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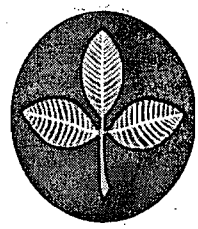

EASTERN REGIONAL HEALTH AUTHORITY
Údarás Réigiúnda Sláinte an Oirthir

# REPORT

## SURVEY OF SERVICES AVAILABLE TO Young Chronically Ill and Physically Disabled People Aged between 18 – 65 years

# 1. EXECUTIVE SUMMARY

Many Persons with physical and / or sensory disability are faced with numerous obstacles in their efforts to attain an optimal quality of life and to play a full role within their families and communities. Among the requirements to help ensure that people with physical and sensory disabilities can participate fully in their communities is the availability of a range of accommodation options together with a variety of health and social supports to maximise their independence. This range of accommodation and support options should be flexible enough to meet the particular needs of each individual.

This review aims to address the current situation in regard to the accommodation and support needs of the young, chronic disabled client in the Eastern region i.e. that person between the age of 18 and 65 years with either a congenital or an acquired disability, that may be either progressive or static, and is irrespective of any accompanying cognitive impairment.

From the outset, it should be noted that the Review Group is of the opinion that "young chronic disabled" is not an ideal term; however, in view of its general usage, it was agreed that in the absence of a more acceptable term, this term should be adopted for the purpose of the review.

The remit of the Working group established to coordinate the review – on which this report is based - was to attempt to identify this need and to propose new service developments for young chronic disabled clients within the Eastern region. The Review Group comprised representatives from the Eastern Regional Health Authority and the three Area Health Boards, together with a range of Service Providers from the Voluntary sector. The members of this group are listed in ***Appendix I.***

Findings around the needs of young chronic disabled persons revealed that at the time of the survey, 404 residential beds were provided within the Eastern region while a further 674 persons were awaiting placement in appropriate accommodation. Many of these people – both those in residential accommodation and those awaiting placement in suitable accommodation – were considered to be placed in accommodation that was not appropriate for their needs and wishes It is pertinent to note, too, that a percentage of young disabled clients, ready for discharge from hospital, can remain there for periods of up to 12 months because of a shortage of appropriate accommodation and associated care. Clearly, this has implications for the effective management of bed usage in acute and secondary hospitals.

Additionally, the survey indicated a need for the development of specialist services to address the needs of young chronic disabled clients presenting with challenging behaviour. A further significant finding of the review is the lack of community-based therapy, support and associated rehabilitative services for young chronic disabled clients within their communities.

Recommendations informed by the survey of the needs of the young chronic disabled thus include proposals around the development of a range of appropriate accommodation options as well as the development and enhancement of associated services aimed at providing integrated comprehensive care to the young chronic

disabled. The range of services necessary as identified as a result of the review includes:

- Comprehensive care – including care for those clients who require respiratory assistance.
- Independent/Supported living.
- Respite services.
- Enhanced home support for clients with high service needs.
- Challenging behaviour service
- Rehabilitation and associated services

Other issues identified included the management of referrals and waiting lists together with development of models of good practice around provision of accommodation acceptable to the disabled service user. Recruitment and retention of therapeutic and care staff is critical to successful outcomes of all the initiatives directed towards the needs of the young chronic disabled client.

All the recommendations are in line with the philosophy embodied in "Towards an Independent Future" and thus are aimed at providing an integrated, seamless service designed to promote the full inclusion of the young disabled client into society. It is envisaged that the implementation of the National Physical and Sensory Disability Database - the report of which was launched in March 2002 - will further facilitate identification of the needs of the young chronic disabled client and thereby inform future planning and development around these needs. This database will provide a picture of the specialised health and personal social service needs of people with a physical or sensory disability. The database will monitor current service provision and future service requirements over a 5 year period.

It is evident that the implementation of the recommendations will demand significant capital and revenue expenditure. The cost of providing a comprehensive range of accommodation and support services to meet the needs of the significant number of people identified in the review will be substantial. The capital and revenue costs required to meet the needs of a client group who have high support needs is significant. Services for people with challenging behaviour will also be very costly. Nevertheless, preliminary exercises around costings and cost benefit analysis would seem to indicate that in certain instances at least, viz. provision of services for persons demonstrating challenging behaviour, implementation of the recommendations would prove cost effective. At the same time, the benefits in terms of health and social gain to all young chronic disabled clients, derived from implementation of the recommendations contained in the review, would be expected to be significant.

The report outlines costed proposals for a range of identified accommodation options. Certain of these proposals are highly innovative and reflect a greatly increased degree of cooperation and interaction between service providers within the Eastern region. Other proposals are more traditional, but have attractive financial implications. All proposals are informed by models of good practice. According to these submissions, approximately 90 places could be developed over a 3 year period, with capital expenditure of €9,130,000 and accompanying revenue. While not resolving all client's needs for provision of appropriate accommodation, such a programme of development would impact significantly on current needs for improvement and enhancement of services for the young chronic disabled.

During 2002, the provision of a range of new services as well as strengthening of existing services for young chronic disabled clients was identified as a priority by the ERHA as well as by the Regional Provider Forum for Physical and Sensory Disability. Priority was thus accorded this client group in the allocation of funding for new developments across the region. To this end, funding was provided for the creation of 12 beds for young chronic disabled clients at Royal Hospital Donnybrook, and a further 5 respite beds at MS Society, while allocations were made to Peamount Hospital towards appointment of specialist support staff working with young chronic disabled clients. Additionally funding was allocated towards a range of services addressing the needs of the young chronic disabled in the community; such funding spanned support to a number of agencies, facilitating expansion of home based support or outreach services, to allocations and provision of support to agencies actively promoting independent living, such as the Peter Bradley Foundation. It is anticipated that a large portion of development funding in 2003 should continue to be allocated towards addressing the many unique needs of the young chronic disabled in the Eastern region.

## 2. INTRODUCTION : CONTEXT

The Eastern Regional Health Authority was established in 2000 "to plan, arrange for and oversee the provision of services in its functional area". It is thus the Authority's responsibility to plan, commission and provide services to persons with physical and sensory disability. Services are delivered via a range of providers, including the three Area Health Boards, Voluntary Agencies funded directly by the Authority and Agencies funded by the Area Health Board through Section 65 grants. One of the Eastern Regional Health Authority's key priorities for a Physical and Sensory Disability service includes the development of a range of appropriate living accommodation and support options for disabled service users, in particular for those who are young chronic disabled service users i.e. those persons with either congenital or acquired disability and for whom the disease process may be either progressive or static and is irrespective of any accompanying cognitive impairment. ***Appendix II*** details some examples of conditions suffered by young chronic disabled service users.

The newly published Health Strategy (2001) expresses a commitment to improving the nature and extent of health service delivery to persons with disability so that all disabled people who use services should be empowered to avail of a comprehensive support package tailored to meet individual needs. Furthermore, the proposed Disability Bill places obligations on the Health Authority to provide appropriate care, health and social support to disabled service users.

There has been a dramatic increase in expansion of disability related services during the past few years; in the period 1997 – 2002, 179m euros has been allocated nationally towards the physical and sensory disability sector (Michael Kelly 2002). However, it is acknowledged that much additional expenditure is demanded in this area, in order to achieve further measurable health and social gain (ibid.). Despite increased expenditure on provision of health and related social services to persons with physical and sensory disability however, the experience of the growing

population of young chronic disabled persons is one of inadequate residential, respite and day services. In addition, community services essential for supported living continue to be inadequate. The critical shortage of therapy and allied care staff in the community is confirmed by the Bacon Report (2001) which states that there is an immediate need for initiatives directed at recruitment and retention of these personnel. A further constraint exists in relation to Psychological services and challenging behaviour programmes, which are generally not standardised or comprehensive, and in some areas, are not available.

Of immediate concern to Health Service Providers is the lack of appropriate accommodation for people who fall into the young chronically disabled category. At present some people are living in inappropriate accommodation such as Nursing Homes where the emphasis rests on nursing care rather than on social input, and in the community where geographical location and inadequate transport contribute to social isolation. It follows that many young chronically ill men and women are unable to enjoy a full life. A substantial number of those living in the community are living with their families, who experience enormous pressure due to the limited support available to them.

It was identified in 1984 in "Towards a Full Life" that people with physical sensory disabilities were living in Welfare Homes, Centres for the Mentally Handicapped, District Homes and Homes for Incapacitated. A commitment was made at that time to ensure such inappropriate placing of people would not be continued or repeated.

The figures identified in "Towards a Full Life" thus demonstrate that the shortage of appropriate accommodation is historically rooted; while immediate solutions to this situation are required, the overall emphasis of service delivery here should focus on proper and long term planning to provide for the needs of these disabled clients.

## 3. Work of Review Group

In early 2001 the Eastern Regional Health Authority sought to address the crisis in accommodation affecting people with long-term physical disabilities between the ages of 18 – 65 years. In April 2001, a Working Group comprising the Authority's Planner for Disability Services and representatives from the three Area Health Boards was established with the objective being to "identify need and propose new service developments for young chronic disabled clients in the Eastern region.

It was decided by the Working Group that it was necessary to conduct an audit of current service provision for young chronic disabled service users as well as some assessment of the needs of people placed on waiting lists for a range of residential accommodation.

At its second meeting in June 2001 the group agreed to request information from the Directors of Disability Services in the region for use in compiling a profile of services from which an audit could be conducted. A second exercise was proposed through which the number of people waiting for suitable long - term residential placement could be identified. It was agreed to circulate questionnaires to all agencies providing

care within the region, including nursing homes where individuals are supported by the Health Boards. A sample of that questionnaire is contained in ***Appendix II.*** *A total of 39 Agencies were involved in completing this questionnaire. These Agencies are listed in Appendix 1V.*

At a later meeting in August 2001 the working group was expanded to include multidisciplinary representatives from Hospitals and other Service Providers. A list of members of the Working Group is present in ***Appendix I.***

Detailed study of case histories was recommended to identify needs. For this purpose it was agreed to develop a tool suitable for assessing the needs of people on the waiting list. As people may be placed on waiting lists in more than one agency, the group also identified a need to validate the waiting list.

A sub Group was delegated to develop a standard assessment tool for use in assessing individual client needs. This group met on 24th August 2001 and agreed that assessment should be categorised where possible, in to one of five categories. Broadly speaking these categories are;

- Independent Living
- Supported Living
- Secondary rehabilitation
- Comprehensive Continuing Care
- Challenging Behaviour Service

A sample of the assessment tool together with a definition of terms used, is contained in ***Appendix IV.***

The service providers contacted for the purpose of the survey included hospitals, residential centres and nursing homes in the region; it was not, however, deemed practicable to include community group homes or hostels in the survey. Agencies participating in the survey are listed in ***Appendix V***

Following the circulation of the questionnaire investigating services for the Young Chronically Disabled, forms were sent to Hospitals and Residential Centres requesting a list of people waiting for accommodation. To ensure client confidentiality, only initials and dates of birth were requested. Agencies responding here are listed in ***Appendix VI.***

At this stage, it was decided to recruit a researcher with the remit to:

- conduct an audit on the review
- validate the waiting list
- assess the needs of individuals waiting for accommodation
- report back to Review Group.

The Review Group recommended use of the Assessment Tool by the Researcher, Multidisciplinary Team and Service User. This exercise would best validate client needs and provide a resource database useful for service development.

Once the Researcher had compiled and presented initial findings, a series of meetings of the Review Group took place, during which all findings were examined, recommendations discussed, and proposals drawn up around means to best implement these recommendations.

## 4. FINDINGS OF REVIEW GROUP

Details around the methodologies used to investigate services available to young chronic disabled clients, as well as to establish the number of these persons awaiting placement in appropriate accommodation, are available in the fuller document: "Draft Survey of services available to young chronically ill and physically disabled people, aged between 18 –65 years".

At the same time as findings of the survey are considered, it should be noted that current data returned from the 9 hospitals dealing with Accident and Emergency situations has also been utilized to form on ongoing picture of delayed discharges of young chronically ill and disabled clients form these hospitals. It is pertinent here that the average number of young chronically disabled patients waiting placement for the period January to June was 60; this figure represents an increase of 30% on the same period in 2001. The implication this holds for blockage of beds is clear.

The Review group considered findings around issues relating to numbers of this client group placed on waiting lists for accommodation and associated support services. The main finding indicated that while 404 residential places are provided within the Eastern Regional Health Authority area for this care group, a further 674 clients are awaiting placement in accommodation appropriate for their needs.

Other findings complied via the survey and through discussion with both Service Users and Service Providers spanning a range of care, include the following:

**Findings: Review of Services Available**

Discussions with Service Providers spanning a range of professional services are included in this review. Their recommendations and the information collected from the questionnaires combine to describe the current service.

- There is an historical need for accommodation for the young chronically ill. Currently, it appears that 674 people are waiting for appropriate long-term residential accommodation.

- 120 people are living in centres that cannot provide an adequate social care programme. A complete list of people living in Nursing Homes was unattainable.

- Nursing Homes are being used as a short-term solution to a long-term problem. As stated earlier, this accommodation, by its nature, is not appropriate for the young chronic disabled. There is no means of evaluating or formally monitoring service delivery, as nursing homes are not compelled to provide service protocol documentation.

- Certain hospitals have, of necessity, resorted to discharging patients to Private Nursing Homes and for the present are meeting the costs of this arrangement out of their own budgets. Such arrangements give rise to the risk of premature hospital re-admission, are not cost effective and may frequently lead to institutionalisation of service users with accompanying deleterious effects.

- Lack of Day Services is a major cause of delay in discharging people back into their own community.

- People are experiencing delayed hospital discharge. Many would benefit from having a Personal Assistant to assist him/her in a personalised social development programme during this transitional period.

- The Personal Assistant Service is not available to people in hospitals or nursing homes and the number of Assistants falls short of the demand for service. Employment issues surrounding this service would seem to be an obstacle for some disabled people. The ERHA is currently completing a review around the service.

- In some areas the Home Help service has broken down due in part to low pay and to loss of benefits to workers such as the loss of medical cards. Incentives need to be introduced to encourage people to take up this work. The absence of home help leads directly to poor social well being and included such anecdotal examples as failed distribution of "meals on wheels".

- Disabled people living at home and their Carers have and continue to require crisis management services due to the lack of regular respite facilities.

- Personalised development programmes are not standard within the service.

- Psychological care is often inadequate and does not usually extend to provision of support to the person or his/her family.

- Standardisation and monitoring of services within Health Boards was not

evident.

- It was not possible to objectively measure the success of independent or supported living arrangements. However, the expressed popularity of such accommodation, as expressed by disabled people, prompts the need for interdepartmental co-operation to provide long-term accommodation built to lifetime adaptable standards.

- There is an urgent need for the development of a Secondary Rehabilitation service.

- The development of a challenging behaviour service to address in particular the unique needs of those young persons with acquired or traumatic brain injury, who demonstrate challenging behaviour, is regarded as an urgent priority. No such unit currently exists in the Eastern Region.

**Findings: Waiting Lists and Related Issues**

- Vacancies for accommodation appear to arise so infrequently that these are awarded on the basis of greatest need not according to place on list.

- Disabled people and their families prefer to be located as close to their local community as possible. This would become an option if resources were invested in community housing modelled on the service provided to people who are intellectually disabled.

- Delayed discharge causes enormous stress to the person and his/her families.

- 50% of people waiting for discharge from hospital are doing so for 9 months or longer (range 9 – 18 months).

- Young physically disabled people continue to be placed in nursing home beds for the elderly.

- Currently there are a number of young chronic disabled persons ready to move to either supported or independent living units. Resources to facilitate these transitions are scarce. Preparation for transitions to all new living environments is crucial to ensure that people succeed in their new environment. Investment in such transition preparation will have long term benefits both in terms of health as well as social gain.

- All 47 service users experiencing delayed hospital discharge had applied for long term accommodation; although the majority applied to a number of Centres it was found that their names did not necessarily appear on the waiting lists of units to which application was made. Many difficulties were evident around the management of waiting lists.

- Although it is difficult to quantify the extent of this need, it is evident that there continues to be a high demand for Comprehensive Continuing Care Services.

- The degree of physical disability can have little to do with the aspiration to live independently. Many people with significant physical disability and significant support needs live very independent and full lives.

- Among the 26 reviewed case histories were two service users who chose Independent Living as a lifestyle option. Both persons will require twenty - four - hour support for this to be feasible.

- Finding appropriate accommodation and support for people with challenging behaviour, especially those with no mobility problems, is particularly difficult. Currently, those clients who present with Challenging behaviour are being placed in Units in the United Kingdom; while numbers and costs around such placements are difficult to ascertain, it is estimated that by the National Rehabilitation Hospital that at least 12 clients per year are sent from the Eastern region to be placed in Challenging behaviour services within the U.K. at a cost of circa 3,000 euros per week.

- Homeless people with a history of alcohol abuse experience greater delays in finding long-term accommodation.

- At present Peamount Hospital is the main provider of accommodation for people with tracheostomies.

- There appears to be inadequate provision of day care service in all areas, with little monitoring of existing services.

- There is a need for improved co-ordination of existing services, as well as for improved interagency collaboration and planning.

## 5 RECOMMENDATIONS

Recommendations are informed by policy documents mentioned previously, as well as by the findings of the Review group. In line with this, therefore, the review group recommends the development of a range of quality accommodation and support services for young chronic disabled people that will facilitate them reaching their full potential. For this purpose, and in line with the Department of Health and Children's recommendations on the cross-sectoral issues affecting people's health status, the group recommends immediate service development in the areas of

- Comprehensive care services
- Supported living accommodation
- Respite services
- Challenging behaviour service
- Community based services
- Rehabilitation and allied services
- Environmental Controls / Smart house technology
- Transitional programmes

In line with the findings of the review, the three health boards in the Eastern Regional Health Authority area have submitted proposals for service development together with plans of action for their implementation. Principles of partnership dictated that other agencies should also be invited to submit proposals.

In keeping with Health Strategy guidelines all approved proposals should describe standards of care and identify performance indicators in all services. Regular review and monitoring will ensure a high standard of care is being provided.

The further group recommends an urgent review of service users inappropriately placed in institutions such as nursing homes, centres for the elderly, centres for children and elsewhere. This review should include people living in the community whose needs are not being met due to inappropriate housing, aging carers, geographical isolation or any arrangement that makes it difficult for them to enjoy and support an optimum standard of living and maximum independence. An audit of nursing homes and evaluation of their standards of care is essential to identify current service inadequacies. Every effort must be made to facilitate people in institutions to move to supported or independent accommodation.

Specific issues impacting on effective management of service delivery eg. Management and coordination of waiting lists, collaboration between agencies, should be addressed.

### 5.1. Comprehensive Care Services

It is envisaged that this service will provide 24-hour medical cover and nursing care, as well as access to dedicated therapeutic/paramedical services on a consultative basis with regular divisional activities.

New accommodation is required and should be incorporated in development planning. In the interim, Health Boards are requested to review current service users with a view to assessing the appropriateness of their continued residency. The review identified a small number of people capable of living a more mainstream life than that which is possible in units providing comprehensive continuing care. Personalised development programmes would facilitate graduation from high dependency units to supported living accommodation.

In accordance with the Health Strategy, and in line with the process soon to be commenced by the National Disability Authority, all service providers including those providing comprehensive care will be required to conform to and document agreed standards of care.

Each unit should have a mix of service users. Clients with compromised respiratory function and/or tracheotomies should be accommodated in units closest to their family's community. The current practice of accommodating the majority of this client group in Peamount Hospital is placing enormous social and financial strain on service users and their families and is one of the factors leading to the delay in the discharge of clients from hospital.

The provision of a service to a person in a Comprehensive care unit does not mean that this represents a final solution for meeting his/her accommodation and support needs. Indeed, the ethos of each of these Comprehensive care units should be to provide service users with the opportunity, confidence and skills to move to the living environment of their choosing.

It will be necessary to develop a range of innovative and mainstream accommodation options. It is incumbent on the Authority to work with all providers to explore and develop a range of accommodation that best meets the needs of these service users.

## 5.2 Supported Living Accommodation

A range of accommodation and personal support options should be developed to meet the needs and wishes of young chronically disabled adults. As each of these people has a housing need, schemes such as the Capital Assistance Scheme should be used to provide the housing element of projects. ERHA capital funding should be used to provide communal facilities and to ensure that all facilities are fully accessible. This practice would be in line with Government policy of mainstreaming which, as stated in the Health Strategy requires that specific services for people with disabilities should be the responsibility of those state agencies which provide the services for the general public.

All accommodation should be built to a lifetime adaptable standard, so as to avoid the traumatic experience of having to move to alternative accommodation, as people age or experience increased or decreased disability.

Consideration needs to be given to means though which Private / Public partnerships may be used to maximise use of all possible sources of funding.

The group recommends an urgent review of service users inappropriately placed in institutions such as nursing homes, centres for the elderly, centres for children and elsewhere. This review should include people living in the community whose needs are not being met due to inappropriate housing, aging carers, geographical isolation or any arrangement that makes it difficult for them to enjoy and support an optimum standard of living and maximum independence. An audit of nursing homes and

evaluation of their standards of care is essential to identify current service inadequacies. Every effort must be made to facilitate people in institutions to move to supported or independent accommodation

A comprehensive range of accommodation is needed. There is a need for innovative accommodation options including campus based and community based independent and supported living options. Adapted or purpose built community options need to be explored. The Health Strategy recommends introducing programmes to foster voluntarism and community responsiveness. Such programmes would extend the model of community housing enjoyed by the intellectually disabled community, to the physically disabled community. The implementation and effectiveness of such interventions should be closely monitored.

### 5.3: Respite Services

A review of respite service provision in the Northern Area Health Board is close to completion. Findings here should further inform development of appropriate respite options. Innovative and adaptable use of current respite facilities would alleviate the current shortfall in service provision. Respite services should be viewed in terms of resident population rather than bed ownership. Should a client spend regular time in the community with family, the time away from the institution could be viewed as time available to another person for respite care. Such a system would rely on partnership between management and staff and assurances must be given to ensure that the extra beds are not used to increase the resident population without a review of staffing levels.

The home-based respite care service recently introduced in the region needs to be evaluated and its cost effectiveness measured. The Health Strategy targets respite services for investment.

### 5.4: Challenging Behaviour Service

Challenging behaviour service provision is grossly inadequate. In its absence, hospitals continue to experience huge obstacles placing people in suitable accommodation. This is a particular problem among service users with a history of homelessness or alcohol abuse.

A challenging behaviour outreach service needs to be provided as well as an accommodation service. Appropriate person centred individual programmes would improve life for service users and their carers. Resources are urgently required to initiate this service as soon as possible.

### 5.5: Community based Services

The need for a range of community based services has been identified as what is currently being provided is inadequate or under funded. Effective operation and co-ordination of community based services is essential if adequate, appropriate, quality support is available to facilitate young chronically disabled clients to function optimally within the community. Major constraints identified here include the lack of Occupational, Physio, and Speech & Language Therapists employed within the community; other personnel including Home Care Assistants and Personal Assistants are also under resourced. A key recommendation thus is to emphasise the urgency of recruiting paramedical personnel and to provide additional funding to enhance community based services

Further investment in co-ordination of all services is required. This should also include development of common policy, standardisation and monitoring of services across the 3 Area Health Boards.

In line with the Health Strategy 2001 expansion of day services is needed. Such services should incorporate person centred development programmes for each person utilising such services, with regular appropriate reviews.

Home support services need to be expanded and the Personal Assistant service enhanced.

In accordance with the Health Strategy's commitment to mainstreaming service for people with disabilities it will be necessary to promote wheelchair accessible General Practitioner and Family Planning services to encourage uptake of health screening programmes. Wheelchair accessibility is an essential pre-requisite in the location of the planned primary care co-operatives.

Inadequate training and transport remain impediments to independent living for the disabled community. Flexible and innovative community services are therefore essential. Support packages should be needs led rather than location dependent.

Introducing or expanding complementary therapies would be beneficial for people with physical and sensory disabilities.

### 5.6: Rehabilitation and Allied Services

The lack of Rehabilitation Specialists and Neurologists combined with a chronic shortage of rehabilitation facilities and beds present a clear challenge to the development of rehabilitation services in the region. There is urgent need for expansion of primary and secondary rehabilitation at a national and local level. In accordance with the Health Strategy, an Action Plan for Rehabilitation services should be developed by the Department of Health and Children by the end of 2002.

A comprehensive review of Rehabilitation services has been proposed for 2002/2003.

### 5.7: Environmental Controls/Smart House Technology

There has been huge investment into the benefits of new technology that benefit disabled and elderly people and assist them to control their living environment in other situations. The availability of such technologies not only enhance the autonomy of disabled people but also lesson the dependency on staff to do simple tasks such as operating Television Sets, lights, Personal Computers, opening and closing doors/curtains etc. The Working Group recommends that the Authority invest in making environmental controls/smart house technology available in all new accommodation and support services.

### 5.8: Transition Programmes

For a person who has been living in an institution or hospital for a prolonged period, moving to a more appropriate, mainstream accommodation can be a hugely difficult and traumatic experience. For such a transition to be a success the Working Group believes that the Authority should invest in transition programmes that will enable people to gain the experience, skills and confidence to prepare for their move.

## 6. IMPLEMENTATION OF RECOMMENDATIONS

### 6.1: Cost implications

The complex and varied needs of this unique user group are reflected in the absence of accurate, standardised information around costs of providing appropriate accommodation and related health and social services for them. Due to the dearth of information, the Review Group decided to formulate estimates of revenue costings related to the level of care and support required by the young chronic disabled client. These estimates were based on investigation of average costs incurred in providing residential care and associated health services across the Health Boards, as well as by a study of allocations made to various service providers delivering services to specific clients or groups of clients within this category. The need for agreeing estimates underlines the urgent need for compilation of a body of information around the cost of services pertaining to this client group.

Estimates were agreed in terms of revenue cost per placement and thus include core costs of provision of nursing and therapeutic care and associated supports:

- Independent living / Supported living / Community based residential placement: 80,000 euros
- Respite care placement: 60,000 – 80,000 euros
- Acquired brain injury: 80,000 – 100,000 euros
- Challenging behaviour: 100,000 – 120,000 euros
- Comprehensive care: 100,000 – 250,000 euros

Capital costings for building of appropriate accommodation to cater for the needs of each category of placement, were more readily available.

**6.2: Proposals for development of services / accommodation**

Based on the above, and following consultation among themselves and with their Consultative Committees, members of the Review Group formulated proposals for development of a range of accommodation options for young chronic disabled service users in the Eastern region. Submissions across the region reflected a great degree of collaboration between service providers and, additionally, enabled the Authority to compile further information around means of developing accommodation, costings relating to this, and potential sites for development.

Proposals outlined in the following table demonstrate that capital expenditure of approximately 9 million euros over a 3 year period, together with accompanying levels of revenue expenditure, should create approximately 90 places / suitable accommodation for young chronically ill and disabled clients across a continuum of care.

# Table
## Proposals: Development of Accommodation Options for Young Chronic Disabled Clients

| 2003 (Yr1) | NAHB | Capital | Revenue | SWAHB | Capital | Revenue | ECAHB | Capital | Revenue |
|---|---|---|---|---|---|---|---|---|---|
| Comprehensive Care | | | | Lisbri/ (6places) | €254,000 | €500,000 | | | |
| Independent/ Supported Living Units | Chapelizod/ (6 places)<br>Nth Cnty (6 places)<br>Brain/Injury (8 places) | €380,921<br>€253,947<br>€666,612 | €457,105<br>€457,105<br>€812,632 | Lisbri/ (6places) | €300,000 | €507,895 | | | |
| Respite | | | | | | | Respite Unit | €572,000 | €458,000 |
| Challenging Behaviour Unit | | | | | | | | | |
| Rehabilitation/ Transition/ Outreach | | | | Rehab for 6 Clients Peamount | €450,000 | €600,600 | Royal Hosp.12 Beds.<br>Outreach | Nil<br>€610,000 | €972,000<br>€381,000 |
| 2002 (Yr1) | NAHB | Capital | Revenue | SWAHB | Capital | Revenue | ECAHB | Capital | Revenue |
| 1 Year 1 | | €1,301,480 | €1,726,842 | | €1,004,000 | €1,608,495 | | €1,182,000 | €1,811,000 |

**YEAR 1 TOTAL CAPITAL €3,487,000 TOTAL REVENUE €5,146,337**

# Proposals: Development of Accommodation Options for Young Chronic Disabled Clients

| 2004 (Yr2) | NAHB | Capital | Revenue | SWAHB | Capital | Revenue | ECAHB | Capital | Revenue |
|---|---|---|---|---|---|---|---|---|---|
| Comprehensive Care | Enhancement of Cuan Aoibheann for Clients with intensive needs<br><br>12 private-purchase beds | €190,460<br><br>Nil | €558,684<br><br>€793,586 | | | | | | |
| Independent/ Supported Living Units | | | | | | | Flower Grove:<br>6 Units<br>Royal Hospital:<br>6 Units<br>Peter Bradley Foundation:<br>8 Units<br>Smart Technology | <br>€318,000<br><br>€585,000<br><br>€585,000<br><br>€127,000<br>€1,615,000 | <br>€458,000<br><br>€458,000<br><br>€610,000<br><br>€12,700<br>€1,538,700 |
| Respite | Respite 6 Places | €634,869 | €458,000 | | | | | | |
| Challenging Behaviour Unit/Outreach | | | | 6 places | €952,304 | €700,000 | | | |
| Rehabilitation/ Transition | | | | | | | | | |
| 2005(Yr2) | NAHB | Capital | Revenue | SWAHB | Capital | Revenue | ECAHB | Capital | Revenue |
| 2 Total | | €825,329 | €1,810,270 | | €952,304 | €700,000 | | €1,615,000 | €1,538,700 |

YEAR 2 TOTAL CAPITAL €2,392,633 TOTAL REVENUE €4,048,970

## Proposals: Development of Accommodation Options for Young Chronic Disabled Clients

| 2005(Yr3) | NAHB | Capital | Revenue | SWAHB | Capital | Revenue | ECAHB | Capital | Revenue |
|---|---|---|---|---|---|---|---|---|---|
| Comprehensive Care | | | | | | | | | |
| Independent/ Supported Living Units | | | | | | | | | |
| Respite | | | | Newbridge(Cheshire Foundation) Project Providing 5 new places from 2003 | €1,218,948 | €609,474 | | | |
| Challenging Behaviour Unit | Possible Joint Funding with 10 places ECAHB Challenging Behaviour Unit Huntington's Chorea Unit | €1,016,000 (NAHB portion) | €1,372,000 | | | | Possible Joint Funding with NAHB 10 places | €1,016,000 | €1,372,000 |
| Rehabilitation/ Transition/ Outreach | | | | | | | | | |
| 2005(Yr3) | NAHB | Capital | Revenue | SWAHB | Capital | Revenue | ECAHB | Capital | Revenue |
| Total | | €1,016,000 | €1,372,000 | | €1,218,948 | €609,474 | | €1,016,000 | €1,372,000 |

**YEAR 3 TOTAL CAPITAL €3,250,948 TOTAL REVENUE €3,353,474**

**TOTAL CAPITAL YEARS 1-3 = €9,130,581**

## 7. IMPLEMENTATION PLAN

The proposed order of implementation of the recommendations follows a broad sequence:

1. A process of identifying those clients currently in hospital, who could move into supported living accommodation, if this was available, should be agreed upon and commenced. Arrangements around this process may need to be linked with ongoing implementation of the Regional Physical and Sensory Disability Database.

2. Concurrent planning should take place around creation of additional facilities for the next 3-5 years, and beyond. Such planning should take both capital and revenue issues into consideration. In this regard, potential usage of the Capital Assistance Scheme should be explored. Preliminary planning around usage of capital funding for developments should be agreed by the end of January 2002, while a broad, overall plan for extended usage of this capital should be complete by April 2003.

3. Guidelines and protocols around accessing of services should be developed. Specific attention should be directed towards the development and implementation of a co-ordinated, transparent, user friendly database.

4. Recommendations for the development of rehabilitation and associated services in the Region are required. The Health Strategy requires the development of of an Action Plan on Rehabilitation for persons with physical and sensory disability by the Department of Health and Children, by the end of 2002. The Department has acknowledged that the outcomes of the Conference on Rehabilitation in October 2002, cohosted by the Eastern Regional Health Authority and the National Rehabilitation Hospital, will underpin development of this plan. In this regard, a comprehensive review of existing rehabilitation services in the region should be initiated with a remit to examine models of good practice and to address the current situation, gaps identified within the service, existing constraints, projected needs and development and so on. This review will highlight issues around service provision for young chronic disabled clients and inform the development of the Action Plan. The terms of reference of this review, together with appointment of a Researcher, should be concluded by the end of November, and preliminary findings released by the end of March 2003. Such findings should thus also further inform planning and implementation of recommendations around the young chronic sick review.

5. Representations should be made on an ongoing basis to the Department of Health and Children around the need for development funding addressing the critical identified needs of young chronic clients as a matter of priority. This is especially important in the light of high costs associated with provision of appropriate accommodation, support and care of clients.

6. All progress made, as well as constraints experienced, should be recorded on a quarterly basis, starting at the end of December; an interim report, detailing outcomes and evaluating progress, should be prepared by the Service Planner by the end of March 2003. Findings here should inform allocations for 2003 in terms of additional identified need and services requiring further expansion and enhancement.

8. Standards and models of good practice around provision of suitable accommodation, together with levels and nature of care, should be developed to facilitate some consistency and standardisation around the management of young chronic sick clients throughout the region. These will be developed in line with the process initiated by the National Disability Authority and should be agreed by mid March 2003.

9. Costings around provision of a range of accommodation, together with appropriate care and support should be investigated and a costing model developed in this regard. This should be initiated by the end of October and concluded by the end of February 2003. Issues around costings of bed occupation in an acute hospital by a young chronic disabled client, should also be addressed in this research.

10. Final decisions around development of accommodation should be approved by April 2003. Planning and design of units / houses should commence, and planning permission should be sought. Following this, it is anticipated that development could commence as per the framework of the proposals outlined previously.

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*10.Michael Kelly; ( May 2002) Investment in Health: Are we getting a return? Annual Conference of the Fiscal Studies Foundation.*

*Appendix I.*

**Working Group on Young Chronically Ill**

| | |
|---|---|
| Ms Mary Van Lieshout | Eastern Regional Health Authority |
| Ms Diane Nurse | Eastern Regional Health Authority |
| Ms Leonie O'Neill | East Coast Area Health Board |
| Mr John O'Sullivan | East Coast Area Health Board |
| Mr Brian Burke | South Western Area Health Board |
| Ms Regina Buckley | South Western Health Board |
| Ms Violet Harford | Northern Area Health Board |
| Ms Kay Hennigan | St Vincent's University Hospital |
| Ms Mary Shore | St Vincent's University Hospital |
| Ms Catherine McDaid | Adelaide, Meath & National Children's Hospital |
| Ms Mary Walshe | Peamount Hospital |
| Ms Barbara Fitzgerald | Peamount Hospital |
| Ms Eilish Macklin | National Rehabilitation Hospital |
| Ms Celine Deane | Beaumont Hospital |
| Ms Phil O'Neill | Mater Hospital |
| Ms Sheila White | Mater Hospital |
| Mr Conor Leonard | Royal Hospital Donnybrook |
| Mr Ian Carter | St James's Hospital |
| Mr Michael Murphy | Our Lady's Hospice |
| Mr Mark Blake-Knox | Cheshire Homes |

*Appendix II*

**Glossary of Terms**

A number of conditions lead to physical disability and it would be impossible to include all in this section. People with physical disabilities are a heterogeneous cohort. In general many persons with physical disability suffer from a Neurological condition. Neurological disorders can be *congenital* as in Huntington's Disease, Alzheimer's Disease, Neurofibromatosis, Spina Bifida and Friedreich's Ataxia or *acquired* as in Multiple Sclerosis, Brain Injury and Spinal Injury.
Neurological disorders can be classified as either *static disabling diseases* or as *progressive disabling diseases*.
Some Neurological conditions involve cognitive impairment and / or decline i.e. Parkinson's disease and Traumatic Brain Injuries but not in every case. Equally, inappropriate behaviour can result from brain injury but only in a small percentage of people.
Table 1 lists a sample of both static and progressively disabling neurological conditions.

**Table 1.**

| Progressively Disabling Neurological Conditions | Static Disabling Neurological Conditions |
|---|---|
| Alzheimer's Disease | Cerebral Palsy |
| Certain Brain Injuries | Dyspraxia |
| Dystonia | Head Injury (can also be progressive) |
| Friedrich's Ataxia | Neuropsychiatric conditions |
| Huntington's Disease | Old Polio |
| Motor Neurone Disease | Some forms of Epilepsy |
| Multiple Sclerosis | Spina Bifida |
| Muscular Dystrophy | Hydrocephalus |
| Myasthenia Gravis | Spinal Cord Injury |
| Neurofibromatosis | Stroke |
| Parkinson's Disease | |
| Post Polio Syndrome | |
| Spinal Cord Injury | |
| Syringomyelia | |
| | |

*Appendix III*

**Eastern Regional Health Authority Review of Services for Young Chronically Ill persons in the Eastern Region**

Thank you for assisting us in this effort to develop new services for young chronically ill persons in the Eastern Region. For the purposes of this mapping exercise the following definition applies for the term young chronic ill: " ***Persons between the ages of 16 – 65 years with some form of physical disability resulting in damage to the Central Nervous System".*** Examples of the main causes include: congenital abnormalities, (e.g. Friedreich's ataxia); brain damage at birth, progressive deterioration (e.g. multiple sclerosis) and Traumatic incidents, (road traffic accidents)

**Name of Agency** _____

**Please state the following:**

1. Do you offer residential places for young chronically ill persons?___Yes/ No

If yes, please state the number of places offered__ _____

Please state number of vacancies _____

Do you operate a waiting list for this service? Yes / No

If so, state the number of people on the waiting list as of 30 June, 2001 _____

2. Do you offer respite places for young chronically ill persons?____Yes/ No

If yes, please state the number of places offered_____

Please state number of vacancies_____

Do you operate a waiting list for this service? Yes / No

If so, state the number of people on the waiting list as of 30 June, 2001 _____

3. Do you offer Day places for young chronically ill persons?_____ Yes/No

If yes, please state the number of places offered_____

Please state number of vacancies_____

Do you operate a waiting list for this service? Yes/No

If so, state the number of people on the waiting list as of 30 June, 2001_____

Community Based/Home Supports

4. Does your agency provide a community based/outreach physiotherapist service? Yes/No

If yes, state the number of physiotherapists employed in your service_____

5. Does your agency provide a community based/outreach occupational therapist service? Yes/No

If yes, state the number of occupational therapists employed in your service_____

6. Does your agency provide a community based/outreach speech and language therapist service? Yes/No

If yes, state the number of speech and language therapists employed in your service__

7. Does you agency provide personal assistants to young chronically ill persons in your area? Yes/No

If yes, how many personal assistants in your service are providing service to young chronically ill persons? _____

How many clients avail of the personal assistant services?_____

8. Does your agency provide home help to young chronically ill persons in your area? Yes/No

If yes, how many clients are availing of this service _____

If you are offering other services for young chronically ill persons in your area, please describe these:

_____

_____

_____

_____

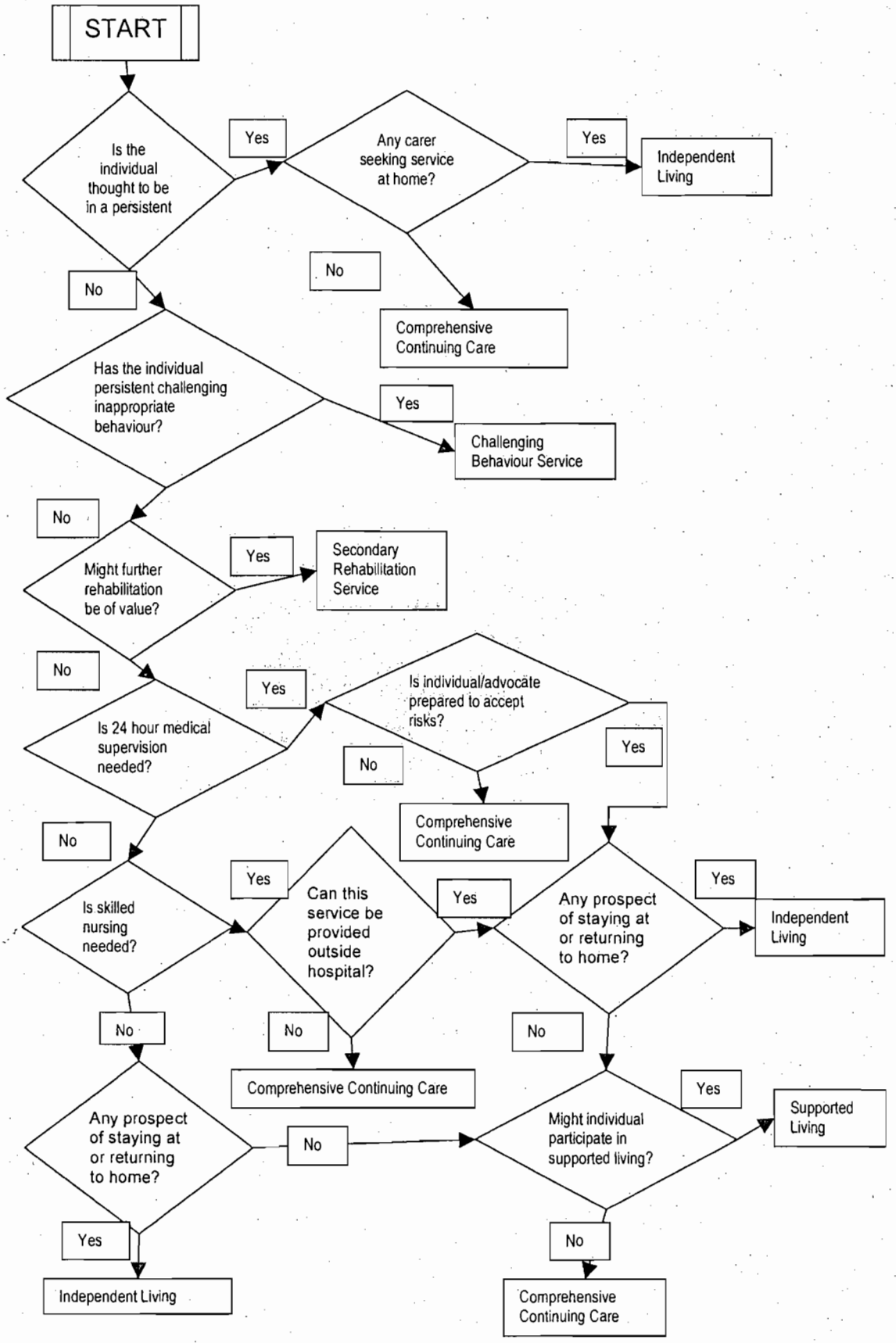
_____

_____

Thank you for your support in this research.

Service Planner
Disabilities Services
ERHA

*Appendix IV.*




**Proposed Draft Standard Assessment Tool for ERHA Young Chronic Sick Review**

The ERHA working group, which includes the above service providers, envisages five broad types of provision to meet the needs of people under 65 who have submitted applications for accommodation and support services. These are as follows:

**Independent Living**

Individuals living in their own home with whatever support is required to facilitate this, either that be from 10 minutes of home help to 24 hour nursing support, (but excluding daily medical presence). The individual or their advocate should be willing and able to negotiate the level of support and direct its provision where required e.g. instructing personal attendants. Many people with medical conditions have lived at home successfully with the support of family/carers and community nursing and often support services. Therapeutic/paramedical services would be provided through community services. A link to a secondary rehabilitation facility to deal with sudden changes in health status would be available. For the purposes of this exercise, supporting a severely physically and cognitively compromised person at home is classified as a form of independent living.

**Supported Living**

Individuals living in accommodation where up to 24 hour social (not necessarily nursing or medical) support is provided. Accommodation may be private or shared. The role of the support is to ensure that individuals are supported to participate in activities that maintain health and social gain e.g. taking medication at appropriate times, keeping appointments, undertaking normal activities such as vocational training, work, shopping and social activities with level of abilities. Medical input and therapy/paramedical services would generally be on a General Practitioner or out-patient basis, although some residents may have more regular therapeutic/paramedical input. Medical nursing intervention if needed should be assessed from community services. A link to a secondary rehabilitation facility to deal with sudden changes in health status would be available.

**Secondary Rehabilitation**

A facility for individuals who require the opportunity of an extended period of comprehensive rehabilitation (envisaged as being up to 18 months) to allow maximum recovery of adaptation from an onset of disability. Standard services would include medical cover and the full range of nursing and paramedical rehabilitation e.g. PT, OT, SLT, Social Work, Nutrition. Staff ratios would be such as to facilitate seven day, twenty-four hour therapeutic input based on meeting the support needs of service users. Individuals may or may not have already undergone an acute phase of rehabilitation where some progress has been shown, but where the need for further time is indicated. Individuals would have to progress to another form of care at the end of the rehabilitation period. Individuals may return for planned periods of additional service of for emergency respite. Accommodation may be private, semi-private or ward based.

## Comprehensive Continuing Care

A facility with 24-hour medical cover and nursing care, access to dedicated therapeutic/paramedical services on a consultative basis, with regular diversional activities. Individuals envisaged for this service would be medically compromised to the extent that medical or nursing cover is considered essential, and/or physically or cognitively compromised to the extent that any of the other forms of service provision described would be unlikely to meet their needs. Accommodation might be private, semi-private or ward-based.

## Challenging Behaviour Service

A service that is designed to cope with and potentially modify persistent challenging or inappropriate behaviours i.e. screaming, verbal and/or physical aggression, inappropriate sexual behaviour. Individuals may be independently mobile or wheelchair users. Medical, nursing and therapeutic/paramedic services for rehabilitation would be a key component, as in secondary rehabilitation. Locked wards/facilities may be an element of the service. It is hoped that individuals would progress to an alternative form of service provision, but it is recognised that for some this might not be possible.

### Process for Assessment of Service Needs

It is envisaged that the assessment process will be in two stages.

Stage 1: The applicant or their advocate will be given a copy of the service descriptions and will be asked to select their preferred type of service.

Stage 2: In the second stage, a multidisciplinary team (MDT) familiar with the individual will be asked to read the service definitions and then use the flow chart below to aid decision making in regard to the most likely service type to be of benefit to each applicant. Where no MDT is involved, a health professional will be asked for an opinion.

Analyses of the person/advocates own preference compared to MDT/professional view would then be undertaken.

It is acknowledged that quantitative, rather than highly objective, decisions will be required at some stages in this process. The following definitions are provided to assist:

1) Prospect of staying/return to home:

For a "yes" answer the following would probably apply:

- An individual (or their carer/advocate) clearly wishes to stay at/return to home

**And**

- there is a home to return to (modified, if necessary/possible), **and**
- any other family at the home are willing to support the individual's return.

2) Persistent /Challenging behaviour

Behaviours such as persistent screaming/shouting, verbal and/or physical aggression and/or inappropriate sexual behaviour. Such behaviours should occur daily and persist for extended periods e.g. an hour. The behaviour should occur in the absence of any identifiable stimulus, and may occur even when attempts are being made to occupy the individual. A medical history of brain injury is likely, possibly with prior alcohol abuse or psychiatric illness.

3) Medical supervision

Any condition and/or intervention that requires daily monitoring, maintenance or supervision by a medical practitioner e.g. Tracheotomy, Assisted mechanical breathing, Hickman lines.

4) Skilled nursing

Any condition and/or intervention that regularly require the skills of a qualified nurse e.g. PEG feeding, NG tubes, Supra-pubic catheter, and colostomy. Someone who is not a nurse may be trained up to undertake some elements of the work, but the supervision and assistance of a nurse would still be required regularly.

5) Participate in Supported Living

It is envisaged that individuals in this form of living would be independently capable of some degree of social interaction, either with carers or other residents (if accommodation is shared) and be capable of participating in social/vocational/recreational opportunities. In exceptional circumstances, someone is capable of interacting but who needs a constant nursing presence may be suitable for this service.

*Appendix V*

| Agency Name | Total Agencies in Study: 39 |
|---|---|

"Cuan Aoibheann", St Mary's Hospital, Phoenix Park

Adelaide & Meath Hospital, incl. National Children's Hospital,

Ardeen Cheshire Home, Shillelagh, Co Wicklow.

Barrett Cheshire House, Herbert Street, Dublin 2.

Beaumont Hospital, Dublin 9.

Blackrock Cheshire Apartments

Cara Cheshire House, Phoenix Park, Dublin

Central Remedial Clinic, Vernon Ave, Clontarf, Dublin 3

Cheshire Foundation in Ireland, 1-4 Adelaide Rd, Glasthule,

Co Wicklow Ass. For the Mentally Handicapped

Cystic Fibrosis Association of Ireland

Debra Ireland

Enable Ireland - Wicklow Service

Enable Ireland, Dublin Services

Friedreich's Ataxia Society Ireland

Headway Ireland

Irish Motor Neurone Disease Association

Irish Wheelchair Association ERHA Region

LISBRI, Cherry Orchard Hospital, Dublin 10

Mater Misericordiae Hospital, Dublin 7.

Molyneux Home for the Blind, Leeson Park, Dublin 6.

Multiple Sclerosis Society of Ireland, Bloomfield Ave,

Muscular Dystrophy Ireland

Naas Hospital, Blessington Road, Naas, Co Kildare

National Association for Deaf People

National Council for the Blind

Our Lady's Hospice, Harold's Cross, Dublin

Peamount Hospital, Newcastle, Co Dublin

Post Polio Support Group

RehabCare, Ballyfermot, Dublin 10

RehabCare, ERHA

Richmond Cheshire House, Monkstown, Co Dublin

Royal Hospital, Donnybrook, Dublin 4

St James Hospital, Dublin 8.

St Mary's Hospital, Baldoyle

St Mary's Centre for Visually Impaired, Dublin 4

St Mary's Residence for Deaf Girls, Cabra, Dublin

St Vincent's Hospital, Athy, Co. Kildare

St Vincent's University Hospital, Dublin 4

## *Appendix VI Agencies responding to queries around Waiting Lists*

| | |
|---|---|
| 1 | St Vincent's University Hospital |
| 2 | St James Hospital |
| 3 | St Colmcille's Hospital, |
| 4 | The Mater Misericordiae Hospital |
| 5 | Adelaide & Meath incl. National Children's Hospital |
| 6 | Beaumont Hospital |
| 7. | St Michael's Hospital |
| 8 | James Connolly Memorial Hospital |
| 9 | Naas Hospital |
| 10 | Our Lady's Hospice |
| 11 | Royal Hospital Donnybrook |
| 12 | Peamount Hospital |
| 13 | Cheshire Foundation |
| 14 | LISBRI, Cherry Orchard |
| 15 | St Mary's Hospital, Baldoyle |
| 16 | Cuan Aoibhean |
| 17 | Nursing Homes† |

†Details of People residing in Nursing Homes and who may or may not wish to be transferred to more stream lined accommodation is not available on this occasion. Three Nursing Homes were forthcoming with information. However as contact was established late in the study this valid information contributes valuable but unverifiable data.