very much into training for staff.”

The group also talked about access to specialist services, which is seen as important to tackle challenging behaviours. One point to note from the discussions around this topic is the variability in access to specialist services, and as a result, this issue again was discussed in both positive and negative ways. One principal was very positive about a nurse the school had recently been allocated, while another talked about having regular access to a psychologist, speech and language therapist, physiotherapist, and a social worker, each visiting the school each week or at most each fortnight. Negative issues included the problem of waiting lists; with one participant reporting "we now have children waiting to see a psychiatrist for years ... [for one child] it took us three years to get any sort of intervention.” The group also discussed the impact of changes in other services such as staff turnover or loss of previously received services. One principal commented that their difficulty in accessing services was a result of the level of intellectual disability that they serve, "there are literally no services from the Department of Education and because we are in the mild category we kinda fall between two stools with the Health Board as well.”

One topic that came up in relation to specialist services was communication and sharing of information. The group felt that this was essential but often missing. One participant reported, "information is not shared, I'm very angry about this because when you are meant to deal with challenging behaviour it should be a team effort and everybody to do with this child sits down ... the [health board] policy is you are only told on a need to know basis, that's not good enough.” Another principal, talking about dealing with other professionals, reported, "I have often said this, I think there has to be a lot more sitting down and outing the information on the table and sharing it.”

However, communication was not just considered in relation to outside agencies communicating with the school, the group also discussed the need for good communication and teamwork within the school, with one participant referring to “time to meet with staff, to get together to discuss these behaviours, to actually analyse them and to see what interventions are going to be effective for this child, and meeting the parents.” This also came up when the group were discussing strategies to prevent the occurrence of challenging behaviour, “if there isn’t a sharing of what works with a particular child, when you put someone on a child that is challenging and they are very good with that individual child that’s fine but there is a day when that individual is out sick or whatever ... so I think the sharing of what works, what makes this person tick is very important.”

Another topic discussed by the group that related to external services was the process of assessment. The participant described a variety of difficulties with assessment including the lack of regular assessments. One participant reported, “we just get the child which could have been assessed at two and a half years and it could be going [on] six, that's all we get.” However, one participant felt that assessment was not necessary as the staff generally have a good sense of how a child is progressing.
6.4.5 Strategies for tackling challenging behaviour

The group discussed some of the strategies they were using to tackle challenging behaviour on a day-to-day basis. The benefits of one-on-one ‘specialisation’ were mentioned on a number of occasions. Another participant described a strategy of splitting the children with challenging behaviour across classes that may not be age appropriate but allowed for better management of challenging behaviours.

One participant described how the school had set up a ‘Care team’, which responds to behaviour in the following way, “if there really is a problem we meet with the teacher to support the teacher, we meet with the child and if necessary we call in the parent ... we are supporting the teacher who is at their wits end and we are also supporting the child if we can and the parent if we can get them in.” Another participant described how their school had benefited from positive programme training, “that was very helpful and changed the way we looked at challenging behaviour as well and I suppose it opened up the whole question just how flexible the school day can be and the curriculum. Other strategies mentioned included sensory and relaxation programmes. Another speaker described a situation where the system of break time for students been adapted to reduce challenging behaviour, they had found that mixing junior students and post-primary students led to fewer incidents. Another issue raised by the group was the need to draw on staff experience, as one participant explained “I think teachers have a lot of expertise I really do, and often we don’t appreciate that and draw them out of it, they really have a lot of the answers themselves.”

In addition the group discussed crisis intervention and the strategies employed in these situations. The group described removing the child to a quiet place, but also the difficulty they often experience in finding somewhere suitable. One participant reported, “we need quiet places too, a place where you can remove someone to.” Another participant added that this would prevent other children being disturbed by the incident. Finally, the group discussed strategies to prevent challenging behaviour occurring. One of the participants talked about the importance of keeping children occupied in the playground and explained how they had bought a number of footballs for the yard so that games could continue even when balls were knocked over the fence. Another participant stressed the importance of “knowing the child and reading the files.” Finally the facilitator asked about involving families and the group felt that this was important but that family willingness to be involved was central.

6.4.6 Summary

- School principals described a variety of behaviours, including physical and verbal aggression.
- Challenging behaviour was described as having a negative impact on the student themselves, their classmates, and staff in the school.
- The importance of early intervention and the influence of parents were highlighted as factors effecting challenging behaviour.
- The group expressed difficulties in supporting staff in tackling challenging behaviour.
- There is wide variation in access to services such as psychology, speech and language, and occupational therapy.
Principals were generally positive about special needs assistants, however they stressed the need for these individuals to be trained or experienced.

The group saw communication and the sharing of information, both within the school and with external services, as central to effectively tackling challenging behaviour.

The group discussed a variety of strategies for dealing with challenging behaviour, including separating students at break time, the use of quiet places, and provision of meaningful activities.

6.5 SERVICE USERS PERSPECTIVES

In order to access and explore the views of service users, two focus groups were carried out. Ten service users took part overall, including three female and seven male service users, with an age range of 15 years to 35 years. In addition, the opportunity arose to carry out an individual interview with a single service user who had not taken part in either of the focus groups. Participants were all either attending a high support service or were members of an advocacy group and represent both individuals with challenging behaviour and those who have been exposed to challenging behaviour.

In reviewing the transcripts of the two focus groups a number of common themes emerged, including the variety of behaviours discussed in response to the term challenging behaviour, the effects of challenging behaviours on others, possible causes of challenging behaviours, and the response of service users to their own and others challenging behaviours.

6.5.1 Types of behaviours

In order to discuss the topic of challenging behaviour the facilitator had to give examples of behaviours and it is important to keep in mind that these examples may have influenced the types of behaviours discussed by group participants. The behaviours described by the group included verbal behaviours (e.g. shouting), physical behaviours (e.g. hitting, hair pulling) and destructive behaviours (e.g. breaking things). These behaviours were also discussed in relation to being directed at staff, other service users, and the participants themselves. One participant described how he would “probably yell at (others) and tell them to leave me alone and I might say a few bad words but that would be all, but I would never strike at them.”

6.5.2 Impact of challenging behaviour

Over the course of the two groups the participants referred to the effects of challenging behaviour on staff and service users. A number of participants in one of the groups initially reported that they were not negatively affected by challenging behaviours. However the group went on to identify a number of effects. In describing an incident where they themselves hit a staff member, one participant reported that this made the staff member “cross and upset.” The group also talked about how other service users’ behaviour made them feel, using terms like “Nervous ... terrifying,” while another participant responded that challenging behaviour was “annoying.” Later in the group's discussions another participant, talking about a resident, reported, “I feel very sad – I'm just waiting for him (resident) to hit me.”
6.5.3 Factors influencing challenging behaviour

One topic that was discussed in the context of what leads to challenging behaviour was attention seeking. When asked why a particular resident acted out, the group responded “probably for notice,” “trying to get himself into trouble,” and “it’s for more notice now than anything else I would say.”

Also discussed was the way in which feelings were involved in challenging behaviour. Another participant, in talking about his own challenging behaviour, described what he saw as the reason for his behaviour, “I get upset because everyone goes home on Friday and I have to stay with (staff member).” In the second focus group another participant spoke about the reasons behind his own behaviour, reported “I would only lose it if someone really p***ed me off a lot.” Another participant, talking about another resident’s behaviour, said “I think that its part of his illness.”

6.5.4 Strategies for tackling challenging behaviour

In discussing challenging behaviour the groups described a variety of responses to challenging behaviour, both their responses to others’ behaviour, and the ways in which they react when they find themselves about to act out.

In discussing their reactions to other service users behaviour, responses included both avoiding the behaviour and reacting to the behaviour. One participant described how he would “try and go to my bedroom and hide somewhere,” and later reported that when two particular residents fight “I just ignore them.” Another participant talked about trying to step in, “I tell (other resident) to stop,” while in the second group one participant reported, in response to someone shouting “I would tell them to lower their voice down just to calm them down a bit.” However later on the group talked about more aggressive responses to other residents’ behaviour, “I’d love to kill him,” “turn around and still hit him.”

A related topic asked participants what should be done about challenging behaviour. Participants talked about getting away from the situation, “move away,” “maybe I should go for a walk.” Later discussions centred on ‘venting’ anger; “if you feel in a temper then go down and box your pillow ... get all the temper out of your head and then you come out fresh in the morning.” In the other group a participant reported one incident and his response, “I just felt I wanted to basically hit him but I decided to walk away and put a dent in my locker. If I get mad I just hit something rather than somebody.”

Finally the group talked about what should be done with residents exhibiting challenging behaviour, and one participant suggested, “maybe if you cornered off a bit of the room to keep him away.” In another group the suggestion was made, “try to talk to him about not starting fights.” The group also talked about sanctions like suspension and loss of pay.

Staff responses to challenging behaviour were discussed on a number of occasions. In one group a participant described how, “one of the staff would usually have a chat with them.” Another participant reported, “they gave me classical music to see would that help and it did.”
6.5.5 Themes from individual interview

A number of interesting issues were raised during the course of the individual interview. When talking about behaviour problems, the participant talked about problems in accessing services and information about services, "(doctor) say there is no psychologists that deal with behavioural, there is one for children but none for the adult, I said I was told there is but he said there isn't, the lack of information is there." Later he talked about problems when he wanted to access a social worker.

The individual also talked about possible causes of challenging behaviour, reporting, "it (CB) would be down to stress, down to an awful lot of stress." Another issue the participant discussed when asked about what would help tackle challenging behaviour was independence and independent living, "I suppose if they had more independence and were reassured and they weren't afraid." This was an issue the participants spent some time talking about, he spoke about wanting to live in a flat and develop living skills "if there was something to help me move into a flat, somebody to help me cook – if someone came into the house once a week to help me cook or show me how to fry an egg or something simple like that."

In some sections of the interview the participant talked about what could be described as models of service, talking about how medical staff have control of the individual, "I think the doctors sort of take control of peoples lives and the community nurses decide whether you go into a flat or you go into a house or whatever and I think that is wrong you should be allowed to make up your own mind once you have got the support."

6.5.6 Summary

- As with other groups service users described a variety of types of behaviours, including physical and verbal aggression, and destruction of property.
- Service users considered the impact of challenging behaviour on both service users and staff.
- Attention seeking and emotions such as anger and stress were seen as reasons for challenging behaviour.
- The groups described a variety of steps to prevent challenging behaviour including leaving the situation and venting anger in other ways.
- Suggestions for dealing with incidents of challenging behaviours that have occurred included isolating the individual and sanctions or consequences.

6.6 DISABILITY COORDINATORS AND LIAISON COUNSELLORS PERSPECTIVES

All disability co-ordinators and liaison counsellors in the region were invited to attend and the final focus group consisted of a total of nine disability co-ordinators and liaison counsellors from within the South Eastern Health Board. This included the regional co-ordinator, a number of area co-ordinators and a number of liaison counsellors. Before considering the themes discussed by this group, it is important to point out that some technical difficulties prevented the full and complete transcription of the session. However the majority of the information was recovered and no impact on the representativeness of the comments is evident.
6.6.1 Models of Service

One issue discussed at length by this group related in a variety of ways to the model of service provided to clients with various levels of disability who also exhibit challenging behaviours. Early discussions focused on the role of teams within the health board and voluntary services. In discussing the early intervention team, the group felt that the current structure meant that the team acted more to gather information from the various professionals who assessed the client and to make recommendations based on this information. Participants felt that this meant they were not overseeing the implementation of recommendations or the implementation of interventions. One participant reported, “it would be actually put down to follow up by a psychologist ... but then we don’t go into detail as to what the psychologist would do.” The point was made later that this team might be making decisions without having had any contact with the client, “what you are going to have is a group who are on the early intervention team but they may not be the therapists who have seen the child”.

One participant suggested that a dedicated team for early intervention would have benefits for both the service and the clients, “a dedicated team for early intervention certainly would save an awful lot of money to the state number one, and I think it would make a huge difference to the children.”

In discussing the process of referring clients to community care services, there was general agreement that this process was not problematic, but one participant stressed that “you are depending on the professional to make an appropriate referral,” but she went on to say, “they do.” The group then went on to discuss some of the procedures for clients accessing a particular service, or moving on if necessary. The main theme here was the flexibility that the early intervention team had to decide on where clients were placed, “if its felt they [client] are ok they may be discharged, but if its felt there are going to be further needs they may be held on just in case.”

A detailed discussion took place around the provision of services for clients diagnosed with a mild intellectual disability who also exhibited challenging behaviours. The main discussion centred on whether these clients fell within the remit of generic community or mental health services or disability specific services. While the practice would be that they were seen by generic services a number of participants argued that disability services ended up dealing with these clients eventually, “usually what happens is they [generic services] come back and say this person has a learning disability and equally because of the limited resources in other areas, they do tend to come back.” The general feeling among the group was that a decision needed to be made around provision for this group and that the services had to be adapted appropriately, as one participant reported “I would say that the very first thing we should do is decide that they are in our service or they are not. I would say that it is a starting point either we deal with mild learning disabilities or we don’t and if we do, and it is in our remit, then we must look at the model of service or what we can develop.”
The group went on to discuss the provision of services for this group and the main thrust of the discussion was that mental health and disability services would have to cooperate and coordinate service provision for this group. One participant summarised this saying, “I think that more and more the health board is going to be challenged to find solutions that are across programmes, some of the solutions might lie in disability services for home support or whatever, some of it might be more in mental health for assessment and treatment, and some of it might be in the voluntary sector for day care but it's the sharing.” The group went on to discuss practical issues around the resources needed to provide services to this group and the funding of these services.

6.6.2 Factors effecting the provision of services

In discussing the service needs of clients with challenging behaviours one problem that was evident was the demand for the various services. As one participant reported, “we have so many [parents] out there that are asking for help.” In addition, the group also discussed the impact that this high demand had on the provision of services, with one participant reporting that they were not able to provide detailed plans for clients due to the sheer numbers involved “we do early intervention but the scope for that is limited because of the number of people you are dealing with ... we would have 120-150 [children] on the register, now its not feasible for that team to work out detailed plans.” Another participant commented that with the increasing numbers the nature of the service had changed, “when we didn’t have those numbers and had much more time for home visits we were able to implement much more stuff, nowadays there isn’t the time, our home visiting hours are cut so much by the virtue of the numbers and I would really see that as a major difficulty in the service now that we can’t catch up with people.”

A related factor is that of resources and these were discussed at various points during the focus group. Central to these discussions was staffing, and the need for both dedicated key workers and access to specialised services. One participant described the need for more key workers in early intervention, and went on to say, “the ideal situation at that level is to have more dedicated workers for prevention of challenging behaviour.” Later another participant discussed the difficulty of accessing disability specific psychiatric services in her region, “we have no psychiatrists for learning disabilities ... and our difficulty is that when someone makes a referral into the learning disability team we don’t have anyone to go to make sure that they are appropriately assessed with a learning disability.” Another participant highlighted the lack of multidisciplinary teams in the various agencies in her area. In discussing the related issue of assessment some members of the group felt that it would be more effective for the health board to be developing their own assessment teams, rather than relying on other agencies.

As one participant reported, “I think that one of the things that is really important is that we have an independent assessment because in some areas the assessment team or the people who do the assessments are actually tied into a particular service and I think that is difficult for them, its difficult for the services and its difficult for us.”
One final issue, which was discussed as a factor effecting service provision at a number of points in the focus group was the need for knowledge of service provision in different areas, and consistency of provision. One participant reported, “we need to be singing from the same hymn sheet,” while another had earlier said “there needs to be clarity around the region, and we all need to be doing the same thing.”

6.6.3 Service development
The final section of the group’s discussions focused on the development of additional services to support clients and their families. The issue of supporting families was seen as essential by many members of the group, as one participant reported, “the one thing at home is definitely ... some of them are cracking up at home with behavioural management problems and we don’t have anyone to do it.” The group also discussed the needs of the parents, one participant reported, “I think its more of a preventative thing, if parents understand that there is other children in the family and not just the one with disability, that you can prevent those problems in the future” while another stressed the need to support the family, “we should provide the help to the whole family.” The group also discussed the need for families to have access to family therapy and counselling services as an automatic service, rather than in response to a specific problem.

6.6.4 Summary
- The role of the early intervention team is to gather information to assess client needs and to make recommendations based on this information. An issue of concern highlighted was that the early intervention team members may not have had direct contact with the clients and do not have direct responsibility to ensure that the recommendations of the team are implemented.
- The process of referral to community care services was viewed positively, and flexibility seemed to be central to this process.
- While clients with mild intellectual disabilities should be referred to generic services, this is not happening. The participants felt that a policy decision needed to be made around provision of services for these clients and that a specific model of service was needed to meet this groups’ needs.
- Independent teams within the health board should carry out assessments, rather than teams based in particular agencies.
- There is a need for more key workers and better access to multi disciplinary teams.
- Teams should be supporting the whole family, with family therapy and counselling made available for families of children and adults with challenging behaviour.

6.7 RECOMMENDATIONS
It is not possible to represent the views of all the people who are directly involved in or impacted by challenging behaviour. However, based on consultations with the key stakeholders, the following recommendations were agreed by the Challenging Behaviour Steering Committee:
**Early intervention**

6.7.1 The escalation of challenging behaviour should be prevented at an early stage. Specialist dedicated teams for early intervention services should provide a comprehensive multidisciplinary assessment of need between the ages of 2-6 years and be responsible for the development and implementation of individualised care plans for children under 6 years.

6.7.2 A Behaviour Specialist should be available to the early intervention team to provide detailed assessments of challenging behaviour at home and at preschool. The Behaviour Specialist should be responsible for training parents, family support workers and other key workers in current best practice in responding to behaviours that challenge and in the development of positive behavioural support programmes for children with challenging behaviour.

6.7.3 Each child should have a person centred plan to facilitate the transfer from early intervention services to other services where ongoing multidisciplinary support is required.

6.7.4 Key professionals should work in partnership with families in coordinating service provision and in developing the plan to meet the child's identified needs. This may include a plan for the provision of educational or day services, medical treatments, respite services, multi disciplinary supports etc.

**Support services**

6.7.5 Challenging Behaviour Specialists should assist with the assessment of challenging behaviour and provide support to families and service providers in the implementation of effective behaviour support plans to address challenging behaviour.

6.7.6 The Behaviour Specialists should be part of a multidisciplinary team which should include a senior psychologist, a speech and language therapist, an occupational therapist and behaviour support workers. These teams would have a number of functions:
- To provide a comprehensive assessment and functional analysis of the challenging behaviour.
- To develop a multi-element challenging behaviour intervention and support plan with service users, family carers and staff.
- To train and support carers and staff in the implementation of the programme.
- To provide hands-on support to families and staff in times of crisis.

6.7.7 People with mild intellectual disabilities and challenging behaviours should have access to a range of supports to live independently in the community. A case manager should coordinate the integration of mental health services, social services and disability specific services for individuals with mild intellectual disabilities and challenging behaviours.
Family Support

6.7.8 Families with children and adults with intellectual disabilities and challenging behaviours need regular short breaks (2-3 hours, 3 times per week) to be able to cope with behaviours that challenge. The current home support service should be reviewed to ensure that families are getting breaks when they need them, particularly in the evenings and at weekends.

6.7.9 School, workshop or day centre holiday times are particularly stressful for families and are associated with increased challenging behaviour in the home, additional home support services should be provided during these periods. Holiday periods in Training/Day centres should be reviewed and where possible staggered over shorter time frames.

6.7.10 A crisis after hours (5pm – 9am / week-end) telephone support service for families of children and adults with intellectual disabilities and challenging behaviour should be developed. This service should be linked to on-call family support workers and an emergency respite service.

6.7.11 The respite service should be expanded and further developed to include alternative models (e.g. shared care) of providing respite and support to families.

6.7.12 Respite services should be provided in a flexible way, at the appropriate times and with the appropriate peer group to meet service users needs. Activities during respite should reflect service users likes and dislikes.

6.7.13 Parents should have more information about services available to them. An information desk with staff responsible for the provision of information should be developed in each region to assist families in accessing services available within the Health Services. Families should have information on the services available to support people with intellectual disabilities in the region and need to know how to access services. Information on all entitlements, grants etc. should be available at the information desk.

6.7.14 Social / leisure activities in the community should be developed, to meet the needs of people with intellectual disabilities, particular in the evenings and at weekends.

6.7.15 Practical skills training and work opportunities should be provided for people with disabilities in the community.

6.7.16 Personal family support workers should provide practical support to people with intellectual disabilities and behaviours that challenge in the home. Specialist training in the management of challenging behaviour and understanding challenging behaviour should be provided to family support workers.
6.7.17 Specialist Challenging Behaviour support services should be available for assessment and management of challenging behaviour in the home. Training and support in the management of people with challenging behaviour should be available to parents.

6.7.18 Family therapy and counselling should be available to support families of children and adults with challenging behaviour.

Supporting service users

6.7.19 Managers of services should promote a culture of supporting people with intellectual disabilities and challenging behaviours, in which they have a right to live as independently as possible, to develop and use their abilities and talents and, to live, learn and work in environments appropriate to their needs.

6.7.20 All service users should have an individualised person-centred plan to meet their needs. Everything possible should be done to enable the individual to communicate their needs.

6.7.21 Practical support should be incorporated into the person centred plan to include training and support in independent living skills (such as, cooking, money management). Additional supports should be provided to empower service users to manage their own behaviours that challenge (e.g. counselling, anger management, assertive communication, stress management etc.).

6.7.22 Service users should be fully informed about all services available to them, with information on how to access services.

6.7.23 The environment should be regularly assessed and adapted to ensure the safety of others. Examples of environmental adaptations include: separating some service users from others, ensuring that service users, particularly those who are non-ambulatory, are not positioned with their back to others who have been physically aggressive towards them.

Building Staff Capacity

6.7.24 Managers of services should develop strategies to maintain staff consistency and reduce staff turnover. Some strategies in this area would include team building, staff training, and supervision of work practices providing opportunities for de-briefing after incidents of assault. Evaluation procedures need to be incorporated into these strategies.

6.7.25 Frontline staff should be supported to increase their understanding of how challenging behaviours develop in individuals with intellectual disabilities and how life experiences and the environment play a key role in the person's behaviour. The use of positive approaches to promote a healing environment to support people with challenging behaviour should be encouraged.
6.7.26 Staff should work together as a team to support each other in the management of challenging behaviour. Team meetings should be scheduled on a regular basis to discuss behaviours that challenge. The purpose of these meetings should be to develop a better understanding of challenging behaviour; to agree on effective ways to address challenging behaviour, to provide staff support and to capitalise on staff experience. Team meetings should be arranged in a way to ensure that all staff are scheduled to attend in so far as is possible.

6.7.27 Managers of services should develop systems to ensure communication between staff. These systems should be reviewed and evaluated on a regular basis.

6.7.28 Training in behavioural assessment and multi-element behavioural support should be provided to frontline and resource staff to promote the use of effective, non-aversive methods that work with individuals who have challenging behaviours so that they can enjoy community participation with dignity and respect.

6.7.29 Training in reactive strategies to manage crisis, including the appropriate use of physical intervention to manage aggressive behaviour, should be provided and targeted specifically in services where there have been incidents of physical injury reported and where there is a need for staff members to physically intervene in order to manage physical aggression in a safe way.

6.7.30 Each organisation should have guidelines on responding to behaviours that challenge, which should include a planned crisis response strategy and guidelines on the use of restrictive physical intervention. The policy should also include guidelines on providing counselling and support after incidents of challenging behaviour.

6.7.31 A Training Coordinator should be appointed to oversee, develop and coordinate training programmes for staff working within disability services in the South Eastern Health Board area.

6.7.32 Internal and external support systems should be established to support staff working with people with challenging behaviours. The challenging behaviour support network should be formalised, facilitated and encouraged by management. The Network should provide a forum for frontline staff and professional to:

- Share experiences of when interventions to address challenging behaviours have worked.
- Promote positive approaches to support people with challenging behaviours.
- Identify training needs and organise training seminars in the area of challenging behaviours.
- Promote inter-agency co-operation in responding to challenging behaviours.
Special Education
There should be a coordinated response between the Departments of Education and Health to the recommendations outlined below in line with the Education for persons with Special Needs Act 2004 and the Education for Persons with Disabilities Bill 2004.

6.7.33 Additional support systems should be developed in special education schools to support teachers and staff in responding to challenging behaviour within schools. These support systems should include:
- Counselling and support services for staff who have been traumatised after an incident of assault in school.
- The development of a challenging behaviour support network in schools that provide special education.
- The designation of a core support team in schools to focus specifically on the management of challenging behaviour in schools and to provide support and guidelines on evidence-based interventions and best practise.

6.7.34 Special needs assistants should provide hands on support to teachers and assist in the implementation of behaviour support plans to manage challenging behaviour in school. Special needs assistance should have specific training in understanding challenging behaviour and in appropriate and effective ways to address challenging behaviour.

6.7.35 Children in school with challenging behaviours and special education needs should have access to holistic assessment to be carried out by people with appropriate expertise (Section 5 – Education for Persons with Special Needs Act 2004). There should be equitable and timely access to multidisciplinary support in all schools that provide special education. A collaborative multi-intervention plan to address challenging behaviour should be developed between parents, teachers and key professionals involved (6.7.35).

6.7.36 Teachers and special should have assistants need appropriate training, preferably as a team, in current best practise in responding to behaviour that challenges and in the development of positive behavioural support programmes for students with challenging behaviour.

6.7.37 Protocols and procedures to facilitate communication and information sharing need to be developed between school and health board staff and families.

6.7.38 School team meetings should be arranged to capitalise on teacher experience, to enable teachers and staff to work together in the development of proactive strategies, and to develop a planned crisis response strategy to manage challenging behaviour in school.
6.7.39 The school environment should be assessed and modified where possible to meet the needs of children with challenging behaviours. Environmental factors for consideration should include:

- Provision of a quiet place where children can go to calm down away from other children.
- Re-structuring break times and separating some classes at break-time.
- The use of equipment and activities for children to occupy themselves during break-time (e.g. footballs).
- The provision of a multi-sensory room in schools providing special education.
- Additional accommodation for therapeutic services (psychological / speech and language assessment).
- The use of soft lighting and soft flooring in classrooms.

6.7.40 Children with special needs in school should have a comprehensive needs assessment with an individualised care plan to meet their needs before they leave school. School principals and key professionals should work in partnership with families and school leavers in coordinating a care plan to meet their needs.
CHAPTER 7
MEETING THE CHALLENGES OF CHALLENGING BEHAVIOUR

7.0 INTRODUCTION

No one model of service can provide all the characteristics, which are required to provide support to the wide range of people with challenging behaviours. Different people may need a completely different focus and type of help. Services in relation to challenging behaviour should be based on the least restrictive, non-aversive approaches to challenging behaviour. Mansel et al (1994)\(^\text{18}\) conceptualised a comprehensive strategy for supporting people with challenging behaviour that consists of four overlapping components:

1. **Prevention:** The prevention of challenging behaviour through, for example, targeting resources at those considered at greatest risk and ensuring that people with severe intellectual disabilities live, learn and work in enriched environments in which they receive appropriate help and encouragement to develop adaptive and socially appropriate behaviours.

2. **Early Detection:** Early detection and intervention to ensure that potential challenges are identified and responded to as they arise. This applies equally to the emergence of challenging behaviour in young children and the identification of signs and potential breakdown in families, residential settings and day services.

3. **Crisis management:** The provision of practical and emotional and technical support to people in places in which they normally live, learn, work, and enjoy their leisure to help them overcome their challenging behaviours. This will require effective approaches for the management of crises.

4. **Specialised long-term support:** For a few people, specialised high levels of community-based practical, emotional and technical support will be required over extended periods of time. A specialist support team or a specialist centre or unit could provide specialised support.

7.1 QUALITY SERVICES

The literature has indicated that better outcomes appear to be associated with those services which employ 'active support' in the areas of person-centred planning, activity planning, training and support of staff (Allen and Felce, 1999\(^\text{19}\)). There are number of factors which, in combination, seem to be central to enhancing the likelihood of good quality service provision for people with challenging behaviours. These include:


• A clear statement of service philosophy with ethical code/ guidelines which are supported by structures, policies and procedures.
• Systematic strategic service planning with regular review systems.
• Individual person-centred planning, reviewed regularly.
• An appropriate safe environment that meets service user needs.
• High levels of social contact and community participation.
• Full use of existing mainstream and generic services.
• Defined procedures and guidelines in crisis management, including the management of instances of challenging behaviour.
• Availability of multidimensional and proven treatment options.
• Monitoring of psychotropic medication.
• A commitment to joint working, skills sharing and a team approach.
• Systematic training with clear objectives.
• Professional and personal support/ supervision for direct care workers.
• Provision for meaningful activities.
• Support and assistance instead of demand and control.
• High levels of management support.
• Appropriate staffing levels and flexibility in the use of personnel resources that are available at the times they are most needed.

Disabilities should have as much control as possible over the services they use, determining their own lifestyle, work options and housing supports. The development of advocacy is essential to ensure that this happens. Funding mechanisms need to be flexible and person-centred. People with greater impairments cost more, particularly those with challenging behaviour.

People with challenging behaviours require
• Person-centred planning
• Intensive case management
• Individualised support systems
• Skilled personal assistance
• Access to respite services

7.2 A PERSON-CENTRED MODEL OF CARE

Carefully matching individual needs with the model of care is essential both in terms of care and cost. People with intellectual
Intensive case management
There are no quick and easy solutions to the management of challenging behaviour. Due to the complex nature of challenging behaviour, people may require a range of services and individualised supports. The planning and coordination of these resources can be slow and labour intensive.

Individualised support systems
A range of supports may be required to support the person with challenging behaviours in their usual environment. These supports may include additional staffing, home support and respite. There may be supports available in the wider community that could be used to address some of the needs of those with challenging behaviour. For example, social groups, leisure activities, bereavement counselling services, etc. Time and resources need to be allocated to building bridges and supports in the community.

Skilled personal assistance
An environment that can support people with challenging behaviour is generally an environment of caring, skilled individuals. There is a need for support and leadership from management, supervision of practise, and systematic training programmes to ensure that the staff have the required skill and technical competence to deal with challenging behaviour to an agreed standard of practise. The focus should be on developing staff with the skills to effectively facilitate and support the participation of people with intellectual disabilities and challenging behaviours in the community.

Access to respite services
Planned relief can provide a breathing space for families, carers, staff and service users to have a break from pressure. Respite services and home support for people with challenging behaviour need to be planned for. Emergency respite places are needed in crisis situations as a short-term measure while local services are developed to accommodate an individual's particular needs.

7.3 A CONTINUUM OF SERVICE PROVISION

A continuum of service provision is required to support the diverse needs of people with intellectual disabilities and challenging behaviour.

Models of service provision include:
- Allocation of additional resources to existing community-based housing or day services on either a short-term or long-term basis.
- Establishment of specialised high support unit-based services.
- Establishment of non-unit based services (special staff teams).
7.3.1 Allocation of additional resources in the community

A full range of residential services, housing supports and day services are needed in order to respond flexibly and individually to a particular set of personal characteristics and circumstances. Residential and Day services will require high levels of staff support to allow users to access a wide range of opportunities, including generic community facilities. For maximum benefit, the provision of satisfying work and meaningful activities with opportunities for community participation must be provided. This will require an individualised and structural approach. People with intellectual disabilities and challenging behaviour have a right to live and spend time in the community, not segregated in residential day and leisure facilities that keep them apart from other members of society.

7.3.2 Specialist challenging behaviour units

Specialised units may have a place in a range of services for people with challenging behaviours. They may provide an effective method of intervention for a small number of people; however, they do not address the problem of how we can provide a comprehensive service for the large number of people with challenging behaviour in our service. There is ongoing debate on the advantages and disadvantages of removing people with challenging behaviours from their usual environment to specialist challenging behaviour units.

Advantages of specialist challenging behaviour units

The main arguments in favour of specialist units are:

- They provide adapted/protected environments suited to the management of challenging behaviours.
- The units can fill a gap in current provision and ownership of the task in providing accommodation for people with challenging behaviour.
- Staff in specialist challenging behaviour units can become highly skilled.
- They can act as a centre of excellence/resource for other units.
- More intensive assessment and treatment can be provided for at a fixed cost.
- The units can sustain high levels of programme implementation and achieve short term reductions in severe challenging behaviour.
- They can protect non-disturbed people from disruption and aggression.
- The costs per person may be reduced when people with high support needs are brought together in one setting.

Disadvantages of specialist units

- Although centralising resources can allow for a more intensive assessment and treatment service for a fixed cost, it is often impossible to redirect those resources to help establish more alternative patterns of provision or support for service users.
- The removal of the person from the mainstream service can lead to a disruption of existing relationships between service users and their family, friends and acquaintances and reduces the need for training and the development of competence within mainstream services.
- The existence of specialist units impedes the development of locally based responses to people with challenging behaviours.
People are removed from their usual environments and any changes that do occur are unlikely to be maintained after discharge. Grouping people together with challenging behaviour provides an unpredictable and stressful milieu for carers and service users alike and often means that the physical environment has to be constructed to take account of a wide range of needs, which tends to make it barren and un-stimulating.

Robertson et al (2002) compared the costs and quality of non-congregate settings where the minority of residents have challenging behaviour; and congregate settings where the majority of residents have challenging behaviour. The results suggest that non-congregate care settings are more cost effective. Further, having a greater proportion of people with challenging behaviour in a setting is associated with a range of poor outcomes. Non-congregate care was associated with greater access to day activities, less reliance on medication and physical restraint to control challenging behaviour and less risk.

7.3.3 Specialist Challenging Behaviour Support Teams
An alternative to removing people with challenging behaviour from their usual environment is to provide a specialist challenging behaviour team to support people with challenging behaviour in existing services.

These specialist behaviour teams focus exclusively on clients with challenging behaviour and have a number of functions:

- To provide detailed assessments of the person and their environment.
- Draw up treatment and intervention programmes to address challenging behaviour.
- Train and support family carers and services staff in programme implementation.
- Provide hands-on support to staff in times of crisis.
- Develop new services for persons with challenging behaviour.

Advantages of Specialist Support Teams
- Specialist teams help to ensure that services and carers become more competent in supporting people with challenging behaviour.
- Specialist teams provide assessments and recommend interventions in situ, and in doing so, increase the likelihood that improvements will be maintained after the specialist has withdrawn.
- Specialist teams have a limited remit thus ensuring ownership of the task at hand.

Disadvantages of specialist teams
- The specialists required to meet the needs of the population of people with challenging behaviours may not be available in sufficient number.
- There may be difficulties in sustaining changes in carer practise once the specialised input is withdrawn.
- Specialist teams may also be prone to the problem of silting up and hence fail to provide the level of specialist support services require.

• Teams in themselves cannot always provide the solution to people who have to be removed from their present residence because of the threat they pose to themselves or others.

Emerson (2001) researched the effectiveness of specialist challenging behaviour teams and found the following:
• There was reduction in challenging behaviours and / or increased staff tolerance to challenging behaviours.
• There was a reduction in the number of admissions/ readmissions to institutions and specialised units.
• Teams were found to be more cost effective than institutional based services.
• Higher carer satisfaction and improvement in the carers coping with these behaviours was reported.
• The person's quality of life and adaptive skills were enhanced with the introduction of specialist teams.

However all teams are not uniformly successful. Allen and Felce (1999) have suggested that the factors that are likely to enhance the effectiveness of specialist teams include:
• A broad skill base that would enable the teams to intervene with the diversity of clients who present with challenging behaviour.
• A capacity for providing long-term support.
• A clear conceptual model for intervention that is based on empirically established models and procedures.
• Sufficient resources to enable the team to offer support to a high proportion of those in need.
• The ability to support carers and staff in reactive behaviour management procedures.
• An efficient and coherent management structure.
• The ability to deploy staff to model or establish effective ways of working with people who present severe challenges.

7.4 BEST PRACTISE

Best practice guidelines (Psychology Society of Ireland, 1998) indicate that effective intervention to address challenging behaviour will include a number of different steps. Each step is an essential part of the overall plan.

1. A comprehensive assessment of challenging behaviour

Fundamentally, the assessment process must result in assisting key people who support the person with challenging behaviours in developing an understanding and knowledge of the person and their needs. The general approach now is that to deal effectively and in the long term with challenging behaviours, a full and detailed assessment is required. It is important to identify any medical, social, environmental or physical factors that may be contributing to challenging behaviour.


This can be a complex process and will require detailed observation and information gathering. Assessment is the basic foundation for any intervention.

2. **Multi-element Intervention Plan**
An individually tailored intervention plan needs to be developed with the individual themselves and key people in their life. The plan should always lead to an improvement in the person’s quality of life.

3. **Implementation Plan**
The implementation plan needs to be set up through discussions with a wide range of people (service users, families, direct care staff, medical staff, and other relevant people) whose involvement with the person with the challenging behaviour will have a considerable bearing on the outcome of the intervention. The implementation plan needs to describe in what way the intervention plan will be reviewed. It is essential to give constructive feedback, training and support to the people directly involved in the plan.

4. **Evaluation Procedures**
Once a comprehensive plan of intervention has been put into action, the effectiveness of that intervention will need to be closely monitored and evaluated. It is important to decide on a realistic measure of success and also to have a realistic idea of the length of time it may take to bring about behavioural change.

### 7.5 INTERVENTIONS THAT WORK

The most effective strategies for challenging behaviour known at the present time are derived from Applied Behaviour Analysis. There are a number of meta-analytic studies that have reviewed the strengths and weaknesses of these approaches (Scotti et al., 1991; Didden et al., 1997). The most recent, by Carr et al. (1999) focused on the use of positive behavioural support strategies (i.e. those that avoided the use of aversive procedures). The review found that using a criterion of a 90% reduction in challenging behaviour from baseline levels, these strategies were successful approximately 52% of the time.

If a criterion of an 80% reduction was applied, this rate increased to around 68%. Positive behaviour support includes strategies to 1) control the environmental conditions that lead to the challenging behaviours and 2) change the person’s repertoire to include more adaptive behaviours. The behavioural interventions are non-aversive in nature.

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Regardless of the specific intervention approach that is used, its success is improved by starting with a functional analysis of the behaviour. A functional analysis of the challenging behaviour looks at what purpose or function the challenging behaviour serves for the individual by varying the situation systematically and seeing whether the challenging behaviour increases or decreases in severity. There is consistent evidence that behavioural interventions can be very effective in reducing or eliminating challenging behaviour when based on a systematic analysis of the function of the behaviour for the individual (Ager & O'May, 2001).

The results of interventions on specific types of challenging behaviour (Didden et al., 1997; Ager & O'May, 2001) have been reviewed. They found that, in general, it is harder to resolve problems that include violence directed at others or destruction of property, than socially disruptive or self-injurious or stereotypic behaviours. Aggressive behaviours seem to respond best to preventative approaches that control aspects of the environment that trigger the aggression. For instance, one intervention focused on improving communication between individuals and staff (Rowland and Treece, 2000). The individuals were given means of support to sign or point to symbols indicating what they wanted. Staff were given training and team support to be better at interpreting the individuals' communicative behaviours. Aggression decreased and so did prescribing of anti-psychotic medications.

Given the evidence for their effectiveness, it is alarming to note that these technologies appear to be considerably under-utilised in services for people with intellectual disabilities. In contrast, approaches with little or no empirical support in terms of their specific effect on challenging behaviour, but which are easier to apply, appear to be used at much higher rates. Most notably, psychotropic medications, which have no evidence in favour of their use as a specific treatment for challenging behaviour (Brylewski & Duggan, 1999), are prescribed on average to around 50% of people showing such behaviour (Fleming et al, 1996).

7.6 CRISIS MANAGEMENT

Even with successful intervention, zero rates of challenging behaviour are rare. Physical aggression is least responsive to behavioural intervention. It is therefore clear that, at certain times, and despite our best therapeutic efforts, carers supporting people who challenge will be faced with behaviours that pose a significant risk of harm to themselves or others. A necessary aspect of dealing with incidents of challenging behaviour is to have clearly defined strategies for responding to incidents when they occur. This is especially important when the person engages in a violent or aggressive manner towards themselves or others.


Crisis management strategies are generally reactive strategies that are not aimed at long-term change. In responding to challenging behaviour, services need to distinguish between managing and changing behaviours:

- Changing behaviours that have a long history can take a long time and will require a detailed assessment and intervention to work. Behaviour change will involve reducing the frequency or severity of the behaviour, or eliminating it altogether. It will frequently involve developing alternative, appropriate skills.

- Managing behaviours, on other hand, involves crisis management and containing a person’s physical contact.

Physical restraint is the use of any part of a person’s body for the purpose of stopping another engaging in a given behaviour. Environmental or mechanical restraint refers to the use of a particular setting or equipment which is designed to prevent a behaviour from occurring, such as strapping arms to a chair to prevent self injury or placing a person in seclusion to prevent aggression towards others. High restraint rates are now understood as evidence of treatment failure.

It is vitally important for all staff to have effective training and support in the use of physical intervention. People with intellectual disabilities have a right to be treated with respect, care and dignity especially when they are behaving in ways that maybe harmful to themselves or others and as a result require physical intervention from staff.

Restrictive procedures can be employed to achieve a number of different outcomes:

- To break away from dangerous or harmful physical contact initiated by a service user.
- To separate one person who is physically aggressive from another.
- To protect a service user from a dangerous situation e.g. the hazards of a busy road.
The use of restrictive intervention should be minimised by the adoption of fully documented risk assessment and preventative strategies whenever it is perceived that the use of force might be required. A restrictive physical intervention must only employ a reasonable amount of force, that is, the minimum use of force needed to avert injury, applied for the shortest period of time.

When any form of restraint procedure is employed (BILD, 2002), there should be:
- Clear written guidelines and policies governing its use (Appendix V).
- Clear reporting and recording procedures.
- Alternative, long-term, positive intervention and behaviour support plans in place.

7.6.2 De-briefing and staff support
There is a need for specific support services for staff or carers who suffer physical injury and or distress as a result of a violent incident or other crisis situations. The trauma of assault needs to be acknowledged and counselling and support facilities should be readily available for staff or carers who have to deal with distressing situations.

7.7 SUMMARY
- No one model of service can provide all the characteristics, which are required to provide support to the wide range of people with challenging behaviours.
- The range of service options to support people with challenging behaviour include allocation of additional resources in existing services; establishment of specialised challenging behaviour units; establishment of challenging behaviour specialist teams.
- People with challenging behaviours require
  o Person-centred planning
  o Intensive case management
  o Individualised support systems
  o Skilled personal assistance
  o Planned relief and emergency respite
- There are four overlapping components in a comprehensive strategy for supporting people with challenging behaviour which consist of:
  o Prevention strategies
  o Systems to enhance the early detection of challenging behaviour
  o Crisis management strategies
  o The provision of specialised long-term support.

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• There are number of factors which, in combination, seem to be central to enhancing the likelihood of good quality service provision for people with challenging behaviours which include person-centred planning, activity planning, staff training and support.

• Effective intervention to address challenging behaviour will include a number of different steps:
  o An assessment of the challenging behaviour
  o An intervention plan
  o Implementation of the plan
  o Evaluation of the plan.

• Behavioural interventions can be very effective in reducing or eliminating challenging behaviour when based on a systematic analysis of the function of the behaviour for the individual.

• Positive behaviour support has been identified as an effective means of addressing challenging behaviours and includes strategies to 1) control the environmental conditions that lead to the challenging behaviours and 2) change the person's repertoire to include more adaptive behaviours.

• A necessary aspect of dealing with incidents of challenging behaviour is to have clearly defined strategies for responding to incidents and managing them when they occur.

• Crisis management strategies may include the use of restrictive physical interventions. Restrictive physical interventions involve the use of force to control a person's behaviour and can be employed using bodily contact, mechanical devices or changes to the person's environment, such as forcible seclusion.

• When any form of restraint procedure is employed, it is essential that there are clear written guidelines and policies governing its use.

• Training and support in the use of restrictive physical intervention is required.

7.8 RECOMMENDATIONS

7.8.1 A range of service options with a continuum of service provision is required to support the wide range of people with intellectual disabilities and challenging behaviour. The range of service options should include:
  o allocation of additional resources in existing services
  o the development of challenging behaviour specialist teams
  o the provision of specialised high support housing.

7.8.2 Carefully matching individual needs with the model of care is essential both in terms of care and cost.
7.8.3 The system should be flexible to provide additional staffing and a range of supports as needed to maintain the person with challenging behaviours in their usual environment. People with challenging behaviours should have:
- Flexible person-centred planning
- Intensive case management
- Individualised support systems
- Skilled personal assistance
- Access to respite services

7.8.4 Challenging Behaviour specialists should provide training and support in the assessment of challenging behaviour. The challenging behaviour assessment should include a functional analysis of the behaviour. The interventions to address the challenging behaviours should be evidence-based and monitored and evaluated regularly.

7.8.5 Specialised high support housing will be needed for a proportion of people with severe challenging behaviour. The type of long-term support required should be based on an individualised and comprehensive needs assessment.

7.8.6 On-going supervision of practice and training programmes should be provided to ensure that all carers have the required skill and technical competence to deal with challenging behaviour to an agreed standard of practice.

7.8.7 Planned relief and short-term breaks should be available to give families/carers a break from the pressure of managing challenging behaviour at home.

7.8.8 An emergency respite care service should be established in each community care area and made available to support families and carers in crisis situations.

7.8.9 Every organisation should have guidelines on responding to behaviour that challenges, which should include clearly defined crisis management strategies for responding to incidents of challenging behaviour when they occur and a policy on the use of restrictive physical interventions. These strategies should be used in conjunction with a long-term intervention plan based on positive programming.

7.8.10 Service models and interventions should be based on the least restrictive, non-aversive approaches to challenging behaviours. If an aversive procedure is used, a multidisciplinary team must sanction this and its use should be recorded and evaluated on a regular basis. Relatives/advocates must be informed or consulted.

7.8.11 Employers and managers are responsible for ensuring that their staff members receive training in responding to behaviour that challenges, including updates and refresher courses, appropriate to their role and responsibilities within the service.
MEETING THE MENTAL HEALTH NEEDS OF PEOPLE WITH INTELLECTUAL DISABILITIES AND CHALLENGING BEHAVIOUR

8.0 INTRODUCTION

Service providers are increasingly recognising the needs of people with intellectual disabilities who have associated mental health needs. People with intellectual disabilities can experience the full range of mental health problems, although the precise impact of mental illness in this population is not clear. It is evident that people with intellectual disabilities may have predispositions towards specific mental illnesses arising from a variety of factors:

- Many intellectual disability syndromes of genetic origin are associated with psychiatric disorders.
- Brain trauma often directly results in psychiatric problems.
- People with intellectual disabilities are much more likely to encounter traumatic life events that make them more vulnerable to mental health problems.
- The social restrictions (rejection, lack of social acceptance, educational failure, lack of job opportunities, boredom and difficulties in finding acceptable sexual outlets despite normal sexual drives) experienced by people with intellectual disabilities may contribute to mental health problems as well as creating environments within which challenging behaviours are more likely to develop.

People with an intellectual disability, challenging behaviour and a co-occurring mental illness are sometimes untreated, or incorrectly treated. Some people may be inappropriately medicated and/or restrained, resulting in limited functioning and reduced quality of life. Some may end up in inappropriate environments, including prison.

Major tranquillisers are the most frequently prescribed forms of medication for challenging behaviour and mental health problems in people with intellectual disabilities. This is despite research showing that such drugs can often be used excessively and without consideration of their appropriateness, for example, some of those prescribed anti-psychotics would benefit more from anti-depressants. It has also been shown that polypharmacy (where an number of different psychiatric drugs are prescribed together) is more common in people with intellectual disabilities.

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There can be confusion about what causes people with intellectual disabilities to experience mental health problems and professionals can encounter difficulties in making an accurate diagnosis. Intellectual disability is generally the first identified disability and as such, it becomes the explanation for all behaviour.

Many people with intellectual disabilities cannot explain what they are experiencing to others because of limitations in communication. This can create obstacles in both assessing and treating mental illness. Personal and medical histories of people with intellectual disabilities are often fragmented and incomplete.

Symptoms of mental health problems, such as self-harming behaviour, may occur as a direct result of the person’s intellectual disability for example, as a result of damage to areas of the brain that controls certain forms of behaviour. However, many symptoms of mental distress such as self-harming behaviour can also occur in people with intellectual disabilities as a result of frustration, difficulty in self-expression, emotional pain or any other psychological problems and the same is true for other psychiatric diagnoses such as depression.

People with intellectual disabilities can experience mental health problems for the same reasons that the rest of us do, although it is far more difficult to distinguish between symptoms and find suitable therapeutic interventions for people with intellectual disabilities. As a result, mental health problems such as depression in people with intellectual disabilities tend to be under-diagnosed and many symptoms of mental illness can be ‘written off’ as challenging behaviour.

8.1 A RIGHTS BASED APPROACH

Services for people with an intellectual disability are currently moving towards a rights-based model, National Disability Authority, A Matter of Rights (2001)

Under the United Nations (UN), the International Covenant on Economic, Social and Cultural Rights (ICESCR, Article 12 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 spell out what is expected of signatory states in full compliance with ICESCR obligations. Principle 1 states:

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

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In relation to the provision of mental health services, 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'

8.2 LEGISLATION

The primary purpose of legislation related to mental health is to offer assessment and treatment to those suffering mental disorder that, due to their disorder and diminished capacity, are likely to cause harm to themselves or others and who are unable or unwilling to accept treatment. The Mental Health Act 2001 was introduced to bring Irish mental health law into conformity with the European Convention for the Protection of Human Rights and Fundamental Freedoms. It is not yet fully enacted. The Mental Health Act provides for:

- Changes to the existing rules on admission to psychiatric hospitals, in particular in the procedures for the involuntary detention of people for psychiatric care and treatment.
- An independent review procedure in the case of all involuntary detentions.
- The establishment of a Mental Health Commission, Mental Health Commission review tribunals and an Inspector of Mental Health Services.
- The monitoring and regulation of the standards of care and treatment in approved psychiatric centres.
- Changes in the legal rights of psychiatric patients.

The Act defines mental disorder as mental illness, severe dementia or significant intellectual disability where:

- Because of the illness, disability or dementia, there is a serious likelihood that the person may cause immediate and serious harm to himself/herself or to other people, or
- Because of the severity of the illness, disability or dementia, the judgement of the person concerned is so impaired that failure to admit the person to an approved centre would be likely to lead to a deterioration in his/her condition or would prevent the administration of appropriate treatment that could only be given by such an admission and the reception, detention and treatment of the person in an approved centre would be likely to materially benefit or alleviate his or her condition.

In the Act "significant intellectual disability" 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.
Under the Act, a person may only be admitted as an involuntary patient to an approved psychiatric centre (effectively a psychiatric hospital or psychiatric unit in a general hospital) if the person is suffering from a mental disorder. People with intellectual disability and a mental disorder are a vulnerable group. Present mental health legislation is only applicable in practice to a small number of individuals with intellectual disabilities. The vast majority are resident in generic intellectual disability centres or community accommodation (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). A number of these individuals may be receiving medication or other psychiatric treatment to which they have not had the capacity to consent. They are 'de facto' detained and are not subject to any formal independent monitoring.

8.3 PREVALENCE

8.3.1 Mental illness and intellectual disability

Epidemiological estimates of mental illness have shifted over time because of changes in the definitions and diagnosis of mental illness. The current UK prevalence estimate is about 25% i.e. every adult has a one in four chance of experiencing a period of mental ill health during their lifetime. The World Health Organisation (WHO) estimated that 50% of people with severe and profound intellectual disabilities would have a mental health problem at some time in their lives, as will 20 – 25% of those with mild & moderate learning disabilities (IASSID, 2000). The incidence of mental illness in the intellectual disabled population is commonly estimated as 25 to 30%, Menolascin (1989), Jacobson et al (1988). People with intellectual disabilities vary from those who have a mild degree of intellectual disability but are physically normal to those who have severe and multiple disabilities requiring specialist care.

There were 3,200 people registered on the South Eastern Health Board intellectual disability database in 2003. This number may be an underestimation of the true prevalence rate of people with intellectual disabilities as it is based on the numbers who are receiving services and who have consented to being placed on the database. Given the above numbers on the database and with a 25% estimated incidence of mental illness, there are approximately 800 people with intellectual disabilities currently in disability services in the South Eastern Health Board region, that require multi-disciplinary mental health services.

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40 British Medical Journal: ABC of Mental Health 1997
Regier DA, Narrow WE, Rae DS, et al. The de facto mental and addictive disorders service system. Epidemiologic Catchment Area prospective 1-year prevalence rates of disorders and services. Archives of General Psychiatry, 1993; 50 (2); 85 - 94

41 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 WHO


8.3.2 Mental Disorder and challenging behaviour

A proportion of people showing severe challenging behaviour will have a mental disorder or a mental illness, but not all will. Conversely, a proportion of people with a mental disorder or a mental illness will not show challenging behaviours.

Many behaviours that challenge appear to be functional adaptive responses to particular environments rather than the manifestations of any underlying mental disorder, however challenging behaviour may occur as a secondary feature of mental disorder among people with intellectual disabilities.

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

- Challenging behaviour may represent the atypical presentation of the core symptoms of a mental disorder in people with intellectual disabilities (e.g. self-injurious behaviours may represent obsessive compulsive disorders).
- Challenging behaviour may occur as a secondary feature of mental disorders (e.g. aggression may be linked with depression as a means of expression to those with poor verbal skills).
- Mental 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 behaviour will terminate these events. Hence episodes of depression becomes linked with increases in challenging behaviours).

8.4 SERVICE MODELS

Bouras et al (1995) describe four of the most common types of service to meet the needs of people with intellectual disabilities and mental illness:

1. Large specialist hospital-based comprehensive service provision including domiciliary, assessment, treatment and continuing care services for the whole range of people with intellectual disabilities. This model includes specialised in-patient psychiatric units for people with mental illness, behaviour problems and intellectual disabilities.

2. A community-based psychiatric service just for those who have an intellectual disability and a mental health problem, integrated mainly with the intellectual disability services. This model has the advantages of being within the community but risks being marginalised by both disability services and mental health services. The latter leads to difficulties in gaining access to in-patient psychiatric facilities. The result can be providing mainly an advisory service with limited clinical involvement.

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*Nick Bouras, Geraldine Holt and Shaun Gravestock, Community care for people with learning disabilities; Psychiatric Bulletin (1995), 19, 134-137*
3. A community-based specialised psychiatric service, integrated with mainstream psychiatric services. Services are provided in the community and the person lives in a community setting with both intellectual disabilities services input and input for the mainstream community mental health services in the person's own home / residential home when necessary. This model has been gaining acceptance as an appropriate service delivery system with two main outcomes. First, the client experiences less disruption and distress as the specialist input they require is usually provided at home. The second is that the model enables local services to develop their own skills in supporting and managing clients with complex needs. There are circumstances where residential services or families are unable to continue supporting a particular individual and a 'back-up' admission facility is then required.

4. Separate challenging behaviour services have been developed as part of disability services. Whether or not challenging behaviour arises for an underlying mental illness, psychiatric assessment is usually needed and input should also be provided by specialist psychiatric services.

8.5 CURRENT SERVICE PROVISION AND POLICY IN IRELAND

Current Mental Health Policy is set out in 'The Psychiatric Services – Planning for the Future (1984)'. This report omitted to include people with intellectual disabilities in the Needs of the Special Groups section. However, two recommendations were made:

'Mentally handicapped persons in psychiatric hospitals should be segregated from the mentally ill and provided with programmes of care and activity to meet their needs. The mental handicap service should take over responsibility for these persons when this has been achieved'.

'Disturbed mentally handicapped persons should be catered for within the mental handicap service'.

Unfortunately, no provision was made to provide mental health services for the 'disturbed mentally handicapped persons'.

The most recent national report on health service provision for people with intellectual disabilities, Needs and Abilities (1990) states that:

'Assessment teams from the services for intellectually disabled persons should carry out a detailed assessment of the condition and total circumstances of such persons who are in psychiatric hospitals' (11.2).

The report does not make provision for how these teams are linked to the mental health service. The report acknowledges that a specialist multi disciplinary team including a psychiatrist would be required to deal with disturbed behaviour.

The Needs and Abilities Report (1990) indicates that the Department of Health and Children policy is that persons with a mild intellectual disability not in contact with intellectual disability services should normally access generic mental health services. The expectation that mainstream mental health services could respond to the needs of people with mild learning disabilities has often proved unrealistic. Firstly, the complex behaviour problems of people with intellectual disabilities could not be managed by generic mental health services. Mainstream psychiatric services lack the expertise, training and skills necessary for the assessment and training for this group of people.

In 1997 the Department of Health produced a discussion document (Mulcahy Report) in relation to the mental health needs of persons with an intellectual disability. The framework for a mental health service in this report consists of an intellectual disability team in each community care area operating at primary health care level and a specialist mental health team operating at secondary level of health care. The specialist mental health team would:

‘Organise and provide treatment programmes, both home-based and in special units for those persons whose treatment is best provided within the mental handicap services. In addition they would liaise with the generic mental health service to facilitate treatment within those services for those whom it is appropriate. Health Boards should provide protocols so that access to these specialist services is clearly defined and understood.

This report also recommends that:

‘The approach to disturbed behaviour in persons with a mental handicap should be dictated by the gravity of the problem rather than an attempt to distinguish between mental health disorders and behaviour disorders’.

The Irish Division of the Royal College of Psychiatrists produced a report for Comhlaire na hOspideal in 1998, that includes mental health services provision for people with intellectual disabilities. This report in keeping with best practise, advocated that a consultant psychiatrist trained in this area is necessary and that mental health services for people with intellectual disabilities, should be catchment area based with appropriate in-patient mental health admission facilities.

In April (2000) the Report on the Establishment of Dual Diagnosis Service in the ERHA was produced. In the forward it noted that:

‘Services for people with mild mental handicap are now largely delivered in the mainstream areas...Individuals in this group who have serious mental health problems are disadvantaged. Their needs may not always be appreciated – thus they may not receive the most appropriate psychiatric interventions in either the generic or mental handicap services. The services for people with moderate, severe and profound mental handicap.....the need for specialised psychiatric treatment for individuals in this category has been identified but not appropriately addressed...’

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49 Irish Division of the Royal College of Psychiatrists (1998). The Future of Psychiatry in Ireland

50 Northern Area Health Board (2000) Report on The Establishment of a Dual Diagnosis Service in the Eastern Regional Health Authority
This report goes on to suggest similar proposals to those in the Mulcahy report that have yet to be funded for implementation.

Mental health services for people with intellectual disabilities are not mentioned in the new health strategy — Quality and Fairness: A Health System for You (2001)\(^5\).

The recent NDA Review of Access to Mental Health Services for People with Intellectual Disabilities\(^2\) (2003) states:

'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.'

In a recently published report (July 2004), prepared by the Strategy Sub-committee of the Faculty of Learning Disability Psychiatry of the Irish College of Psychiatrists\(^3\), at the request of the Department of Health and Children, it is recommended that consultant psychiatrist-led mental health teams for people with intellectual disabilities be established as a priority. Two consultant psychiatrists are required per 100,000 — one in adult psychiatry and one in child and adolescent psychiatry in accordance with the Irish College of Psychiatrists norms. It is also recommended that all catchment areas have access to an in-patient mental health treatment unit specifically for people with intellectual disabilities and psychiatric disorder.

Mental Health services for people with intellectual disabilities remain grossly under resourced and under developed in Ireland.

8.6 SUMMARY

- Mental health problems occur in the intellectual disability population at a much higher rate than in the normal population.
- The incidence of mental illness in the intellectual disabled population is estimated as 25 to 30%.
- Some people with intellectual disabilities and a mental illness will show challenging behaviour but not all will.
- Access to mental health services for people with intellectual disabilities is unclear. The voluntary bodies have no responsibility to provide a mental health service to people with intellectual disabilities.
- The right to care and mental health treatment for people with intellectual disabilities is not fully enshrined in law with clarification as to who has the responsibility to provide and deliver such care and treatment.
- There are a number of different service models to meet the needs of people with intellectual disabilities and mental illness. The service model gaining most acceptance is a dedicated/specialist community-based mental health service for people with intellectual disabilities that is integrated in the mainstream mental health service.


\(^{53}\) Irish College of Psychiatrists, Dublin: Proposed model for the delivery of a mental health service to people with intellectual disability (July 2004)
8.7 **SEHB SERVICE PROVISION REVIEW**

As part of the Challenging Behaviour project, a sub committee (Appendix VI) was established to consider the needs of people with intellectual disabilities and challenging behaviour who have a co-occurring mental disorder or illness (dual diagnosis).

The purpose of this group was to:

1. Review the current / future service needs for people with intellectual disabilities and a co-occurring mental disorder or mental illness (dual diagnosis) and challenging behaviour across the region.

2. Review the resources and structures required to deliver an appropriate service to meet the identified/anticipated need.

3. Specify service developments in the areas of assessment, prevention and crisis intervention, having regard to best practice in meeting the needs of those with intellectual disabilities, challenging behaviour and a co-occurring mental disorder or illness.

**The dual diagnosis sub-committee raised the following issues:**

Inequitable and non-availability of services

1) The care pathways for people with intellectual disabilities and mental illness (dual diagnosis) is very variable and depends on the geographical area a person is living in. Mental health services for people with intellectual disabilities living in the community with family carers or in their own accommodation is largely non-existent in some areas.

2) There are an inadequate number of consultant psychiatrists and mental health teams for people with an intellectual disability. They are not assigned to specific geographical catchment areas or sectors. This results in a fragmented service.

3) There is no clear pathway to support people with intellectual disabilities and their carers during an acute psychiatric episode.

4) There is no clear policy in relation to the admission of people with intellectual disabilities into psychiatric hospitals. In some areas, it has been the practice not to admit people with moderate/severe intellectual disabilities into psychiatric hospitals for assessment and treatment. There is no alternative in-patient treatment service in place. The consultant psychiatrists in learning disability do not have access to acute treatment beds. In other areas, local informal arrangements do exist to provide emergency assessment and treatment.
5) There are no designated psychiatric hospital beds for people with intellectual disabilities. The challenges for staff not familiar with working with people with intellectual disabilities can be compounded when patients with intellectual disabilities are in an unfamiliar environment and feel frightened, confused and unable to communicate effectively. This can cause anxiety in staff and other patients, especially so if the person is behaving in an agitated manner, or displaying challenging behaviour. Beds are needed in an appropriate setting to provide acute treatment for people with intellectual disabilities.

**No multidisciplinary mental health service for people with intellectual disabilities**

6) The generic mental health service have indicated that they do not have the appropriate skills, expertise and treatment facilities to provide for the complex needs of people with intellectual disabilities, mental illness and challenging behaviour.

7) There are no dedicated multi-disciplinary mental health teams to provide an outreach mental health service for people with an intellectual disability.

**After hours / crisis response**

8) In the South Eastern Health Board, no after hour’s case management coverage or crisis response exists within the disability services. Disability service users or their service providers have no resources available to resolve crisis outside the hours of weekly workdays. Situations that could be resolved by community intervention often go unchecked. When a crisis occurs, there is no team with the skills to manage the crisis in the community. This has often resulted in the break down of community placements, and the exclusion and further marginalisation of people with an intellectual disability.

9) Care givers who are frightened, alienated or angered by a person’s behaviour may call on G.P’s who refer to mental health personnel to intervene and request hospitalisation. With no alternatives to hospitalisation, people with intellectual disabilities may be admitted, sometimes involuntarily.

**Prolonged Hospitalisation**

10) When the person has been admitted to hospital from disability services, there may be a reluctance by disability service providers to accept this person back into their service as they often do not have expertise in mental health or access to mental health services in the community. People with intellectual disabilities often remain inappropriately placed in psychiatric hospitals.
11) Some patients with intellectual disabilities and mental illness have difficulty becoming re-established in the community because they require high levels of staff attention due to destructive behaviour towards themselves or others. Residential facilities can be reluctant to accept patients who have histories of assaulting staff or other residents. Patients often remain in hospital beyond resolution of their psychiatric symptoms, awaiting community residential placement through disability service providers.

**Community Placement Difficulties**

12) The admissions criteria applied by voluntary bodies vary substantially. There is a difficulty in some areas of finding appropriate intellectual disability services for persons that may present with challenging behaviours or mental health needs. Significant funds have been expended in the South Eastern Health Board in providing placements outside the region.

**No direct payments**

13) Historically, services are generally block funded. This practice results in money not being released when individuals with challenging behaviour are discharged from service providers.

**8.8 RECOMMENDATIONS**

8.8.1 There should be specific funding towards mental health services for people with intellectual disabilities.

8.8.2 Specialist multi-disciplinary community-based mental health teams dedicated to supporting people with dual diagnosis should be developed. The focus of the service should be on supporting people with a dual diagnosis to live in an appropriate setting within the community.

8.8.3 Geographical catchment areas should be established for the intellectual disability mental health service in order to provide an effective localised service.

8.8.4 Consultant Psychiatrists trained in the psychiatry of learning disability with multidisciplinary teams should be appointed to provide a mental health service for people with intellectual disabilities. The sub committee of the faculty of Learning Disability Psychiatry of the Irish College of Psychiatrists (2004) recommends that 2 Consultant Psychiatrists with multidisciplinary teams are required per 100,000 population – one team for adults with intellectual disabilities and one team for children and adolescents with intellectual disabilities.
8.8.5 The other disciplines of the team should include psychologists, community mental health nurses, social workers, occupational therapists, speech and language therapists, with clerical and administrative support.

8.8.6 The team should provide:
- Multidisciplinary assessment and community-based treatment programmes, including pharmacotherapy, behavioural intervention and psychotherapy.
- Outreach consultation
- Acute care with facilities for hospital admission
- Cross training in local disability services and generic mental health services
- An after hours crisis intervention service
- Treatment plans and comprehensive aftercare planning.

8.8.7 The outreach service should provide support to service users and their families and organisations providing services in the community. The outreach service should include staff training, medication reviews with ongoing monitoring and re-assessment in the person's natural environment.

8.8.8 Appropriate in-patient assessment and acute treatment beds should be provided for people with intellectual disabilities who are mentally ill. The subcommittee of the faculty of Learning Disability Psychiatry of the Irish College of Psychiatrists (2004) recommends that 5 in-patient assessment and treatment beds are required per 100,000 population for people with intellectual disabilities and a mental disorder who present major risks to themselves and others. These beds might be located alongside general psychiatric facilities and while they may have some autonomy they could share resources such as staffing and training. They should provide short-term assessment, and treatment to stabilise patients pending their transfer back to the referring agency or onward toward other services.

8.8.9 Robust arrangements and explicit protocols should be in place for admission and discharge planning and liaison with local services. The goal should be for these individuals to return and live in their communities, with support packages that adequately meet their particular needs.

8.8.10 A 24 hour on-call emergency systems and an after hours crisis intervention service should be put in place that can respond rapidly to emergency situations, usually severe physical aggression or severe self-injury, with medical assistance if required. Members of the team should be on-call to support people in crisis or to refer for in-patient treatment if required.

Irish College of Psychiatrists, Dublin: Proposed model for the delivery of a mental health service to people with an intellectual disability. Occasional paper OPS8 July, 2004
8.8.11 A clear policy should be provided in relation to the admission of people with intellectual disabilities into psychiatric hospitals in the interim pending the development of specialist in-patient assessment and treatment units for people with intellectual disabilities.

8.8.12 There should be consultation and collaborative planning between disability and mental health services. A system should be developed to provide opportunities for collaboration among health care professionals from both disability and mental health systems to support people with a dual diagnosis.

8.8.13 People with intellectual disabilities and mental illness are should have a comprehensive, co-ordinated plan of treatment and supports. A dual diagnosis and planning forum should be established in each geographical catchment area.
CHAPTER 9

SERVICE DEVELOPMENT PRIORITIES

9.0 PRIORITIES

The priority areas that need to be developed to provide a service to support people with intellectual disabilities and challenging behaviours are:

Disability Services
1. To develop Psychologist-led specialist challenging behaviour support service for children and adults with intellectual disabilities in each community care area.
2. To continue to develop high support residential places and day services for people with intellectual disabilities, challenging behaviour and additional high support needs.
3. To increase the number of high support respite beds for people with intellectual disabilities and challenging behaviour.
4. To continue to allocate resources to staff training in the assessment, understanding and management of challenging behaviour.

Mental Health Services
5. To develop specialist consultant-led multidisciplinary mental health teams for people with intellectual disabilities in each catchment area.
6. To provide in-patient assessment and treatment beds for people with intellectual disabilities at risk of serious harm.

9.1 SPECIALIST CHALLENGING BEHAVIOUR SUPPORT SERVICE

A psychologist-led challenging behaviour support service dedicated to working with children and adults with disabilities and challenging behaviours needs to be established in each community care area. This specialist service would support children and adults whose behaviours are:

- Physically harmful to themselves or others,
- Put the person's current placement at risk or place severe strains on existing service provision,
- Cause significant stress to those who live and work with them and impairs their own quality of life to an unreasonable degree,
- Significantly interfere with the learning of new skills or exclude the person from ordinary community facilities.
9.1.1 The function of the Challenging Behaviour support service

Challenging Behaviour specialists and behaviour support workers will work with the multi-disciplinary team in disability services to provide:

**Behaviour assessment and intervention**

The team will provide effective intervention plans to support people with challenging behaviour to participate in the community and to develop their potential. This will require a detailed assessment of the person and their environment and will include identifying any medical, social, environmental or physical factors that may be contributing to challenging behaviour, a functional assessment of the challenging behaviour, an assessment of the person's social and communication skills. It will involve developing ways of changing the environmental conditions that lead to the challenging behaviours and may involve changing the person's repertoire to include more adaptive social behaviours.

**Communication training and Sensory Integration Programmes**

Many individuals with challenging behaviour have very limited communication skills. Challenging behaviour often serves a communication function. The speech and language therapist will assist families and staff on developing communication skills and using augmentative communication systems.

When challenging behaviour occurs careful documentation and analysis of these behaviours is needed to determine if and how they relate to the individual's ability to process and respond to sensory input. If there is dysfunction in how an individual integrates sensory input, the behaviour that results may be inconsistent with what is needed to interact appropriately with the environment. An intervention programme to address sensory integration dysfunction should be provided by an occupational therapist trained and experienced in sensory integration theory and practise.
Training
Training and technical assistance would be provided to families and direct care workers in the functional analysis of the challenging behaviours and to develop behaviour support plans with effective interventions to address the challenging behaviour. The behaviour support plan should include positive programming, i.e. environmental accommodations to meet the person's needs, the teaching of alternative appropriate social behaviours and communication skills and may include a programme to address sensory integration dysfunction if required. Experiencing and practising appropriate social behaviours and developing daily living and communication skills is an important part of the treatment approach for each person with challenging behaviours.

Mental health liaison
The team will liaise with mental health teams in the admissions and discharge and on-going management of people with a dual diagnosis and challenging behaviour.

External placement review/needs assessment
The team will assist with an annual review and needs assessment of the people placed outside the region because of challenging behaviour to see if their circumstances have changed, if they can be brought back, and what services need to be put in place to allow this to happen.

Crisis management and intensive behaviour support
Challenging Behaviour Specialists will provide support to families and service providers in times of crises who are experiencing difficulties with the safe management of challenging behaviour. The team can deploy intensive behaviour support workers with support the family or service providers where there is severe challenging behaviour.

Developing social and recreational activities
Behaviour support workers will develop social and recreational activities in the evenings, weekends and during holiday periods for people with intellectual disabilities and challenging behaviours (e.g. Saturday morning bowling/social club). This would enable families to have a short break while the person is attending the club.

9.1.2 Referral to the Challenging Behaviour Support Team
Children/adults with disabilities and challenging behaviour are to be referred for challenging behaviour support services by disability service providers or members of the disability community care team through the Senior Psychologist for children/adults in Disability Services. Priority will be determined by the impact the challenging behaviour has on the person’s quality of life and the extent and severity of the challenging behaviour.

9.1.3 Resources required:
The challenging behaviour support service should be part of the existing community care disability services and be managed by the Senior Psychologist in Disability services for children/adults. Some areas already have some of these posts in place and therefore the overall cost of the service may be less.
### Challenging Behaviour Support Service Staffing Requirements

<table>
<thead>
<tr>
<th>Staff Position</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Psychologist in Community Care Disability Services</td>
<td></td>
</tr>
<tr>
<td>Challenging Behaviour Specialist/Basic Grade Psychologist x 2 (1 for children and 1 for adults)</td>
<td></td>
</tr>
<tr>
<td>Intensive Behaviour Support Worker (child care leader/ social care leader) x 4 (2 for children and 2 for adults)</td>
<td></td>
</tr>
<tr>
<td>Speech and language therapist x 2 (1 for children and 1 for adults)</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist x 2</td>
<td></td>
</tr>
<tr>
<td>Clerical support/administrator</td>
<td></td>
</tr>
<tr>
<td><strong>Total Pay (includes pension, PRSI and locum costs)</strong></td>
<td>€775.377</td>
</tr>
<tr>
<td><strong>Non Pay (@ 10%, accommodation, equipment etc.)</strong></td>
<td>€77.500</td>
</tr>
<tr>
<td><strong>Initial set up costs</strong></td>
<td>€85.000</td>
</tr>
<tr>
<td><strong>TOTAL COSTS</strong></td>
<td>€937.877</td>
</tr>
</tbody>
</table>

#### 9.2 HIGH SUPPORT HOUSING

It is envisaged that between 24 – 63 high support residential placements in the community per 100,000 of the general population, will be required for people with intellectual disabilities and severe challenging behaviour. People with challenging behaviour will require high levels of staffing and support to enable each person to develop their potential and live as fully participating members of the community. It is critical that staff have the skills and training, and a consistent approach in the management of challenging behaviour and that they work together as a team to support the person with challenging behaviour. Mental health teams and challenging behaviour support teams should provide clinical support to the residential services in the community.

Access to day services: People with challenging behaviour and intellectual disabilities living in the community should have opportunities to participate in meaningful activities during the day, which may include sheltered work, supported employment, day activities and opportunities to engage in a range activities in the community. High levels of staffing will be required to support people in day services in the community.
### Costs:
Separate service proposals with costs for high support residential services and day services need to be developed in each community care area as required.

**Estimated Pay Costs:**
The estimated pay costs for nursing and non-nursing staff to support a high support residential house for 3-4 adults with challenging behaviour is in the region of **€700,000**.

**Estimated Non-pay costs** are in the region of **€140,000**.

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#### 9.3 RESPITE BEDS
Respite beds will be needed to support families and carers of individuals with intellectual disabilities and challenging behaviours.
Separate service proposals are currently being developed to expand the respite service.

#### 9.4 STAFF TRAINING AND DEVELOPMENT
Health and social care staff in disability services need knowledge, training and confidence in managing challenging behaviour. It is critical that resources continue to be allocated to empower frontline staff to support people with challenging behaviour. A staff training and development budget will be required for:

- **Behavioural Assessment and Intervention Training**
  Training in behavioural assessment and multi-element behavioural support should be provided to frontline and resource staff to promote the use of effective, non-aversive methods that work with individuals who have challenging behaviours so that they can enjoy community participation with dignity and respect. It is envisaged that the challenging behaviour support service will play a critical role in training and supporting frontline staff in the use of positive behavioural interventions to support people with challenging behaviour.

The Regional Disability Co-ordinator initiated Training in Behaviour Analysis & Therapy with University College Cork to provide the Certificate in Behaviour Analysis and Therapy Course in Waterford. The course is open to nurses, childcare workers, direct care staff, psychologists and other professions working in a variety of settings within learning disability and mental health contexts.

- **Training in Positive Approaches to challenging behaviour**
Frontline staff should continue to be supported to increase their understanding of how challenging behaviours develop in individuals with intellectual disabilities and how life experiences and the environment play a key role in the person’s behaviour. Frontline staff should be encouraged to use positive approaches and promote a healing environment to support people with challenging behaviour. Training should continue to be provided to families, direct care staff, service managers, and clinical support staff in positive approaches to support people with challenging behaviour.
• **Crisis Management and the appropriate use of Physical Intervention Training**

Training in reactive strategies to manage crisis, including the appropriate use of physical intervention to manage aggressive behaviour, should be provided where there is a need for staff members to physically intervene in order to manage physical aggression in a safe way. Service providers should allocate resources to training in this area.

• **Challenging Behaviour Support Network**

Local challenging behaviour support networks have been established in local community care areas and have offered peer review services to staff persons who are struggling to figure out how to best support someone who has been challenging them. The challenging behaviour support network group is a group of peers who have been struggling perhaps with similar problems with a range of experiences, lessons learned and successes. The challenging behaviour support network should be formalised, facilitated and encouraged by management. This requires coordination and administrative support at local and regional level. In the long-term, it is envisaged that the challenging behaviour specialists will assist with the coordination of the challenging behaviour support networks.

| Training Budget Required: €40,000 per Community Care area |

9.5 **SPECIALIST MENTAL HEALTH TEAM FOR PEOPLE WITH INTELLECTUAL DISABILITIES**

The model proposed is to develop a community-based specialised mental health service for people with disabilities integrated with general mental health services. Services are provided in the community and the person lives in a community setting with both intellectual disabilities services input and input from the mental health services in the person's own home or day service when necessary. The model enables local services to develop their own skills in supporting and managing clients with complex needs. A consultant-led mental health team specialising in people with dual diagnosis needs to be established in each community care area.
9.5.1 The Specialist Mental Health Service

**Fig. 8: The specialist mental health service**

A specialist mental health team will provide the following:

**Multidisciplinary assessment, diagnosis and treatment**
The treatment will include pharmacotherapy, behavioural interventions and psychotherapy, which may include individual, group and/or family therapy.

**Outreach consultation.**
The outreach service should provide support to service users and their families and organisations providing services in the community. Through outreach to homes, hostels, day activity centres and sheltered workshops, clients should be seen at the sites where they live and work. Advice should be provided to staff on the spot so that treatment procedures can be implemented more successfully. The outreach service should include staff training, medication reviews and ongoing monitoring and re-assessment in the person's natural environment.

**Cross system training, planning and coordination**
Cross system training, planning and coordination will be provided between local disability services and generic mental health services. People with intellectual disabilities and mental illness are entitled to a comprehensive, co-ordinated plan of treatment and supports. A dual diagnosis and planning forum should be established in each geographical catchment area where staff from both mental health and disability services meet to:

- Plan development of services to meet the mental health needs of people with intellectual disabilities.
- Establish, oversee and support the implementation of cross systems policies and procedures.
- Avert unnecessary hospitalisation.
- Plan for admission to/discharge from acute services.
• Ensure a comprehensive assessment of the individual and their mental health needs.
• Facilitate cross system planning and assist in problem solving.
• Develop collaborative individualised treatment/support plans.
• Promote flexibility in use of existing funding to provide comprehensive, coordinated plan of supports.
• Promote and sponsor cross systems training.
• Ensure availability of appropriate crisis intervention.

An after hours crisis intervention service
24 hour on call emergency systems should be put in place that can respond rapidly to emergency situations, usually severe physical aggression or severe self-injury, with medical assistance if required.

9.5.2 A coordinated model of care
Referrals to the disability mental health team can be made through the GP, a health professional working in disability services or the generic mental health team. If the person with dual diagnosis presents with challenging behaviour, the Challenging Behaviour Specialists and the community intellectual disability mental health team will work together to provide a comprehensive assessment and treatment plan. Admissions and discharges to and from the acute care unit are planned for at the dual diagnosis forum meetings.

Fig. 9. A model of coordinated care
9.5.3 Mental health team composition
The teams should be catchment area based. There should be one specialist mental health team to work with adults with dual diagnosis per 100,000 of the general population, that should include the following:

<table>
<thead>
<tr>
<th>Mental Health Team for adults with intellectual disabilities staffing requirements</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant Psychiatrist in Learning Disability</td>
<td></td>
</tr>
<tr>
<td>1 Senior Clinical Psychologist</td>
<td></td>
</tr>
<tr>
<td>1 Basic Grade Psychologist</td>
<td></td>
</tr>
<tr>
<td>2 Community Mental Health Nurses</td>
<td></td>
</tr>
<tr>
<td>2 Social Workers</td>
<td></td>
</tr>
<tr>
<td>2 Non-consultant Hospital Doctor</td>
<td></td>
</tr>
<tr>
<td>1 Occupational Therapist</td>
<td></td>
</tr>
<tr>
<td>1 speech and language therapist</td>
<td></td>
</tr>
<tr>
<td>2 administration officers</td>
<td></td>
</tr>
<tr>
<td><strong>Total Pay (includes pension, PRSI and locum costs)</strong></td>
<td>€1383.792</td>
</tr>
<tr>
<td><strong>Non Pay (@ 10%)</strong></td>
<td>€383.000</td>
</tr>
<tr>
<td><strong>Initial set up costs</strong></td>
<td>€50.000</td>
</tr>
<tr>
<td><strong>TOTAL COSTS</strong></td>
<td>€1.6m</td>
</tr>
</tbody>
</table>

health team to work with adults with dual diagnosis per 100,000 of the general population, that should include the following:

9.6 INPATIENT ASSESSMENT AND TREATMENT

Some form of acute short stay assessment and treatment facility is required if there is a serious likelihood that the person may cause immediate and serious harm to himself/herself or to other people. The in-patient assessment and treatment beds can offer short-term assessment and treatment and a place of safety with appropriate care for people with intellectual disabilities. They can be approved under mental health legislation as places where staff and service users can be provided with protection under legislation. All treatment centres must be designated units under the Mental Health Act, 2001. The service should be delivered as close as possible to the user’s primary service. 5 treatment beds are needed per 100,000 populations for people with intellectual disabilities at risk of serious harm, as per the Irish College of Psychiatrists recommendations (2004).

A separate cost analysis is required for this service, depending on the location of the unit. The specialist mental health team should have responsibility to the unit. Additional mental health nursing staff will be required to staff the unit.
9.6.1 Referrals to the in-patient assessment and treatment unit
The specialist community-based mental health teams in the area should manage referrals to the unit. People should only be admitted for acute treatment if the specialist mental health team is satisfied that they cannot be given appropriate care in their own service. Strict admissions and discharge policies will need to be developed with the specialist mental health team for the acute unit.

9.6.2 After-care planning
The mental health team and disability service providers should work together with the service user and key people in the person’s life to provide comprehensive after care planning.

9.7: IMPLEMENTATION AND ACTION PLANNING

In order to support the implementation of the recommendations contained in the report, the South Eastern Health Board will need to start building capacity and expertise to that the specialisms involved in the delivery of services to people with challenging behaviour can evolve and develop.

Strategies for action:

- Local implementation groups from disability and mental health services need to be established in each community care area so that the recommendations outlined in the report can be analysed with respect to the priorities and gaps in operational services that exist at local level.

- Each local area will need to review the resources currently available to the management and delivery of services to people with challenging behaviour and to identify the short, medium and long-term service priorities in the context of the report.

- The local implementation groups need to set out interim arrangements to address the recommendations of the report and to develop action plans and tasks with a time frame for implementation to address the recommendations of the report.

- A regional post in the area of developing a strategic response to challenging behaviour needs to be established so that the project is sustained past the point of recommendation and through to the development and implementation of action plans at local level.
APPENDIX I:

Challenging Behaviour Questionnaire

Instructions:
A separate questionnaire is to be completed for each setting within the organisation (e.g. 1 per house, 1 per day centre, etc.). If a person lives in a group home and attends a day centre, they may be counted for twice, if they present with challenging behaviour in both settings. This survey is to determine the extent of challenging behaviour and management difficulties within each setting.

1. Write down the name and address of the service in which the questionnaire was completed. (e.g.: Brothers of Charity, Park side, House 1, Belmont Park, Waterford)

   Name of Organisation
   Address
   County

2. Tick the service/setting in which this questionnaire was completed
   (only one box is to be ticked per questionnaire)

   Psychiatric Hospital  Residential Community Home  Residential Campus Home
   Preschool  Day Activation / cntr for Children  Day Activation / cntr for Adult
   School  Sheltered work  Rehabilitative Training Cntr  Supported employment
   Other

3. How many people are living in/attending the service in which this questionnaire was completed?

4. According to the criteria below, how many of these people are presenting with challenging behaviours?
   (if none pls skip to Q15)

A person is to be identified as having challenging behaviour if their behaviour meets one or more of the following:

- The behaviour causes repeated injury (bruising, bleeding, tissue damage) / repeated risk of injury to self or others or serious property damage
- The behaviour seriously limits the use of or results in the person being denied access to ordinary community facilities
- The behaviour causes significant management problems (Intervention requires more than 1 member of staff for control, behaviour causes daily disruption of at least an hour disruption)

(If a person does not present with challenging behaviours in your setting (e.g. school) but you are aware that his/her behaviour is challenging in another setting, (e.g. home) do not include, as a questionnaire has been sent to each setting)
5. Outline what you think are the key factors/main reasons for these challenging behaviours?

6. How many of the people identified in Question 4 cause significant management problems in your setting? (E.g. behaviour requires more than one member of staff for control, causes daily disruption to normal activities)

6a. Please outline what you think are the key factors/reasons these behaviours are difficult to manage within the existing resources

7. How many of the people identified in Question 4 do not cause significant management problems in your setting? (E.g. behaviour is managed effectively with existing resources with minimal disruption to activities)

7a. Please outline what you think are the key factors/reasons these behaviours are effectively managed?

8. How many of those people identified in Question 4 are within the age groups below (Example)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>2–6 years</td>
<td>0</td>
</tr>
<tr>
<td>7–18 years</td>
<td>7</td>
</tr>
<tr>
<td>19–65 years</td>
<td>0</td>
</tr>
<tr>
<td>Over 65</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
</tr>
</tbody>
</table>

9. How many of the people identified in Question 4 have either a mild, moderate, severe, or profound level of intellectual disability? If you do not know, please record the number of people whom their level of intellectual disability is not known in the 'don't know section'.

**Level of Intellectual Disability**

<table>
<thead>
<tr>
<th>Level</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>1</td>
</tr>
<tr>
<td>Moderate</td>
<td>6</td>
</tr>
<tr>
<td>Severe</td>
<td>0</td>
</tr>
<tr>
<td>Profound</td>
<td>0</td>
</tr>
<tr>
<td>Don't Know</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td></td>
</tr>
<tr>
<td>Profound</td>
<td></td>
</tr>
<tr>
<td>Don't Know</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
</tr>
</tbody>
</table>
10. How many of these people identified in Question 4 have current behaviour management programmes? (i.e. behaviour intervention plans to manage the person’s challenging behaviour that has been developed by a Psychologist/Psychiatrist/Behaviour Therapist in conjunction with the staff or family within the last 3 months).

11. How many of these people identified in Question 4 with challenging behaviours are on medication for their challenging behaviour?

12. How many of these people identified in Question 4 with challenging behaviour have had an Assessment or review by a Psychologist in the last 3 months?

13. How many of these people identified in Question 4 with challenging behaviour have had an Assessment or a review by a Psychiatrist in the last 3 months?

14. How many of these people identified in Question 4 have had other specialist interventions to address their challenging behaviour (e.g. sensory integration therapy, communication training). Please specify the type of intervention used.

   Type of intervention

15. How many people in your service have sexualised assaultive behaviour that poses a danger to others?

16. How many incident reports of physical injury to others have been made in the last 4 weeks?

17. Do you feel that your service has the capacity to provide a service for additional people with Challenging Behaviours?

   Yes    No

Name: ___________________________________________ Contact Number: ___________________________________________

Thank-you for taking the time to complete this questionnaire.
APPENDIX II – LIST OF ORGANISATIONS SURVEYED
The names of the organisations that returned questionnaires and the type of service provided in each Community Care area in the SEHB region.

<table>
<thead>
<tr>
<th>TYPE OF SERVICE</th>
<th>KILKENNY/ CARLOW</th>
<th>WATERFORD</th>
<th>WEXFORD</th>
<th>SOUTH TIPPERARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Pre-schools</td>
<td>Enable Ireland/ O Neil Centre</td>
<td>Sesame pre-school</td>
<td>Ard Aobhinn</td>
<td>Brothers of Charity (Noonan centre Lus na Greine)</td>
</tr>
<tr>
<td>Day activation Centres for children</td>
<td>Holy Angels Day centre</td>
<td></td>
<td>Ard Aobhinn St. John of God House</td>
<td></td>
</tr>
<tr>
<td>Day activation Centres for adults</td>
<td>Delta Centre Ltd. L’Arch – day service Rehab Care SOS</td>
<td>Brothers of Charity (4 centres) Spring Garden Srs. of Bon Sauveur</td>
<td>Ard Aobhinn WCW- (St. Anthony’s unit) Kilcannon Ind. St. Aidans</td>
<td>Brothers of Charity (Dun Aobhinn) Damien House Acquired Brain Injury</td>
</tr>
<tr>
<td>Sheltered work settings</td>
<td>Brothers of Charity (4 centres) Rehab care</td>
<td>WCW-Enniscorthy Windmill T.Unit. Rehab Care</td>
<td></td>
<td>Moorehaven Centre Rehab Care</td>
</tr>
<tr>
<td>Rehabilitative Training centres</td>
<td>Beam services NTDI Carlow NTDI Kilkenny</td>
<td>Brothers of Charity (2 centres) NTDI Waterford</td>
<td>Kilcannon Industries NTDI Wexford St. Aidans</td>
<td>Brothers of Charity (Nagle Centre) NTDI Clonmel</td>
</tr>
<tr>
<td>Supported employment services</td>
<td>The Watergarden (Camphill)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential houses in the community</td>
<td>Alacantra House Caomhnu Holy Family Centre KASHMA Kingsriver Comm. L’Arch (3 houses) SOS (12 houses) Cheshire home</td>
<td>Brothers of Charity (19 houses)</td>
<td>An Breachadh Nua CWCW- Bellefield CWCW – New Ross (2 houses) SEHB Res. Services (3 houses) St. Aidan’s centre</td>
<td>Brothers of Charity (7 houses) Damien house St. Bernards group home Transitional living unit</td>
</tr>
<tr>
<td>Houses on campus/ grounds of services</td>
<td>St. Patricks (10 houses)</td>
<td>Brothers of Charity (4 houses) Srs. Of Bon Sauveur (5 houses)</td>
<td>CWCW – Bellefield</td>
<td></td>
</tr>
<tr>
<td>Life sharing community</td>
<td>Camphill (5 houses)</td>
<td>Camphill - Duffcarrig</td>
<td>Camphill (9 houses)</td>
<td></td>
</tr>
<tr>
<td>Psychiatric hospital</td>
<td>St Otterans</td>
<td>St Senans (2 wards)</td>
<td>St. Lukes (3 wards)</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX III:

Members of subgroup to identify needs of those with challenging behaviour placed outside the region or with no service because of challenging behaviour

JULIA KELLY
Chairperson, Regional Service Manager, Brothers of Charity

SHEILA KISSANE
Challenging Behaviour Project Leader, South Eastern Health Board

JACINTHA CULLITON
Area Coordinator Disability Services, South Eastern Health Board

MARY O’HANLON
Hospital Manager, St. Canice’s Hospital, Kilkenny

MARGARET BROWNE
Area Coordinator Disability Services, South Eastern Health Board

ANN KENNELLY
Regional Coordinator Disability Services, South Eastern Health Board
APPENDIX IV

QUESTIONNAIRE FOR PEOPLE PLACED OUTSIDE THE REGION OR WITH NO SERVICE

This questionnaire should be completed in respect of:
People placed and funded by Disability Services outside the region because of challenging behaviour

People who currently have no service or who are at risk of imminent discharge from a service because of challenging behaviour

Name _____________________________ Pin no. ________________________________

Date of Birth ______________________ Date of Admission to current placement (if applicable) __________________

Degree of I.D. __________________________ Date of discharge from last placement (if applicable) __________________

Additional Associated Difficulties e.g. Autism

__________________________________________________________________________

__________________________________________________________________________

Additional Medical Problems (e.g. epilepsy)

__________________________________________________________________________

__________________________________________________________________________

Nature of Challenging Behaviour (describe in detail)

__________________________________________________________________________

__________________________________________________________________________

Service History prior to current placement

__________________________________________________________________________

__________________________________________________________________________

Current Placement

__________________________________________________________________________
Reason for Current Placement

If placement is outside the region was there a placement option in the region
  Yes ☐ No ☐
If yes please state reasons why not availed of

Cost of placement (per annum)

Was needs assessment done
  Yes ☐ No ☐
If yes by whom _____________________________ When ______________________
If yes what was recommended

Was the current placement the subject of Court Proceedings
  Yes ☐ No ☐
If yes please provide details

Has the person access to Psychology / Psychiatry

If yes how are these provided

Reason for Imminent Discharge from current placement (if applicable)
Any other relevant information e.g. indications of appropriate placement etc.

Form Completed by: ____________________________  Date ____________________

Please provide care plan if available or summary of most recent review
Policies on restrictive physical interventions are expected to include the following:

- Statements to explain how service users, their families and advocates participate in the planning, monitoring and reviewing the use of restrictive physical intervention.

- Strategies for preventing the occurrence of behaviours that precipitate the use of physical intervention.

- Strategies for ‘de-escalation’ or ‘diffusion’ that can avert the need for physical intervention.

- Procedures for post incident and support and de-briefing for staff, service users and their families.

- The distinction between planned physical interventions which are pre-arranged methods based upon risk assessment and recorded in care plans and emergency or unplanned use of force (which cannot be reasonably be anticipated).

- The first aid procedures to be employed and those responsible for implementation in the event of an injury or physical distress arising as a result of a physical intervention.

- A clear description of unacceptable practices that might expose service users or staff to foreseeable risk of injury or psychological distress.

- The concept of ‘reasonable force’ with reference to:
  a) The seriousness of the incident
  b) The relative risks arising from using physical intervention compared with other strategies
  c) The age, cultural background, gender, stature and medical history of the service user concerned
  d) The application of gradually increasing or decreasing levels of force in response to the person’s behaviour

- The identification of situations where breakaway or disengagement strategies, which involve minimal use of discomfort, may be sanctioned as the least intrusive method that is consistent with the safety of staff and service users.

Agency policies on restrictive physical interventions should be explained to service users, including those who might be exposed to physical interventions. All those who experience physical interventions should be offered the opportunity to discuss the way in which staff has responded to their behaviour and to express their concerns and preferences about future management.
Recording of Physical intervention

The use of a restrictive physical intervention, whether planned or unplanned (emergency) should always be recorded within 24 hours of the incident by the person's involved in the incident.

The written record should indicate:

- The names of staff and service users involved;
- The reason for using a physical strategy (rather than another strategy);
- The type of physical intervention employed;
- The date and duration of the physical intervention;
- Whether the service user or anyone else experienced injury or distress and, if they did, what action was taken;
- The views of the service users involved in the incident should also be recorded wherever possible.
APPENDIX VI

Members of the Dual Diagnosis Working Group

MS. ANN KENNELLY
Regional Disability Coordinator, Chairperson

DR. MIRIAM CUSSENS
Consultant Psychiatrist, Adult Mental Health, South Tipperary

DR. GEORGINA O BRIEN
Consultant Psychiatrist, Brothers of Charity, Waterford

MS. LIZ KINSELLA
Disability Coordinator, Wexford

DR. NAN FERRAI
Consultant Psychiatrist, Brothers of Charity, Waterford

DR. NICK BLITZ
GP, Camphill Communities

MS. MARY O HANLON
Hospital Manager, St. Canice's Hospital, Kilkenny

MR. JOE MEANEY
Case Manager for Rehabilitative Training, St. Canice's Hospital, Kilkenny

MS. SHEILA KISSANE
Senior Psychologist, Project Leader, Challenging Behaviour

MS. STEPHANIE LYNCH
SEHB Head Office, Kilkenny

DR. JOAN DALY
Clinical Director, Wexford Mental Health
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<td>23</td>
</tr>
<tr>
<td>3</td>
<td>The number of people with an intellectual disability placed in service category in the SEHB region</td>
<td>24</td>
</tr>
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<td>The percentage of people with an intellectual disability and challenging behaviour in each service category in the SEHB region</td>
<td>25</td>
</tr>
<tr>
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<td>The number of people with intellectual disabilities in each service category in each of the SEHB community care areas</td>
<td>26</td>
</tr>
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<td>6</td>
<td>The numbers of people with an intellectual disability who have challenging behaviour in each service category in each of the community care areas</td>
<td>27</td>
</tr>
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<td>The number of incident reports of physical injury to others in a four-week period in each service category in each community care area</td>
<td>29</td>
</tr>
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<td>The number of incidents of physical injury reported over a four-week period by service category in the SEHB region</td>
<td>30</td>
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<tr>
<td>11</td>
<td>The number of physical assaults reported over a four-week period by service category in the SEHB region</td>
<td>30</td>
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<tr>
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<td>The number of people in each setting presenting with sexualised assultive behaviour in the SEHB region</td>
<td>31</td>
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<td>13</td>
<td>The percentage of people with intellectual disabilities and challenging behaviour in each age category in the SEHB region</td>
<td>32</td>
</tr>
<tr>
<td>14</td>
<td>The percentage of people within each level of intellectual disability who have challenging behaviour in the SEHB region</td>
<td>32</td>
</tr>
<tr>
<td>15</td>
<td>The percentage of people in each service category in the SEHB region with challenging behaviour that causes significant management difficulties</td>
<td>34</td>
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<tr>
<td>16</td>
<td>The percentage of people with intellectual disabilities and challenging behaviour in each service category in the region who are on medication for their behaviour</td>
<td>36</td>
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<td>17</td>
<td>The percentage of people with challenging behaviour in each service category in the region who were assessed/reviewed by a psychiatrist in the last 3 months</td>
<td>37</td>
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<tr>
<td>18</td>
<td>The percentage of people with intellectual disabilities and challenging behaviour in each service category in the SEHB region who have a behaviour management programme</td>
<td>38</td>
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<td>19</td>
<td>The percentage of people with challenging behaviour in services in the SEHB region that have had a psychological assessment/review within the last 3 months</td>
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<td>20</td>
<td>A model of the Challenging Behaviour Support Service</td>
<td>103</td>
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<tr>
<td>22</td>
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<td>109</td>
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REFERENCES


MEETING THE CHALLENGE OF CHALLENGING BEHAVIOUR


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 WHO.

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