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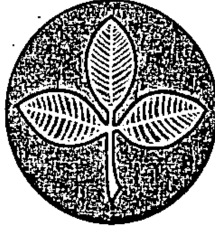

Proposed Specialist Service for Clients with Intellectual Disabilities Presenting with Severe Challenging Behaviour and/or Psychiatric Illness

(1) Copy Willie for his info + discussion with me on my return

Eastern Regional Health Authority
January 2002

(2) put original on CP file ([illegible]) on my desk

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SUMMARY

Severe challenging behaviour and/or psychiatric illness among people with intellectual disabilities is a pressing and serious problem for the individuals themselves, their families, friends, those who care for them and society generally. This document describes the specialist services that are needed to ensure that these individuals receive focused and effective care.

The aim of this service is to:

- Improve the quality of life for the individuals concerned.
- Remove a potential threat to themselves and the community.
- Prevent the disruption that this behaviour causes to the current service.

This document defines challenging behaviour as being of such intensity, frequency or duration that the physical safety of the person or other is likely to be placed in serious jeopardy, or behaviour which is likely to deny access to the use of ordinary community facilities. While it is difficult to establish precise figures for the extent of the problem, the report established that over 10% and possibly up to 30% of those with intellectual disabilities may exhibit challenging behaviour during their lifetime.

The report reviews the options available for the management of challenging behaviour. It defines the principles that should guide any proposed solution. **It specifically recognises that the service user must return to and be accepted back by their own community and service agency at the end of their treatment or special care.**

The sub-committee proposes that each Area Health Board will have:

- A dedicated outreach and assessment team
- Two assessment beds
- A ten-bedded unit with associated day services. These beds will be for people with intellectual disability behaving in a challenging way and/or having psychiatric illness
- A five-bedded rehabilitation unit.

We outline how the service will operate. It stresses that these services will complement the existing services and that people will receive their treatment in close co-operation with the referring agency. The referring agencies are expected to play an important role in the overall care of the individual.

The report envisages people exhibiting challenging behaviour moving through a three-phased process of (i) induction, (ii) treatment and rehabilitation, (iii) pre-discharge and rehabilitation leading to their re-integration into their home service.

The service will need extra resources and the report describes the level of resources needed to provide an effective service. There will be both capital and revenue involved as well as an increase in staff numbers. The report recognises that the quality

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and commitment of staff will determine the success of this initiative. The personnel working in the service will need training and continuing development and support to meet peoples' needs.

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INTRODUCTION – THE BACKGROUND

The Eastern Regional Health Authority was established on 1st March 2000 "to plan, arrange for and oversee the provision of services in its functional area". (ERHA Act, 1999). The ERHA provides services for people with intellectual disability in the Eastern Region through a variety of community and residential settings. A range of providers, including the three Area Health Boards, voluntary agencies directly funded by the EHRA and agencies funded by the Area Health Boards through section 65 grants deliver these services. The ERHA's key priorities for the service include the development of early intervention services, respite care, day places and the development of a range of residential care options. People with specific needs require specialist services staffed with appropriately trained staff. A small number of people with intellectual disability need to receive services in a specialist environment so that their individual needs are met.

Some people with intellectual disability may display challenging behaviour resulting in serious consequences for the individual. It is also a problem for those involved in their care and the community generally. The person manifesting the behaviour runs the risk of damaging themselves, their families, those caring for them, both professional and voluntary, and occasionally others in the community. They may also damage property, and premises, sometimes reducing the effectiveness of the wider service.

The individuals behaving in a challenging way have a right to proper treatment and care. Those living and working with them have the right to proper protection. Professionals charged with managing those exhibiting challenging behaviour need the proper environment to ensure that they can deliver the best service to these clients safely and securely.

There is a lack of appropriate services for those exhibiting challenging behaviour in Ireland generally although this document focuses on the Eastern Regional Health Authority area. This lack of services applies to all those behaving in a challenging way. Those with an intellectual disability and who engage in challenging behaviour have very specific requirements. This report addresses this issue and proposes a cost-effective workable solution that meets the needs of the clients, their families, those working with them and the community at large.

Psychiatric Illness - a serious issue for some with intellectual disability

Challenging behaviour tends to be obvious and easily identified. People with intellectual disability are also more prone to psychiatric illness than the general community. Research and experience show that up to half of those with intellectual disability will also have a psychiatric illness, depending on the criteria used. In some

instances, the individuals are treated and managed as part of the overall service provision. Others need specific care in a dedicated service.

The background to this report

The Eastern Regional Health Authority established the Regional Planning Forum for Intellectual Disability Services to advise on the development and delivery of effective services for those with intellectual disability in the ERHA area. At its first meeting on the 23rd November 2000, members of the Regional Planning Forum identified that there was an immediate need for a service that met the needs of people who engage in severe challenging behaviour. The Forum established a sub-committee[1] to:

"Propose to the regional planning forum an implementation plan for the development of regional services for persons with an intellectual disability who present with or develop severe challenging behaviour."

This document contains that proposal.

How the sub-committee operated

The sub-committee began its work by reviewing the current literature and also the reports prepared by previous committees and agencies on the topic. Based on its analysis of this information it prepared an action plan, known as "The Framework for the Development of Specialist Services for Service Users with Intellectual Disability and Severe Challenging Behaviour and/or Psychiatric Illness in the Eastern Region[2]."

The Action Plan proposed to help service users, staff, agencies and families by providing a range of new services. The proposed services would address the prevention and management of both challenging behaviour and/or psychiatric illness. The sub-committee did not address the needs of the small number of people who require a specialised forensic or high-security service. It believed that the needs of this group should be met by the forensic service. The sub-committee addressed the needs of adult service users.

The proposed service, described in the Action Plan, involved a range of agencies and took a multi-faceted and regional approach to the issues involved. The sub-committee adhered to the ERHA's principles for the commissioning of all new services. In addition, the Action Plan emphasised:

- A client & family centred approach
- A commitment to community-based outreach and support strategies
- A multi-agency approach
- Partnership between voluntary and statutory bodies
- A commitment to supporting and developing current services rather than duplicating or replacing them.

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[1] We include the membership of the sub-committee in Appendix 1.

[2] Referred to henceforth as the "Action Plan"

Consulting with the key players

The sub-committee circulated 26 copies of the Action Plan to service providers, carers, experts, and bodies representing the interests of those with intellectual disability. The recipients copied the document and circulated it further within their own organisations and institutions so that as broad a spectrum of views as possible was canvassed. The sub-committee received 11 written responses and conducted 12 individual interviews. The sub-committee gained an insight into current best practice by reviewing the service provided by seven organisations outside of the ERHA area. The sub-committee involved a broad range of professions in the process including psychiatry, psychology, nursing, social work, education, administration and planning.

What is challenging behaviour?

The sub-committee used the following definition for challenging behaviour:
"Behaviour 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 which is likely to deny access to the use of ordinary community facilities."[3]

The sub-committee used the following criteria, developed by Qureshi and Albros (1992)[4], to further refine the definition. The behaviour must:

- At some time have caused injury to the person themselves or to others, which has required immediate medical treatment or destroyed the immediate environment
- Occur at least once a week and require the intervention of more than one member of staff to control, or places in danger or causes damage which could not be rectified by care staff, or causes more than one hour of disruption
- The behaviour occurs at least daily and causes more than a few minutes of disruption.

The extent of the challenge –the service user

There are no precise figures available for the prevalence of challenging behaviour and/or psychiatric illness among people with intellectual disability. Recent studies in Ireland have begun to establish prevalence figures. A study by Walsh et al. in Galway (1995)[5] found that 29% of a group of adults with intellectual disabilities exhibited serious challenging behaviour when measured using the Behaviour Disorder Scale.

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[3] Emerson et al. (1987), Developing services for people with severe learning difficulties and challenging behaviours. Canterbury: Institute of Social and Applied Psychology

[4] Qureshi, H & Alborz A, A (1992) Epidemiology of Challenging Behaviour, mental Handicap Research, 5 (2), 130 –145.

[5] Walsh, P.G., Hunt, D & Harsch, S (1995) A survey of challenging behaviour exhibited by people with intelectual disability in the West of Ireland employing the behaviuor disorder scale. A report by the psychology Dept. Kilcornan Centre, Clarenbridge, Galway.

Another study, also published in 1995,[6] carried out in the Southern Health Board region found that over 14% of their sample presented with seriously challenging behaviour. St Michael's House Psychology Department found that 37% of their service users displayed some level of challenging behaviour.[7] In 2000, COPE Foundation in Cork found that over half of their clients with mild intellectual disability and approximately 75% of those with profound intellectual disability also displayed problem behaviour.[8]

In the ERHA's area, a report on the establishment of a dual diagnosis service stated that psychiatric disorders occur more frequently in people with an intellectual disability than in the population generally. This study suggested that up to 50% of those with intellectual disability may also have psychiatric problems based on some published research[9] while other studies cited rates of between 10% and 40%. Such rates are significantly higher than are found in the population generally.

A challenge for staff

By definition challenging behaviour affects more than the individual using a service. Staff providing services to those with intellectual disability may be subjected to violent attack or the threat of attack. A UK study found, in a study of violence against social care workers, that 70% of those working in the field experienced a violent incident in the previous year. 87% of nursing staff working with the same client group experienced feelings of threat or actual physical assault at some point in their careers.[10]

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[6] Connelly et al., (1995) Challenging behaviour: Report of the task group for the Cork and Kerry region, unpublished report, South Western Health Board.

[7] Mulrooney et al., (1997) A survey of challenging behaviour in a large organisation for people with learning disability. St Michael's House and the Eastern Health Board.

[8] Desmond, M., Fitzgerald, M., Quinlan, D., Smith, M. & Tierney, E (2000) A survey of problem behaviour among the client population of COPE Foundation, Cork. COPE Foundation.

[9] Dual Diagnostic Committee (2000) Report on the establishment of a dual diagnostic service in the Eastern Regional Health Authority, Available from the ERHA.

[10] Emerson & Hatton, Review of violence against social care workers supporting people with learning difficulties, Access: Department of Health's website.

A NEW APPROACH FOR THE ERHA – OUR PROPOSAL

The sub-committee paid close attention to the views and ideas expressed during the consultation process. It developed this new proposal in the light of these deliberations. This section describes the proposed new approach.

A service built on core principles

There is a general agreement that the new service should have an ethos that is underpinned by the following general principles:

- The service should be delivered in or as close as possible to the user's primary service.
- The assessment and outreach service should provide a major part of the support needed. This should be properly resourced and the staff appropriately trained.
- People should only be admitted to a special unit as a last resort with the intention of discharging as soon as is appropriate.

The service will operate in accordance with the criteria set down in the Mental Health Treatment Act 2001.[11] It will be a psychiatry of intellectual disability service developed within the generic learning disability service.

The options – building on experience

This sub-committee started from the premise that the ERHA needs to provide a service specifically aimed at meeting the needs of those exhibiting challenging behaviour. It also recognised that the current situation could not continue.

Other services have approached this issue in two ways. One approach is to provide services through a specialist treatment unit while the other approach delivers these through the generic services. These are not black and white options as they are combined in a variety of ways.

The Psychological Society of Ireland examined 13 units in the UK identified the advantages and disadvantages of the specialist treatment units in the UK. These are listed below.

The advantages of specialist treatment units:

- They offer improved access for clients and more efficient use of resources and procedures
- It is easier to monitor and supervise staff in a centralised unit
- It is possible to provide more intensive assessment and treatment at a fixed cost
- Staff in these units can implement and sustain programmes at a high level and achieve short-term reductions in severe challenging behaviour

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[11] Mental Health Act 2001

- The units improve access to procedures, such as time out or seclusion rooms, not usually available in normal settings. These help to contain aggressive or violent behaviour.

There are potential disadvantages to these units including:

- They have difficulty in returning people to the mainstream service. This results in the unit being filled with people who should properly be returned to the mainstream service but who are not accepted by that service.
- The relationship between service users and their family, friends and acquaintances may be disrupted while the service users attend the centralised unit-based services.
- Removing people from their natural environment may make it more difficult to find ways of maintaining behaviour change in ordinary settings
- It is generally difficult to arrange peoples' discharge from intensive units
- Concentrating people with challenging behaviour in one place may create a stressful environment for carers and service users.
- It is difficult to maintain an acceptable quality of life for people while they are in a specialist treatment unit
- There is generally a high staff turnover in special treatment units
- Special treatment units demand very specific resources that cannot be redirected easily to help in the establishment of alternative services or to provide support for users as their challenging behaviour decreases.

Our review shows that the issue of the specialist service becoming clogged is an important one. This points to the need for some form of rehabilitation unit, in addition to the specialist centre, whose purpose would be the re-integration of people into the mainstream facilities. This re-integration unit will allow the service user to make the transition back to the mainstream services and to their normal life.

Another issue, which must be addressed, is the loss of the service user's place in the mainstream service. This results in a deterioration in the client's quality of life at a time when they are especially vulnerable. It also contributes to the clogging of the specialist unit. It is critically important that in any future system the referring agency accepts the person back into its service after treatment in the specialist unit.

Specialist services with dedicated resources have the advantage of concentrating and accumulating experience. Staff can focus their attention on the individual's problem behaviour and decide the interventions needed. Staff can monitor, supervise and support people more easily in a centralised service allowing them to deliver the high levels of care essential for a successful outcome.

Well-trained committed staff are central to the success of any intervention. Any future development must address the training needs both of the local service provider's and the specialist unit's staff. Training local staff may allow them to take greater ownership of some of the problems that they face. It may allow them to deal with less severe or complex problem locally as well as being able to judge when more specialised intervention is needed. Any proposal must recognise the critical need for proper staff training and development to ensure that the service can achieve its capability.

The next section describes the optimum approach to meeting the needs of those presenting with challenging behaviour. It builds upon the experience of others to ensure that people gain the optimum benefit both from the new service and also the services already in place. It also ensures that the Health Boards make the most effective use of the resources at their disposal and that they avoid unnecessary duplication or overlap.

How the service will operate

The sub-committee proposes that each Area Health Board will have:

- A dedicated outreach and assessment team
- Two assessment beds
- A ten-bedded unit with associated day services. These beds will be for people with intellectual disability behaving in a challenging way and/or having a psychiatric illness.
- A five-bedded rehabilitation unit.

The sub-committee recognises that there may be a need to adjust the number of places to take account of the different population numbers in the areas.

Local service providers will make all referrals to this specialist service. The local disability manager should refer those that are not attending a service. This will ensure that the service user receives support during and after the required intervention.

Who the service is for?

This service is for people:

- With moderate, severe or profound intellectual disability
- With mild intellectual disability[12]
- Who are eighteen years old and over
- Living in the ERHA catchment area
- Presenting with serious challenging behaviour and/or psychiatric illness
- Who should properly be cared for in an intellectual disability service
- Have been assigned a staff member from their local service to liase with the local service
- Are supported by their referring agency to the extent that they agree to collaborate in the development and implementation of appropriate care plans.

The service is not suitable for:

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12 The sub-committee supports the view that was expressed in the discussion document entitled 'The Mental Health Needs of Persons with Mental Handicap,' prepared by the Department of Health which stated that "most people within the mild level of mental handicap with adjustment and emotional difficulties, both children and adults, can be effectively treated within the generic child and adult mental health services on an out-patient basis. A proportion, perhaps a third, representing those with additional disabilities, should be referred to the mental handicap services. The defining criteria for referral should be the long-term interests of the person involved. The majority of persons with a mild level of disability are never ascertained as such and thus avoid stigmatisation."

- Clients needing a forensic service
- Those individuals who are inappropriate for care within the intellectual disability services.

Who will operate the service?

A consultant psychiatrist will lead a multi-disciplinary team in delivering this service in each Area Health Board.

The assessment and outreach team will:

- support clients in their own community and service agency
- develop local staffs' skills and competence in the speciality through training
- support local unit staff by offering a consultancy and advice service
- ensure that clients that are transferred to another unit only as a last resort and after every effort has been made to support the client in his or her local unit
- give follow-up advice and support to local units.

The assessment process

The assessment and outreach team will be based in the Area Health Board designated office. Referring agencies will usually contact the assessment team there. Where necessary, members of the team will visit local units to support, advise and train staff about the appropriate interventions.

The outreach team may refer a client to one of the two assessment beds or directly to the treatment unit. It may be possible for those referred to the assessment beds to return to their local unit following their assessment.

The service will carry out a complete assessment of the client's needs. The team will carefully assess the supports and interventions that the client needs. The assessment team will prescribe an intervention and refer the client either to the admission unit or the referring agency.

Admission to the service

As already stated, people will only be admitted to the assessment/ treatment units when the assessment and multi-disciplinary team is satisfied that they cannot be given appropriate care in their local unit. Planning for discharge will precede admission. The referring agency will have to agree to the following conditions:

- They nominate a named, key staff member to work closely with the specialist service and to liase between the referring agency and the service. This person may also act as the service user's advocate if this is required.
- They accept the multi-disciplinary team's assessment and treatment advice and support
- They receive the client back into the local service following the planned discharge by the multi disciplinary team.

The sub-committee recognise that occasionally a client's needs may require that he or she is transferred to a service other than the referring agency in order to receive the support and interventions required.

Progress through the service

Once admitted, a client will move through a planned three-phased programme. This programme will match the progress that the client makes for - example reducing the need for environmental restriction as the client takes more personal responsibility for their behaviour. We give a short description of these phases below.

Phase 1 – Induction

The multi-disciplinary team will observe and supervise the client closely while giving them a high level of support focused on all of the client's needs.

During this stage the team will:

- Study the client carefully
- Stabilise the client's behaviour
- Reduce the client's acute challenging behaviour
- Plan and begin a treatment programme.

Phase 2 – Treatment and Rehabilitation

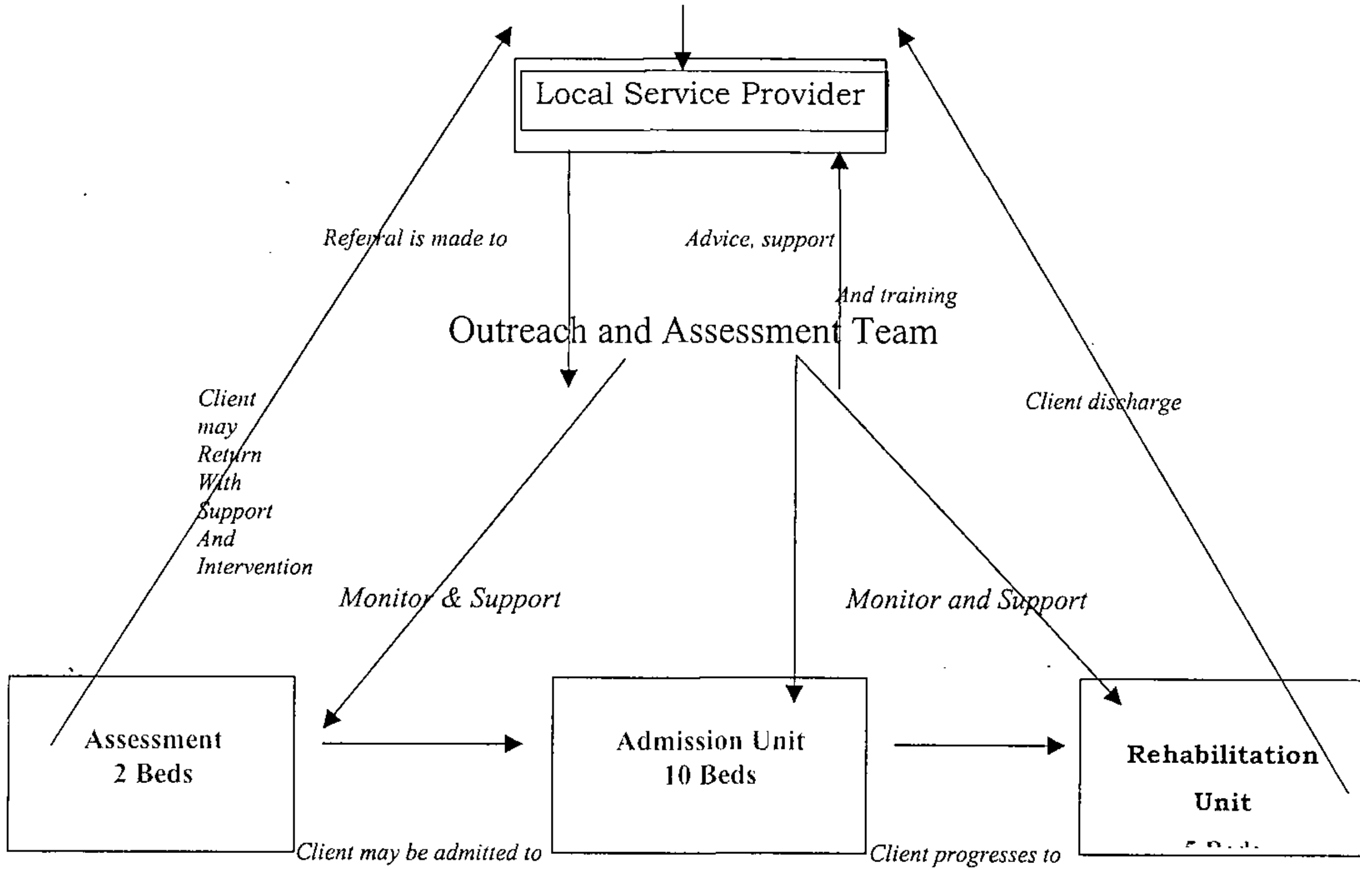
The client will undergo an extensive treatment programme in accordance with the client's individualised prescribed plan. The client will also be prepared for their rehabilitation period.

Phase 3 – pre-discharge and rehabilitation

In this final phase the client is prepared for transfer to the rehabilitation unit. This unit has five beds and will prepare clients for a planned reintegration into their home services.

CLIENT PATHWAY THROUGH THE NEW SERVICE

Client presenting with severe challenging behaviour and or psychiatric illness referred by



RESOURCES NEEDED TO DELIVER THE SERVICE

This service will require new, additional resources. The service itself will take time to initiate, staff and put into operation. In this section we estimate the resources required and outline the programme for its introduction.

Capital costs

We estimate that it costs approximately €160,000 per residential place giving a total cost of €2,857000 for each Area Health Board for residential places. The day services will incur a capital cost of €635,000. The clinical team's capital cost will also be €635,000. This gives a total capital cost for each Area Health Board of close to €4 million.

Revenue Costs

Core Multi Disciplinary Team

1 Consultant Psychiatrist (Learning Disability)
1 Senior Registrar
1 Senior Clinical Psychologist
1 Basic Grade Psychologist
1 Head Occupational Therapist
1 Senior Social Worker
Sessional Speech & Language Therapy
Sessional Physiotherapy
2 Nurse Managers (CNM2)
Administrative Support

Unit Based Staff

10 Staff Nurses Dual Qualified
15 Staff Nurse
Location Allowances x 25
Premium Pay
9 Care Assistants

Consultants on Call
On Call per Patient
Medical Cover

Other Non Pay

Total Costs (as at October 2001) €2,025,210

Each of the units will need the normal revenue associated with the operation of the unit. In addition there will be specific vehicle, transport and other costs specifically

needed for the delivery of this service. Security expenditure will be higher than normal. Repair and the maintenance costs will also be higher.

This report stresses the need for specialist training and staff development if the units are to function effectively. Staff will need initial, induction training and continuous professional development and improvement.

Development programme

We envisage that the units will take three years to become fully operational. We outline the key milestones that will be achieved in each year as follows:

Year One

- Recruit and appoint the outreach team
- Plan and design the units
- Seek planning permission
- Establish contingency fund to cover costs of beds in interim phase.

Year Two

- Build residential units and premises for day services
- Establish assessment beds

Year Three

- Build step-down facility.

Appendix 1

The Sub-Committee of the Regional Planning Forum for Intellectual Disability Services which prepared this document is comprised of the following members:

Ms. Regina Buckley, South Western Area Health Board

Mr. Paudie Galvin, South Western Area Health Board
Ms. Violet Harford, Northern Area Health Board
Mr. John O'Sullivan, East Coast Area Health Board
Mr. David Dunne, St. Michael's House

Dr. Mary Staines, Clinical Director, Stewarts Hospital

Brother Laurence Kearns, Hospitaller Order of St. John of God

Ms. Mary Van Lieshout, Chair of the Sub Committee on behalf of the Eastern Regional Health Authority

Appendix 2

The sub-Committee wish to extend sincere thanks to all who contributed to the document including:

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