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# Nowhere to go

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**The Continuing Education Needs  
of People with Intellectual Disabilities  
in the Bray Area at the Time of  
Reaching Adulthood**

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February 2005

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**February 2005**

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**Trutz Haase & Karena Byrne (February 2005)**

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### Disclaimer

The views and opinions contained in this report are those of the authors and do not necessarily reflect the views or opinions of the National Disability Authority or any other of the funders. The NDA and other funders do not assume any legal liability or responsibility for the accuracy, completeness or usefulness of information provided, and no cause of action shall accrue against them in respect of this research.



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## Executive Summary

In 2003 eight young people with a learning disability from the Bray area had nowhere to go when finishing their formal schooling. The distress for the young people and their families was considerable, and this should clearly never have happened. For every ordinary family the transition to adulthood involves considerable challenges for both the young person and their family. For a person with learning difficulties and in need of special provision and assistance the choices are more restricted and the hurdles to overcome are infinitely greater.

After considerable political pressure was applied through public meetings, last-minute accommodation in adult services was obtained for the eight young people towards the end of 2003, but questions remained as to how the Irish education and health care systems could have failed to meet their responsibilities to such an extent. For this reason, the Disability Cluster Group of the Bray Partnership sought and received funding from the National Disability Authority, the HSE East Coast Area and Comhairle to commission a study of the needs of young people with intellectual disabilities at the time of their transition to adulthood. The Bray Partnership, in turn, commissioned Trutz Haase and Karena Byrne to undertake the study. This report is the outcome of the work that they undertook between May and October 2004.

The study takes place against a background of rapid change in how society provides for people with disabilities, in general, and people with intellectual disabilities in particular. Broadly speaking, this change involves a move from a mainly medically-based and highly institutionalised response, towards a socially-based model where people are understood as having different abilities. Some people are in need of special assistance to fulfil their potential within society, and society has an obligation to provide the necessary supports to include everyone to the maximum possible.

This development, while being omni-present, is nevertheless also uneven. Some institutions are faster and others slower in their adaptation to the changing paradigms. This is reflected in differing attitudes and expectations by those who have special needs, their carers, those who are providing services for those with special needs and the legal and institutional environment. One major act of disability legislation was passed in the Oireachtas during the period in which this study was undertaken alone, and two more introduced as a Bill, indicating the magnitude of change currently taking place. This study highlights at the micro level where current changes are operating well and where adaptation to the changing environment is lacking. As such, the study aims to highlight not only the circumstances that led to the failure of the state's institutions to deliver adequate care, but also to reflect on the structural shortcomings that need to be addressed in the emerging legislative and institutional frameworks.

### The Study Participants

Participation was sought from families with a child with intellectual disabilities aged between 13 and 18 years and attending school, or a family member aged between 18 and 25 years and attending adult services. The purpose of seeking the co-operation of these two cohorts was that the first group would provide us with information about the young people who will leave school over the next five years, while the second group would provide valuable information about how those concerned have experienced the transition to adulthood over the past few years.

As a result, 25 young people participated in the study, all of whom were in the moderate to severe range of intellectual disabilities. In most cases, extensive structured interviews were held with both the young person and at least one of their parents. Considerable emphasis was placed on encouraging the young person to contribute as much as possible to the interview and to

express their own concerns. The degree to which this was possible, however, depended on the degree of disability, both intellectual and physical, and in a significant number of interviews all information was provided by or mediated through the parent. In addition, systematic information was sought from all major stakeholders who are involved in either the provision of services or on behalf of the clients.

### **The Experience at School**

One of the most welcome findings of this study is the positive response of young people with intellectual disabilities and their parents to their overall school experience. Nine out of ten respondents rate the support that they have been given by their (special) school as either good or very good. The other ten per cent rate the school as reasonable, with no respondent rating their school as bad or very bad. This is a most welcome outcome and seems to acknowledge the significant changes that schools have undergone in recent years.

At the root of this positive response is the fact that each of the schools in question are able to integrate, at least to a certain extent, the various aspects of support required by the young person. Rather than having to deal with multiple service providers, the schools provide, in general, access to a variety of services in addition to looking after educational needs, including the assessment of a student's learning ability, the allocation of educational counsellors/advisors, school transport, as well as access to speech therapy, physiotherapy, occupational therapy, and respite care, where needed. The schools thus, at least to some degree, provide a one-stop-shop for the young person and their family. This being said, the school context is not completely without conflicts and difficulties and the report identifies some of the specific shortcomings.

### **The Experience after School**

The first observation with regard to adult services in the Bray and Wicklow area is the limited choices that young people have after finishing school. In itself, this does not mean that the quality of services is poor, but that the provision of educational services for young people with intellectual disabilities is highly concentrated in two service providers: Sunbeam House Services and the National Training and Development Institute (NTDI). Other service providers are comparatively small in terms of the number of clients that they can cater for, although certain services are of a very specific nature, and thus of huge importance to the individuals concerned. The consultants thus identify the need for greater dispersion of services throughout the area in the longer run, mainly to provide greater choice between service providers, as well as to provide community-based services closer to where people live throughout the whole of the county.

The experience of the young people and their parents after leaving school could not be more different from that at school. Unlike the comprehensive care that is provided by special schools, adult services are first and foremost training providers with specialist services being provided through the Health Services Executive on the basis of individual needs. In practice, this means that either the service provider or parents must apply for each individual service, and provision relies on the extent to which services are generally available in the Health Services Executive area. The struggle for parents to secure an adequate package of services for their young adults is considerable and often frustrating.

By far the greatest shortcoming is with respect to speech therapy. In our sample, ten out of twelve young people attending adult services were in need of speech therapy. Only two received speech therapy at an adequate level. In eight out of ten cases, the level of provision fell short of what was deemed appropriate, and in four cases the young person had absolutely no access to speech therapy, despite being profoundly affected by speech impediments.

Fortunately, physiotherapy seems to be better provided for in the area. Five out of twelve respondents indicated a need for physiotherapy and four of these were receiving appropriate support.

The same numbers were in need of occupational therapy. Three of these indicated mild to moderate needs but had no or only marginal access to occupational therapy, thus indicating a considerable shortfall in this area of service provision.

Transport to and from adult services and other activities is a major issue and, overall, there is considerable dissatisfaction with the level of specialist transport services being provided and the existing work practices of those services that do exist.

With regard to the education of young adults, all of the service providers adhere, in principle, to a person-centred planning approach, reflecting the clear shift in educational paradigms over the past decade. Indeed, one could say that the special education sector is probably at the forefront of change in this regard within the education sector as a whole. However, there are some shortcomings as to how the person-centred planning is being implemented.

Adult service providers tend to treat their clients as adults, thus largely relying on communication with the clients themselves, rather than their parents in developing individual educational and service plans. In contrast, the parents generally hold that the young adult, because of their intellectual disability, does not have the capacity to always see the full implications of their own decision making. They thus frequently feel that their children, albeit being adults, are not being challenged sufficiently and left too much to their own devices.

The consultants do not believe that there is an insurmountable problem with this point of contention, but have noted rather poor paths of (structured) communication between the service providers on the one hand, and the parents on the other. It is thus welcomed that this shortcoming has already started to be addressed by some of the service providers during the course of this study.

### **Addressing Future Learning Needs**

Without doubt, the most important issues arising from this study concern the proposed disability legislation and the emerging frameworks and institutional settings for people with special needs. Indeed, due to the study's particular focus on the needs of young people with intellectual disabilities *at the time of their transition to adulthood*, this study highlights some of the present shortcomings which, if not addressed, are likely to persist into the future.

The main issue in question is how a person-centred planning approach for the (educational) needs of a young person is put into practice at the time of their transition to adulthood. As we have pointed out, both special schools and adult service providers alike have generally adapted well to a person-centred planning approach, but there prevails a remarkable lack of such an approach to the transition itself.

Notwithstanding the fact that each of the (special) schools provide specific transition programmes, such programmes largely depend on bilateral relationships between each of the schools and specific service providers. There is currently no specific needs assessment undertaken towards the end of schooling to facilitate the planning for continuing education into adulthood. At present, it is generally the adult service provider who will undertake such an assessment after the transition has taken place. This, however, falls far short of the needs of the young person as he or she has to consider all of his or her options before finishing school.

This shortcoming is partially addressed in the *Education for Persons with Special Educational Needs Act 2004*, which stipulates that the future special educational needs shall be assessed during the 12 months prior to which a person is reaching the age of 18. The Act further stipulates



that, to this end, the wishes of the child concerned and of his or her parents be ascertained. However, the Act is far from guaranteeing a comprehensive and person-centred approach in planning for the continuing education needs of young people with intellectual disabilities.

Firstly, the act is ambiguous about who is *ultimately* responsible for such assessment being made as it leaves it somewhat open whether the assessment should be made by the principal of the relevant school, or by the relevant special educational needs organiser, who will be employed by the Health Services Executive. This is a recipe for disaster, as it allows two authorities to point the finger at one another, instead of clearly allocating an overall responsibility to one authority.

Secondly, the Act foresees a certain role of the newly established National Council of Special Education (NCSE) in reviewing an education plan for a child who has special education needs and who within the following 12 months will reach the age of 18 years. However, no role whatsoever is given to the Council after the young person has reached the age of 18. Thus there is no guarantee or even responsibility to ensure that the plan actually takes effect.

Thirdly, a comprehensive and person-centred approach to planning for the future educational needs of a person with (intellectual) disabilities comprises an array of additional elements that are not included in the present legislation. These are:

- the need for advance visits to each family approaching the transition before the young person leaves school, providing a “one-stop-shop” approach to service provision;
- the provision of comprehensive information about all educational options available to the young person;
- the provision of comprehensive information in relation to the young person’s and the family’s entitlements to benefits and services;
- ensuring that an appropriate package of educational placement and complementary services (therapies, personal assistant, assistive technology, resource teacher, job coach etc.) be put in place for each young person with intellectual disabilities upon leaving school.

These concerns are partially dealt with under the *Disability Bill 2004* and the *Comhairle (Amendment) Bill 2004*, both of which are currently at the ‘bill’ stage; i.e. they are not yet passed as legislation and the final Act(s) may still see considerable changes from their current formulation. Furthermore, there is no timeframe yet as to when the two bills may become legislation. It is even less certain when relevant parts may be fully implemented.

The *Disability Bill 2004* largely provides a framework for the mainstreaming of disability services, thus transferring the overall responsibility from a medically-based model to one where all departments and agencies have to take on responsibility for a socially inclusive delivery of services.

The development of an independent personal advocacy service (i.e. independent of the two main service providers: the Department of Education & Science and the Department of Health & Children) is principally provided for in the *Comhairle (Amendment) Bill 2004*. However, there are no indications yet as to how this will be implemented, the resources available, and the timeframe within which a comprehensive service will become operational. The bill further seems to be relating to adults only and thus stipulates no responsibility in advance to reaching adulthood. Finally, the bill is only designed to provide a personal advocacy service upon application, rather than the automatic appointment of an advocate to each young person with special education needs.

The consultants thus conclude that, until such a service is fully operational, the ultimate responsibility for a comprehensive needs assessment in advance of reaching adulthood and the (interim) responsibility for a personal advocacy service has to lie with the regional Health Services Executive.

# 1 Introduction

## 1.1 Historical Background

In 2003 eight young people with a learning disability<sup>1</sup> from the Bray area had nowhere to go when finishing their formal schooling. The distress for the young people and their families was considerable, and this should clearly never have happened. For every ordinary family the transition to adulthood involves considerable challenges for both the young person and their family. For a person with learning difficulties and in need of special provision and assistance the choices are more restricted and the hurdles to overcome are infinitely greater.

Eight young people had no care provision put in place. This represents approximately half the annual average of school leavers with a need for special care provision in the Bray/Wicklow area. How could this have happened? How could the Irish education and health care systems fail to meet their responsibilities to such an extent? How could this have happened, despite the establishment of the National Intellectual Disability Database, which was specifically created in order to assist seamless forward planning for individuals like these? Could it happen again? Where did the failure originate and what structures need to be put in place in order to avoid further breakdowns in state responsibilities? These are the questions that the young people concerned, their parents and other stakeholders involved in the delivery of services for people with intellectual disabilities have been asking.

After considerable political pressure was applied through public meetings, last-minute accommodation in adult services was obtained for the eight young people towards the end of 2003, although the questions posed above remain unanswered. For this reason, the Disability Cluster Group of the Bray Partnership sought and received funding from the National Disability Authority, the HSE East Coast Area and Comhairle to commission a study of the needs of young people with intellectual disabilities at the time of their transition to adulthood. Clearly, lessons must be learned from this experience, lessons that would likely be of relevance beyond the Bray and Wicklow area and potentially of national importance. The Bray Partnership, in turn, commissioned Trutz Haase and Karena Byrne to undertake the study. This report is the outcome of the work that they undertook between May and October 2004.

## 1.2 Aims of the Analysis

The overall aim of the research was to carry out a profiling and analysis of the continuing education needs of people with intellectual disabilities in the Bray and Wicklow area at the time of reaching adulthood. In particular, the following aspects were to be considered:

- To conduct a statistical analysis of people with intellectual disabilities in the Bray area who have completed or are about to complete school and to turn 18 years of age, including age, type and degree of intellectual disability, gender, socio-economic and family characteristics, support networks, etc.
- To examine the progression of service users when they have completed school and entered adult services.

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<sup>1</sup> Note: Throughout this report the terms *learning disability* and *intellectual disability* are being used interchangeably. In the context of the day-to-day experience and the lifelong learning needs of people with intellectual disabilities, we will use predominantly the former, while in the context of the National Intellectual Disability Database we will use the latter term.

- To evaluate the current policy and service response from a number of stakeholder perspectives.
- To identify creative ways of ensuring effective educational progression paths for people with learning disabilities.
- To examine and present good practice models in other comparable jurisdictions and identify the lessons for policy and service planning in the Bray area.
- To offer a set of recommendations for the future development of the policies and services for the target group.

The study subsequently evolved from this set of goals towards a slightly broader consideration of the issues ensuing from the transition into adulthood for people with intellectual disabilities.

### 1.3 Structure of the Report

There are a significant number of young people with mild learning disabilities who are catered for entirely through the mainstream schools and institutions of further education. Although they may, to differing degrees, also be in need of some special assistance, this is generally provided through the respective institution as part of a growing trend towards more inclusive services provision. The focus of this study is on those young people with moderate to severe and profound intellectual disabilities who are in need of substantial support to achieve their educational potential and who, for this reason, are generally registered with the National Intellectual Disability Database.

In Section Two, we will consider some of the general issues related to the transition to adulthood and the concept of lifelong learning. We consider the specific meaning of these terms for people with intellectual disabilities. This section also provides a brief literature review, notably with regard to recent developments in the UK. The Section finishes with a brief outline of recent legislative changes in Ireland, notably the passing of the *Disability Bill 2004* and the *Education for Persons with Special Educational Needs Act 2004*.

Section Three provides an overview of the institutional setting in the Bray and Wicklow area. Starting with an estimate of the average number of people with intellectual disabilities approaching the transition to adulthood in any given year, the section then provides a schematic overview of the schools and adult service providers in the area, as well as showing the main movements of people between these as they approach adulthood. The section finishes with an analysis of the main characteristics of the sample of young adults and their parents who participated in this study.

Sections Four and Five discuss in greater detail what happens within the school and adult services. It provides more detailed information about how the schools provide for the special needs of people with disabilities and then relates those provisions back to the experience of those who participated in the survey. Section Five provides the analogous discussion with regard to adult services and Section Six briefly deals with choices about work.

Section Seven summarises the key issues concerning the future learning needs of people with intellectual disabilities. In doing so, the section highlights conceptual issues and the key role of the regional Health Services Executives in guaranteeing each person with learning disabilities appropriate access to further education.

Section Eight contains a small number of key recommendations. Rather than putting forward a large number of very specific recommendations, many of which can be

overlooked or deemed irrelevant, we have decided to emphasise a smaller number of key recommendations, each of which should be accorded a high priority.

The study involved a large number of in-depth interviews with all of the major service providers and other stakeholders in the Bray and Wicklow area. Rather than dedicating a separate chapter to the views expressed, the information gained through the interviews is taken into account throughout the whole study.

Finally, the study contains a sizable appendix, that provides a considerable number of tables based on the National Intellectual Disability Database. The tables are identical in format to those published in the recent annual report on the database by the Health Research Board, except that they provide the data for the HSE Eastern Region and Bray and Wicklow areas.

## **2 Lifelong Learning and the Transition to Adulthood**

### **2.1 General Issues**

Becoming an adult involves huge changes for the individual concerned and for his or her parents. Ultimately, it is the point where a person is seen to be individually responsible for their own future and well-being. Not everybody is equally equipped to take on this responsibility. Yet, legally all adults are treated in the same way, regardless of their capacity to comprehend and meet the tasks involved.

This raises major issues for those who care for a young person with a learning disability. On the one hand, when he or she reaches the age of eighteen, the young person has to be considered an adult who is capable of making decisions about their own good; on the other hand, as parents frequently point out, because of the intellectual disability, their child doesn't have the same maturity as an ordinary eighteen-year-old and thus cannot always see the implications of their own choices. They may therefore be unable to make far-reaching decisions on their own. As we will see later in this study, this contradiction frequently results in conflict between parents and service providers as they differ in their treatment of the young adult.

This study deals with the learning needs of young people with intellectual disabilities at the time of the transition to adulthood. First and foremost, this is the point at which formal schooling ends and some other provision needs to be put in place for the young person concerned. This is of particular significance as the young person with a learning difficulty is generally believed not to have reached a sufficient level of intellectual maturity to be able to find their own way in society. Thus, by definition, their post-school placement has to be first and foremost educational in character. Furthermore, it must be moulded explicitly to the specific needs of each individual in order to maximise their future prospects of leading a full and meaningful life and participating fully in society. People's needs vary widely in terms of the intensity, nature and duration of the support that they require. Again, and as we will show in later chapters, there can be wide disagreement about what a particular person requires and, even if there is agreement about the person's needs, there can still be a wide gap between what is deemed appropriate and what the relevant institutions can actually provide.

Finally, the current lack of comprehensive services for young people with intellectual disabilities raises fundamental questions about the right of access to education in general. For most of the readers of this report the concept of 'lifelong learning' will be a familiar one. This may be associated, for example, with attending a school to complete basic education for those who left school early, or tackling special educational interests. Alternatively, it may be linked with taking the Leaving Certificate or attending Third Level education having entered work or after having cared for a family at home. These familiar concepts of lifelong learning reflect a broadly-held belief that lifelong learning is not only a luxury, but has increasingly become a necessity to cope with a rapidly changing world.

For most people with intellectual disabilities the situation couldn't be more different. At the mild to moderate level of disability, it may involve some extra years of person-centred education after which the person may, possibly with further assistance, participate in other mainstream educational environments. At the severe to profound level of disability, the lifelong learning aims may involve the most basic levels of life skills and personal interaction or communication. Yet, while providing the wider society with multiple lifelong learning opportunities, the state continues to deny even the most basic educational opportunities to individuals with severe and profound intellectual disabilities. This does not mean that the state does not provide in some way for the individuals and families involved,

but it means that there is no guarantee that sufficient support will be provided; nor can parents legally enforce provision where they feel that the young person's right to an education is not being met. In Ireland, there is no legally enforceable right to education after the age of 18, regardless of what level of education has been achieved by this age.

## 2.2 When School is Finished

When leaving school at age eighteen, a number of possibilities arise in relation to the future learning environment for people with learning disabilities.

Some students with mild learning disabilities may be able to enter other educational establishments. Whether or not they are able to do so may depend in a major way on the access criteria of the school or college, as well as the supports that the school or college can provide. There have been significant improvements over the past few years in this respect with many of the further education colleges providing specific access routes for people from socially disadvantaged backgrounds or with a physical disability.

For many of the young people with moderate to severe learning disabilities the most likely path after leaving school is to enter a special education environment. For historical reasons, these continue to be referred to as 'adult services'. Despite our dislike of the term 'adult services', we will use it throughout this study as it is commonly understood by parents and service providers alike, at least in the Bray and Wicklow area.

Adult services are the primary destination for the majority of the people whose educational needs we are dealing with in the current study. This applies equally to the majority of families interviewed, where the teenager with a learning disability is still attending school, as well as those who have undergone the transition to adulthood in recent years. There is some ambiguity as to what 'adult services' exactly entail: In the view of the service provider, and the professionals working within them more generally, this is an educational service provided to an adult and can be compared with other third level educational institutions, albeit at a much lower educational level than is usually associated with further education. In the view of most of the parents, however, adult services in reality constitute an extension of secondary education. This view is understandable, as they rightly perceive their children as not having achieved the mental maturity typically associated with completing second level. The parents' understanding is further reinforced through the lack of institutional separation of primary and secondary level within the Special Schools system.

A small number of young people with learning disabilities seek to enter employment after leaving school. Frustrated by their difficulties at school and preferring to avoid special attention, while also wishing to gain independent access to money, they would like to enter some kind of paid work. While the number of those who seek direct employment is small, this clearly involves an important transition. Furthermore, for many of those entering adult services, this remains a key goal to confront, albeit at some later time in their life, typically three to four years later.

For a number of young people with a learning disability, particularly where he or she has a primary physical disability, none of the above settings may be feasible. Because of their extensive need for both medical and educational assistance, existing adult service providers are generally unable to offer these individuals a suitable placement. There is some debate as to whether the existing service providers should extend their services to provide for this group or whether new and more specific services need to be set up in the Bray and Wicklow area. Nevertheless, it is very clear from our research that this could become a major shortcoming in the years ahead, if not planned for immediately.

## 2.3 Becoming an Adult

In addition to raising the issue of their current and future educational needs, the transition to adulthood involves a number of areas where the young person with a learning disability may need particular assistance. Among others, these involve:

- effective participation in social life, communication and inter-personal skills;
- looking after one's own well-being in terms of personal hygiene, eating, dressing etc.;
- preparing for/dealing with independent living;
- being able to read and write;
- preparing for/dealing with financial commitments;
- the transition to work and making a meaningful contribution to society;
- being in work.

Where the person with a learning disability also has a primary physical disability, the aims may be much more essential, and involve:

- being able to express oneself and to communicate with others;
- having the use of one's hands and arms;
- achieving independent mobility.

There is no single model that can meet each individual's needs and the best approach to helping them to make advances towards independence as an adult is to adopt what is known as a Person Centred Planning or PCP approach to their education.

A Person Centred Planning approach to education entails the development of an individually tailored education plan for each person concerned. The emphasis is on identifying what a person may wish to achieve in the immediate future as well as further ahead, and to identify the specific supports that need to be put into place to enable that person to reach their aims. While the PCP approach to learning is rapidly gaining acceptance within the professional special education environment, a considerable gap remains between theory and practice. In practice, one still frequently finds that the organisational needs of the educational establishments take precedence over the educational needs of the individual; generally, the individual has to 'fit' into the given institutional set up, rather than the educational establishment asking itself how it can cater for the individual concerned.

## 2.4 Some Lessons from Abroad

It is interesting, in this context, to look at recent developments in the United Kingdom. The UK Government is currently developing a new service – Connexions – which aims to ensure that young people have access to services wherever they live, and that these services are effective regardless of what their background, gender, religion, race, ability, disability or sexuality may be.

The Connexions Service has specific responsibilities for young people with learning difficulties and disabilities. These are set out in the Services for Young People section of the Connexions Business Planning Guidance and have, in part, been informed by the responsibilities that are specified in the Department of Education & Science (UK) Special Education Needs (SEN) Code of Practice and the Learning and Skills Act 2000 (UK). The timetable below, quoted from *Information to Support Connexions Partnerships in their Work with Young People with Learning Difficulties and Disabilities* provides an insight as to how the specific focus on young people with

intellectual disabilities will be implemented. The timetable makes reference to the legislative and other frameworks which may not make much sense to the Irish reader. However, we have decided to quote this timetable in full, as the detailed instructions and tasks identified at varying ages during the transition process are likely to be of considerable interest to some readers.

## **The Connexions Framework - Timetable**

### **Year 8 - suggested activity**

- Personal advisers to ensure that they are aware of all pupils with learning difficulties and/or disabilities
- Personal advisers should liaise with the school to ensure that, as part of information-sharing and referral arrangements, agreement is reached over who supports those young people with learning difficulties and disabilities and how it is organised

### **Year 9 - suggested activity**

- With reference to those young people known to need more sustained support, use the APIR Framework (see Textbox below) to assess needs of statemented and non-statemented pupils including those not in school
- Provision of information on post-16 options by personal adviser/school. Connexions Service has ongoing responsibility to assist the young person and their parents to identify the most appropriate post-16 provision, provide counselling and support, and have continuing oversight of, and information on, the young person's choice of provision
- Personal adviser must be invited to and must attend year 9 review of a young person's SEN statement – Headteacher's responsibility to convene. Local Education Authority convenes review for pupils educated other than at school. This is a requirement of the SEN Code of Practice
- Personal adviser contributes to and oversees delivery of the resulting transition plan as part of the wider Connexions concern to oversee and monitor the student's progress towards adult life
- Headteacher together with Connexions Service should facilitate transfer of relevant information to ensure access to specialist support
- For young people in residential establishments ensure systems are in place for a coordinated approach between home and host partnership

### **Year 10 - suggested activity**

- Ongoing access to information, guidance and oversight of delivery of transition plan; development of APIR process for those with and without statements, including review of progress of young people whose cases are managed via APIR
- Personal adviser attendance at annual review if appropriate

### **Year 11 - suggested activity**

- Ongoing oversight of delivery of transition plan, access to APIR, careers education and guidance, and information on post school options



- Personal adviser should attend review
- Provider of post 16 (non-school) placement should be invited to review
- Section 140 assessment – for young people likely to leave school this year to undertake post-16 education or training or higher education
- Build on process of sharing Section 140 information with Learning and Skills Council to agree range of provision and access
- Ensure transition plans are passed to post-16 provider
- Consider appropriateness of direct payments

#### **Post 16 in school - suggested activity**

- Ongoing support to implement the transition plan and to carry out Section 140 assessment in final year of school – for young people likely to undertake further education or training or higher education

#### **Post 16 in college and training - suggested activity**

- Continue the process of APIR/action planning in the new learning environment, including Section 140 assessments where appropriate
- Personal adviser to set up meetings to arrange transfer to appropriate adult support agency, starting soon after 19th birthday
- Ensure successful transition to post-16 provision

#### **Post 16 not engaged in learning - suggested activity**

- Continue process of action planning to try to reengage in learning
- Help 16/17 year olds with learning difficulties and/or disabilities in receipt of Jobcentre Plus benefits find employment or training; lead responsibility for 18+ in receipt of Jobcentre Plus benefits lies with Jobcentre Plus – ensure transfer of information
- Support those in receipt of other benefits, health and/or social services provision and exchange information as required
- Ensure successful transition to post-16 provision

#### **19-25 - suggested activity**

- Section 140 assessments where appropriate
- Continue process of review and transition planning to facilitate transfer to appropriate adult agency, starting when appropriate after the 19th birthday, and in accordance with the needs of the young person

## Assessment – Planning – Implementation – Review (APIR)

The **Connexions Framework** for *Assessment, Planning, Implementation and Review* (APIR) has been developed to assist personal advisers in their one-to-one work with young people, providing guidance and supporting materials to help them identify need and take action to meet that need. The key aim of the Framework is to ensure a personal adviser takes a holistic view of a young person and produces an action/transition plan that the young person can call their own. There is a strong focus on seeking information from other professionals, so that assessment processes are not duplicated and that specialist services and resources of all relevant agencies are co-ordinated to benefit each young person.

**Section 140** of the *Learning and Skills Act 2000* sets out the statutory provision for the assessment of young people with LDD/statements of SEN in their final year of compulsory schooling who intend to go on to further education or training. The legal requirement is placed upon the Secretary of State and *Connexions Partnerships* must deliver it.

**SEN / LDD** *Special Educational Needs / Learning Difficulties and /or Disabilities*

What is of particular importance in the Connexions framework and the Connexions Partnerships presented above is the clear overall responsibility and independent advocacy role of the service for the successful transition of the young adult with learning disabilities from school to adult services and work where appropriate. We will return to this issue in the next section when discussing the Irish situation and the complete absence of any independent advocacy role outside the existing service providers.

### 2.5 Recent Legislative Changes in Ireland

There are considerable changes currently occurring in the legislative context that guides the education of people with intellectual disabilities in Ireland. Within the period during which the current study took place, one major act was passed by the Oireachtas, and another two bills were proposed. As each of these will have far reaching consequences for the education of and services provision for people with intellectual disabilities, we will briefly outline some of the details contained in the three most significant pieces of legislation.

No attempt is made to comment on the wider aspects of the legislation itself. The acts and bills are too complex to comment on them in the context of this study. We will, however, make some specific observations with regard to those aspects of the legislation which affect the continuing education needs of young people with intellectual disabilities at the time of their transition to adulthood.

We would further like to stress that it is extremely difficult, at this point in time, to have an exact understanding of the implications of the legislation: (i) two of the bills are still under consideration and could thus change significantly before being enacted, (ii) no timetables are yet set for their implementation, and (iii) no resources are yet allocated. It is thus impossible to say with any degree of accuracy what exactly will happen. Our commentary

thus primarily attempts to point out potential shortcomings as they affect young people with disabilities in their transition to adulthood.

Overall, there are six major pieces of legislation that make up the framework of measures which support the social inclusion of people with any form of disabilities in Ireland. These are:

- the Employment Equality Act 1998
- the Equal Status Act 2000
- the Equality Act 2004
- the Education for Persons with Special Educational Needs Act 2004
- the Comhairle (Amendment) Bill 2004, and
- the Disability Bill 2004

We will deal here exclusively with the *Disability Bill 2004*, the *Education for Persons with Special Education Needs Act 2004*, and the *Comhairle (Amendment) Bill 2004*.

### 2.5.1 The Disability Bill 2004<sup>2</sup>

The *Disability Bill 2004* is a positive action measure designed to advance and underpin participation by people with disabilities in everyday life. When passed, it will establish a statutory basis for mainstreaming; i.e. the provision of supports for those with special needs by each department and agency who are delivering services in general, rather than the provision of services to people with disabilities through separate institutional means. Mainstreaming places an obligation on public service providers to support access to services and facilities for people with disabilities, as well as other citizens, to the greatest practicable extent.

Among others, the *Disability Bill 2004* will establish a statutory basis for

- an independent assessment of individual needs and a related service statement
- access to public buildings, services and information
- sectoral plans for six key departments<sup>3</sup> which will ensure that access for people with disabilities will become an integral part of service planning and provision
- an obligation on public bodies to be pro-active in employing people with disabilities

#### **Assessment of Need, Service Statements and Redress**

Not unlike the system outlined in the previous section for the UK, the *Disability Bill 2004* will establish a system for the assessment of individual health and education needs in Ireland. People with disabilities (or their representatives) will have a statutory entitlement to

- apply for an **independent assessment** of their health and education needs

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<sup>2</sup> All information provided here is taken from "A Guide to the Disability Bill 2004", as published on the website of the Department of Justice, Equality & Law Reform <http://www.justice.ie>

<sup>3</sup> The Departments concerned are: Dpt. of Health & Children, Dpt. for Social & Family Affairs, Dpt. for Transport, Dpt. for the Environment, Heritage & Local Government, Dpt. for Communications, Marine & Natural Resources, and the Dpt. for Enterprise, Trade and Employment.

- a **statement of the services** (Service Statement) which it is proposed to provide
- pursue a complaint about the failure to provide these entitlements through an **independent redress mechanism**.

Any person who considers that he or she may have a disability will be entitled to apply for an independent **Assessment of Need**. The assessment will be undertaken without regard to cost or to capacity to provide any services identified in the assessment. Arising from the assessment, the person concerned will be given an Assessment Report.

The **Assessment Report** will indicate

- whether a person has a disability
- the nature and extent of the disability
- the health and education needs arising from the disability
- the services considered appropriate to meet those needs and the timescale ideally required for their delivery
- when a review of the assessment should be undertaken.

There is provision for a relative, guardian or personal advocate to apply for an assessment on behalf of a person with a disability. Each person with a disability will be encouraged to participate in their own assessment, while taking account of the nature of their disability and their age.

The **Health Information and Quality Authority**, a body to be established in the new health infrastructure, will set appropriate standards for carrying out the assessment process.

Each person found to have a need for disability related services, as a result of the Assessment Report, will be given a Service Statement. The **Service Statement** will set out the health and education services that can be provided to the person taking account of

- the Assessment Report
- eligibility criteria for services
- relevant standards and Codes of Practice
- the practicability of providing the service
- the financial resources available.

A Service Statement may be amended because of a change in the circumstances of the person or a change in any of the above considerations upon which the statement is based.

There is provision for informing, with the necessary consent of the person concerned, other service providers about the contents of an Assessment Report so as to facilitate access to services outside the health and education sectors.

### **Educational needs of a child**

A child who has a disability may be assessed under the *Disability Bill 2004* or under the *Education for Persons with Special Educational Needs Act 2004*. If a special educational need is identified as a result of the assessment of a child under the Disability Bill, that aspect of the assessment will be referred to the **National Council for Special Education** or to the Principal of his or her school. Health needs identified in an assessment under the Education for Persons with Special Educational Needs Act will be dealt with in a **Service**

**Statement** under the Disability Bill.

To assist with ongoing planning and improvement of services, the **Health Services Executives** will keep records of assessments and services provided. The maintenance of these records will be in accordance with the requirements of data protection legislation.

#### **How will the new system be managed?**

**Statutory officers** will be appointed to carry out the principal functions as outlined above.

**Assessment officers**, appointed by the Health Services Executive, will arrange for assessments of need and will be independent in carrying out their statutory functions.

**Liaison officers**, appointed by the Health Services Executive, will draw up Service Statements and manage their delivery. They will make contact, if requested, with the providers of public services outside the health and education sectors.

**Complaints officers**, appointed by the Health Services Executive, will be independent in carrying out their investigative functions and will try to resolve a complaint informally or, if this is not possible, will make a written recommendation to the CEO of the Health Services Executive (or the head of an education service provider).

An **appeals officer** will be appointed by the Minister for Health and Children. The appeals officer will provide independent mediation, appeals and enforcement. The appeals officer will have substantial statutory powers to summon witnesses, to enter premises and to obtain information. He or she will head up an **independent office** and will have a budget and staff to support him or her in undertaking these statutory functions.

#### **2.5.2 The Education for Persons with Special Educational Needs Act 2004<sup>4</sup>**

This Act redefines the statutory responsibilities for the education of persons with special educational needs in line with the *Disability Bill 2004*. The act deals exclusively with the education of *children* (i.e. under 18 years of age) with disabilities and is thus primarily concerned with defining the respective responsibilities of schools, the Health Services Executives and the new **National Council for Special Education**, as well as all of the specific operational aspects.

The overall aims of the act are:

- to make further provision for the education of people with special educational needs;
- to provide that their education takes place, as far as possible, in an inclusive environment;
- to provide that they have the same right as everyone else to avail of, and benefit from, appropriate education;
- to help children with special educational needs to leave school with the skills necessary to participate, to the level of their capacity, in an inclusive way in the social and economic activities of society and to live independent and fulfilled lives;
- to provide for the greater involvement of parents of children with special educational needs in relation to the education of their children;

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<sup>4</sup> The information provided here is mainly taken from Citizen Information Database of Comhairle <http://www.cidb.ie/live.nsf>

- to establish the **National Council for Special Education** (this Council has been set up with effect of 1st January 2005);
- to confer certain functions on Health Services Executives in relation to the education of people with special educational needs;
- to establish an independent appeals system – the **Special Education Appeals Board**.

### Planning for Future Education Needs

The act says little about who is responsible for the further education of people with special education needs *after* they have reached adulthood. However, one important aspect which is covered in the act is a responsibility of the school, in co-operation with the Health Services Executive, to set out a plan for the young adult's future education before leaving school. As we will document later, such provision is crucially lacking at the present.

### Planning for Future Education Needs

- (1) In preparing or reviewing an education plan, the principal of the relevant school or relevant special educational needs organiser shall, from the child's attaining such age as the principal or organiser considers appropriate, have regard to the provision which will need to be made to assist the child to continue his or her education or training on becoming an adult.
- (2) In performing the functions under *subsection (1)*, the principal or the special educational needs organiser shall—
  - (a) ascertain the wishes of the child concerned and of his or her parents, and
  - (b) take such steps as are necessary as will enable the child to progress as a young adult to the level of education or training that meets his or her wishes or those of his or her parents and that are appropriate to his or her ability.
- (3) In preparing or carrying out a review of an education plan in respect of the child who has special educational needs and who within the following 12 months will reach the age of 18 years, the Council shall cause an assessment to be made of—
  - (a) the extent, if any, to which goals set out in any previous such plan or the plan, as the case may be, successfully met the special educational needs of the child or student, and
  - (b) the reasons for any failure to meet those goals and the effect any such failure has had on the development of the child, and the plan shall include measures to address any such effect.

*Section 15 of the Education for Persons with Special Educational Needs Act, 2004*

### Who provides the services?

At present, **Health Services Executives** are responsible for providing services to pre-school children and for speech and language therapy services generally while the **Department of Education & Science** is responsible for providing educational services to school-going children. The act broadly proposes to continue this arrangement – the

**National Council for Special Education (NCSE)** will take over the Department of Education's role. The **Health Services Executive** must make available to the non-school-going child the services which are identified as necessary by the assessment and the NCSE must make these available to the school-going child. The NCSE must also provide the services identified in the education plan. The act provides that the Health Services Executive and the NCSE may ask each other to provide certain services. If there is a dispute between the Health Services Executive and the NCSE about who is to provide the service, it must be referred to the Appeals Board within two months and the **Appeals Board** must decide the issues within two months.

While it is welcome that the act principally introduces the development of a continuing education plan upon the reaching of adulthood, there remains considerable ambiguity in the act about whose ultimate responsibility it is to see that this is actually being done.

Furthermore, unlike its UK counterpart, the act says nothing about the allocation of a personal advocate to each young person with special educational needs. It could be argued that this will be covered by the Comhairle (Amendment) Bill, 2004. However, our reading of the proposed bill does not indicate any such role for the evolving service.

### 2.5.3 The Comhairle (Amendment) Bill 2004

The purpose of this bill is to amend the Comhairle Act, 2000, so as to confer enhanced and additional functions on Comhairle, principally involving the introduction of a **personal advocacy service** specifically aimed at people with disabilities. The details of the personal advocacy service are described in Section 4 of the bill and include, among other, the definition of the persons to whom such service is to be made available and the role of the personal advocate.

There are two observations that we believe to be particularly important with regard to the evolving personal advocacy service.

Firstly, in its present form, the bill seems to relate generally only to persons over the age of 18 years and thus no role can be conferred from it with regard to the preparation of continuing educational and other services in advance of the transition to adulthood.

Secondly, in its present form, the bill performs only a reactive function, i.e. a person has to apply for an advocate to be appointed. This is in marked contrast to the UK legislation, for example, which foresees the automatic appointment of an advocate to each young person with special educational needs.

### 2.5.4 How will the new legislative environment affect young adults with intellectual disabilities?

#### When will it happen?

The only piece of legislation which has been passed by the Oireachtas so far is the *Education for Persons with Special Education Needs Act 2004*, which was passed in September 2004. The *Disability Bill 2004* and the *Comhairle (Amendment) Bill 2004* have been introduced as Bills during the second half of 2004 and may still undergo considerable changes before being passed into legislation. But even the *Education for Persons with Special Education Needs Act 2004*, still required orders to bring it, or parts of it, into actual effect. The National Council for Special Education (NCSE), for example, has been

## Details of Personal Advocacy Service

### Definition of a qualifying person

A qualifying person which, in the case of a person 18 years of age or older, is a person who in the opinion of the Director is, by reason of a disability, unable to obtain or has difficulty in obtaining a particular social service without the assistance or support of a personal advocate and there are reasonable grounds for believing that there is a risk to the person's health, welfare or safety if he or she is not provided with the social service in question.

A person under 18 years of age is a qualifying person if his or her sole parent or guardian is a qualifying person or if he or she has a disability, or in the opinion of the Director there are reasonable grounds for believing that he or she has a disability, and the circumstances are such that it would be unreasonable to expect a parent or guardian to act on his or her behalf in obtaining a particular social service without the assistance or support of a personal advocate and, in the Director's opinion, there are reasonable grounds for believing there is a risk to the person's health, welfare or safety if he or she is not provided with the social service in question.

### Role of the personal advocate

The role of the personal advocate is described as

- assisting, supporting and representing the qualified person to apply for and obtain a social service, including an application for an assessment of need, an assessment of need or a service specified in a service statement under the provisions of the Disability Bill 2004;
- pursuing any right of review or appeal on behalf of the qualifying person;
- for the purpose of assisting the qualifying person to promote the best interests of his or her health, welfare and well-being, providing support and training to that person and any member of his or her family, a carer or any other person representing the interests of the qualifying person;
- entering any place that provides day care, residential care or training for the qualifying person for the purpose of representing his or her interests; and
- subject to the requirements of data protection legislation, accessing information, attending meetings or consultations, and identifying any person who may assist the qualifying person for the purpose of performing his or her functions.

*Explanatory Memorandum to Comhairle (Amendment) Bill, 2004*

established on a statutory basis with effect from the 1st January 2005. It will be obliged to report to the Minister *within one year* on the steps necessary to have this act fully implemented *within 5 years*. This report must specify the date on which various sections should start and an estimate of the resources needed for implementation. The report must also address how the special needs can be met pending the full implementation of the legislation.



In plain words: the NCSE will need about five years to implement the structural changes alone. During this period, its role is first and foremost an advisory one, and the Council will not have any role in dealing with individual cases in the foreseeable future. Furthermore, the current role of the NCSE is strictly confined to children under 18 years of age and it thus has no responsibility for the further education of young adults with intellectual disabilities.

### Who is responsible?

The responsibility for authorising the officers who will deliver the **needs assessment system** (assessment, liaison, complaints) is delegated to the CEOs of the **Health Services Executives**. These posts will not exist from 1 January 2005 and clarification from the Department of Justice Equality and Law Reform indicate that there will be a role for the new health organisations including the **Regional Health Offices** and the **Health Services Executive**.

An **Appeals Officer** will be appointed by the **Minister for Health and Children**. Clarification from the Department of Justice, Equality and Law Reform indicates that the Appeals Officer will head a national office with staff to deliver the appeals system. The **Circuit Court** will have responsibility for hearing cases, which are not resolved by the Appeals Officer. The Court will have responsibility for making decisions only on points of law. When provided, **Personal Advocates** under the *Comhairle (Amendment) Bill 2004* will have responsibility for assisting people with disabilities in accessing and using the needs assessment system.

The **National Disability Authority** (NDA) notes in its commentary on the new legislation<sup>5</sup> that it has significant concerns with regard to the effective delivery of the system. Legal opinion provided to the NDA states that '*powers are given in numerous places where duties should arise*'. For example, while both the Department of Health & Children and the Health Services Executives are given a role in the needs assessment system, no clear overall responsibilities are given. The NDA suggests that, **based on the details provided in the new legislation, the Acts should have explicitly stated a national lead role for the Health Services Executive to deliver effective and equitable needs assessment.**

We further add to this that there remains a similar ambiguity as to who is to provide a personal advocacy service to young people with intellectual disabilities, both in advance of reaching adulthood and thereafter, and the comprehensiveness of this service. In particular, we believe that a personal advocate has to be appointed automatically to **each** person (family) and that such service must not be based on application to such service only.

Overall, it will thus take considerable time before all elements of the new disability legislation will become actual law, let alone be operational. Furthermore, at the moment the new educational legislation deals almost exclusively with children under the age of 18 years, while the new legislation on advocacy deals almost exclusively with adults only.

**One therefore has to conclude that the chief responsibility for the educational needs assessment of young persons with intellectual disabilities, including the provision of comprehensive and automatic advocacy services will, for the foreseeable future, remain with the new Health Services Executives.**

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<sup>5</sup> The National Disability Authority has posted since 1st February 2005 a detailed commentary on the Disability Bill 2004 on its website: <http://www.nda.ie>

### 3 A Profile of the Bray/Wicklow Area

This study is concerned with the adequate provision for the continuing education needs of people with intellectual disabilities in the Bray and Wicklow area at the time of reaching adulthood. As the planning for and provision of adult services is largely the responsibility of the Department for Health and Children and, more specifically, the HSE East Coast Area, the study area has been defined as the Bray and Wicklow catchment areas, as far as they fall within the remit of the HSE East Coast Area.

#### 3.1 Young People with Intellectual Disabilities

The task of planning for the needs of people with intellectual disabilities in Ireland finds a valuable support in the National Intellectual Disability Database (NIDD). *The NIDD was established in 1995 to ensure that information is available to enable the Department of Health and Children, the health boards and the voluntary agencies in the Republic of Ireland to provide appropriate services designed to meet the changing needs of people with intellectual disability (mental handicap) and their families. The database is intended to provide a comprehensive and accurate information base for decision-making in relation to planning, funding and management of services for people with intellectual disabilities.*<sup>6</sup>

The database is believed to be highly accurate and therefore provides an appropriate starting point to define the population with which this study is concerned. The 2003 Annual Report has recently been published and contains considerable information for the country as a whole. We therefore requested equivalent information for the HSE Eastern Region and Bray/Wicklow area from the Health Research Board, which kindly obliged. We would like to express our gratitude for the information received and specific thanks to Steve Barron who prepared the data for us. We have been told in the course of our interviews that this information is not generally available to the public or indeed to institutions and agencies involved in the development and delivery of services, and we will therefore include all tables in the Appendix to this study.

Tables 1A to 1C show the numbers of people with intellectual disabilities in Ireland, the HSE Eastern Region area and the Bray and Wicklow areas respectively. Tables 2A to 2C show the prevalence rates for the same areas. In total, there are just over one thousand (1,067) people with intellectual disabilities living in the Bray and Wicklow area. Of these, 69 are aged between 15 and 19 years and 319 persons are aged 20 to 34 years (Table 1C). If we take the cohort of 15 to 19 year olds as the basis, we find that an average of about 14 people with intellectual disabilities will reach adulthood annually over the next five years. However, if we take the cohort of 20 to 34 year olds as the basis, about 21 people with intellectual disabilities reached adulthood each year over the previous fifteen years.

Tables 2A to 2C show that the overall prevalence rates in the HSE Eastern Region or the Bray and Wicklow area are very similar to those pertaining nationally. The overall prevalence of people with intellectual disabilities in the HSE Eastern Region area is marginally below the national average (6.1 per 1,000 compared to 6.5 per 1,000 for Ireland). The prevalence in the Bray and Wicklow area is shown in the tables to be somewhat higher than both the national and the HSE Eastern Region area at 9.7 per 1,000. However, some care needs to be taken in the interpretation of the local rates. We included in our calculation every person who may be either registered or using any service

<sup>6</sup> Health Research Board *Annual Report* 2003 (p. 14)

in the area, and this inevitably results in a higher figure than would have obtained with a more restrictive definition.

Depending on which cohort we are basing our calculation on, a projection of about 14 to 21 individuals who reach adulthood each year matches what the Bray Partnership indicated to the consultants at the start of the study and thus provides a reliable baseline figure for planning the educational needs of people with intellectual disabilities in the area. It also highlights the enormity of the health authorities' failure to put in place adequate and timely provision for the eight young people who left school in 2003.

**Table 1A: Incidence of Intellectual Disability by Degree of Disability, Ireland**

Age Group	Not Verified	Mild	Moderate	Severe and Profound	All Levels
0-14	1,104	2,069	1,564	706	5,443
15-19	52	1,765	943	348	3,108
20-34	178	2,629	2,892	1,477	7,176
35 & over	313	2,857	4,150	2,510	9,830
<b>All Ages</b>	<b>1,647</b>	<b>9,320</b>	<b>9,549</b>	<b>5,041</b>	<b>25,557</b>

**Table 1B: Incidence of Intellectual Disability by Degree of Disability, HSE Eastern Region**

Age Group	Not Verified	Mild	Moderate	Severe and Profound	All Levels
0-14	467	419	445	233	1,564
15-19	20	572	311	110	1,013
20-34	71	907	976	437	2,391
35 & over	123	1,138	1,552	793	3,606
<b>All Ages</b>	<b>681</b>	<b>3,036</b>	<b>3,284</b>	<b>1,573</b>	<b>8,574</b>

**Table 1C: Incidence of Intellectual Disability by Degree of Disability, Bray and Wicklow Area**

Age Group	Not Verified	Mild	Moderate	Severe and Profound	All Levels
0-14	76	28	50	32	186
15-19	11	8	30	20	69
20-34	27	130	103	59	319
35 & over	35	172	219	67	493
<b>All Ages</b>	<b>149</b>	<b>338</b>	<b>402</b>	<b>178</b>	<b>1,067</b>

**Table 2A: Prevalence of Intellectual Disability by Degree of Disability, Ireland**

Age Group	Not Verified	Mild	Moderate	Severe and Profound	All Levels
0-14	1.3	2.5	1.9	0.9	6.6
15-19	0.2	5.6	3.0	1.1	9.9
20-34	0.2	2.8	3.1	1.6	7.6
35 & over	0.2	1.6	2.3	1.4	5.4
<b>All Ages</b>	<b>0.4</b>	<b>2.4</b>	<b>2.4</b>	<b>1.3</b>	<b>6.5</b>

Table 2B: Prevalence of Intellectual Disability by Degree of Disability, HSE Eastern Region

Age Group	Not Verified	Mild	Moderate	Severe and Profound	All Levels
0-14	1.7	1.5	1.6	0.8	5.6
15-19	0.2	5.3	2.9	1.0	9.5
20-34	0.2	2.3	2.5	1.1	6.1
35 & over	0.2	1.8	2.5	1.3	5.8
<b>All Ages</b>	<b>0.5</b>	<b>2.2</b>	<b>2.3</b>	<b>1.1</b>	<b>6.1</b>

Table 2C: Prevalence of Intellectual Disability by Degree of Disability, Bray and Wicklow Area

Age Group	Not Verified	Mild	Moderate	Severe and Profound	All Levels
0-14	3.1	1.1	2.0	1.3	7.5
15-19	1.3	0.9	3.5	2.3	8.0
20-34	1.1	5.3	4.2	2.4	13.0
35 & over	0.7	3.3	4.2	1.3	9.5
<b>All Ages</b>	<b>1.4</b>	<b>3.1</b>	<b>3.7</b>	<b>1.6</b>	<b>9.7</b>

## 3.2 The Schools and other Education Service Providers

Figure 3.1: Main Schools and Service Providers for People with Intellectual Disabilities

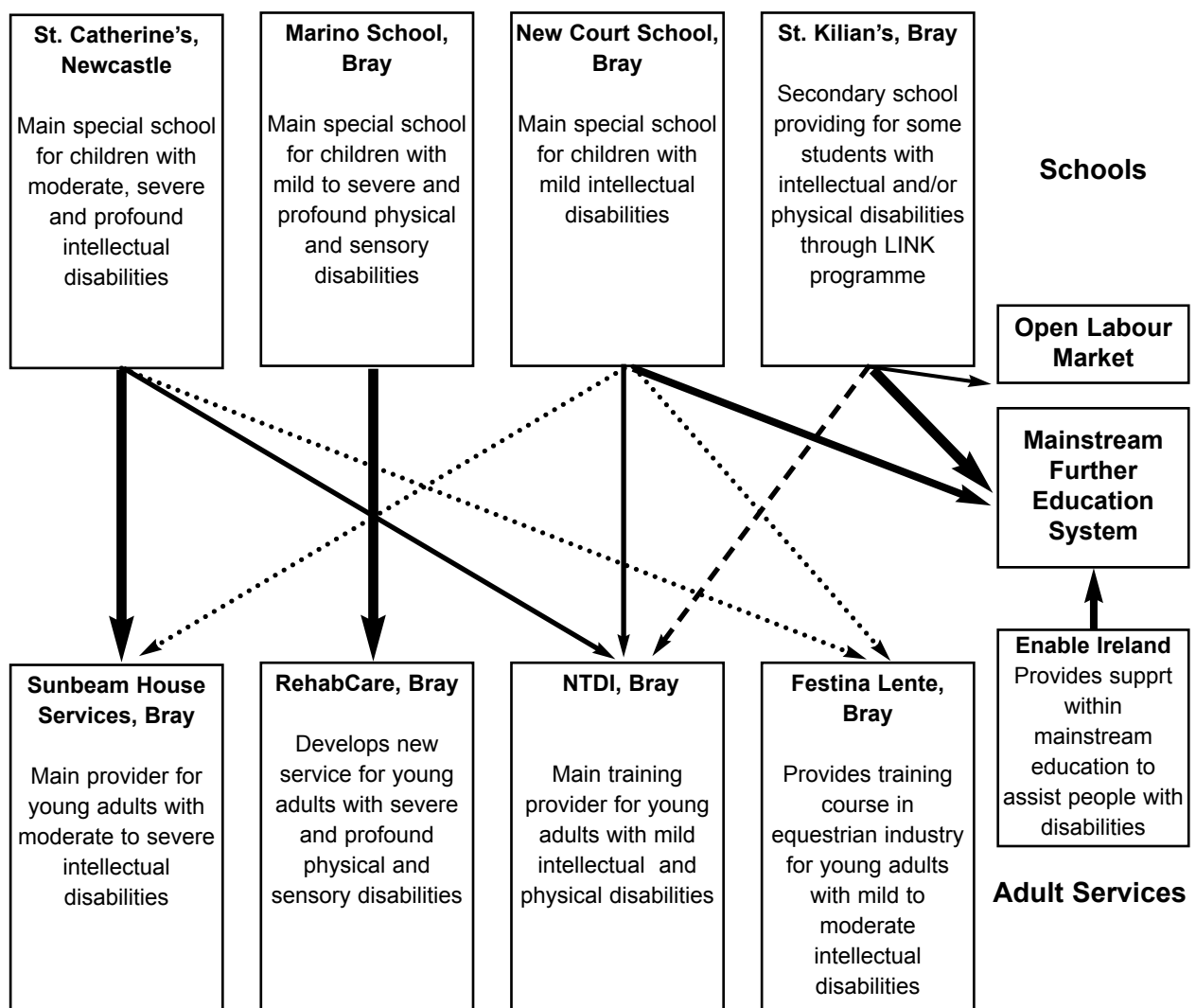


Figure 1 above provides a rough picture of the most important schools and educational providers for people with intellectual disabilities in the Bray and Wicklow area and the main destination paths (indicated by arrows of varying thickness) as the young adults leave school.

### 3.2.1 The Main Schools for People with Intellectual Disabilities

**St Catherine's** (Newcastle) is the most important Special School catering for young people with moderate to severe intellectual disabilities in County Wicklow. The school currently caters for a total of about 175 children. However, 70 of these are under 18 months old and participating in the early intervention programme. The programme is very far-reaching and effectively every child in County Wicklow diagnosed with even a slight developmental delay is referred to this unit, highlighting the strong emphasis placed on early intervention. Many of these infants will later participate in the mainstream education system. About 95 children avail of continuous day services at various levels, all of whom are diagnosed with moderate, severe or profound intellectual disabilities. In addition, St. Catherine's caters for 8 children with severe dual disabilities (autism). As is the case for most Special Schools, the school does not follow a prescribed curriculum, but emphasises a client-centred planning (CCP) approach to identify and cater for the individual needs of each child. The school provides extensive speech therapy, physiotherapy and occupational therapy where necessary. St. Catherine's is the main feeder school for Sunbeam House Services, with a small number of young adults advancing to the National Training and Development Institute (NTDI).

**Marino School** (Bray) provides education for children with mild to severe and profound physical disabilities, some of whom may also have a learning disability. Marino School works in close co-operation with Enable Ireland Wicklow Children's Services, which provides comprehensive therapy, nursing, social work and psychological services to some of the children who attend Marino School. Marino School was originally set up by Enable Ireland well over 40 years ago. The school moved into a new, high quality and purpose-built building some years ago, and the first cohort of students that have been attending the new school reached adulthood during 2003. At this point, major difficulties arose, as Sunbeam House Services did not feel that it was equipped to cater for the high level of medical care which these young people require and Enable Ireland, the school's parent organisation, has seen itself unable to develop a new adult facility which ultimately would have to provide full-time residential care. In the event, students were allowed to stay on for an extra year at Marino School during which intensive negotiations took place as to their future placement. Finally, RehabCare offered to develop a new facility which, when it is completed in the near future, will cater specifically for a small number of young adults leaving Marino School.

**New Court School** (Bray) accommodates a significant number of children (5 to 18 years) with mild general learning disabilities. The school has a primary and post primary sector. At post primary level, students follow the Junior Certificate School's Programme and Leaving Certificate Applied Course. Having completed, a small number of students go to Sunbeam House Services, while others find a place at the National Training and Development Institute (NTDI), Festina Lente, or other educational services. Each year also some students directly enter the labour market.

**St. Kilian's** (Bray) is a large Secondary School with over 600 students which also caters for a limited number of students from Marino and New Court Schools through the Schools LINK programme; i.e. the students are generally enrolled in the Special Schools but attend

certain courses which they could not avail of at their own school. The school has extensive support facilities for these students, although it is sometimes difficult for the resource teachers to make other teachers accept that their role is to act as a support to a limited number of individuals with special education needs, rather than acting as a general support teacher.

### 3.2.2 The Main Adult Service Providers

**Sunbeam House Services** (Bray) is one of the two main adult services providers in the Bray and Wicklow area, catering for about fifty young adults. While in earlier years it primarily catered for young adults with mild to moderate learning disabilities, Sunbeam House Services now largely caters for those with moderate to severe learning disabilities. Sunbeam House Services provides a large range of training provision, together with an intensive life skills programme towards achieving a range of *Personal Outcomes*. Traditionally, the courses lasted three years, with a limited number of individuals leaving after the course. However, in 2003 it was decided (in conjunction with the HSE East Coast Area) to extend the programme to a structured four-year programme. It was this change, together with the delay in funding from the HSE East Coast Area to accommodate the intake of new students (mainly due to leave St. Catherine's), which led to the crisis in 2003, leaving eight young adults with nowhere to go.

**National Training and Development Institute** (Bray). NTDI is the other major training provider for people with intellectual and/or physical disabilities in the Bray and Wicklow area. The Bray and Wicklow training centres cater for about 100 students, one third of whom have a mild learning disability, one third physical and sensory disabilities and the remaining students suffer from mental health problems. In addition to a large range of specific vocational training courses, NTDI also provides a two-year community-based personal development and vocational exploration course.

**Enable Ireland** (Dun Laoghaire) provides services for adults with a primary physical disability. Services available include a rehabilitation training programme (WHEELS), supported employment, evening social programmes and holiday house. The service was established with funding from the Health Services Executive to provide a local service to people in the general Dun Laoghaire area, and is thus generally not available to residents in the Bray and Wicklow area.

**RehabCare** (Bray) operates community-based health and social care services for people with disabilities, their families and carers and those who are marginalised. Services include resource centre activities, respite care, independent living programmes, supported accommodation and sheltered work. The importance of RehabCare in the context of the present study is that it has developed a plan and successfully sought funding for the first phase of a day service for three young adults who were due to leave Marino School last year. Provisional accommodation opened in Autumn 2004 in Kilpeddar, to take in the first three young adults with a view to taking in another three at a later stage. In the meanwhile, a permanent location has been acquired in Wicklow and will be converted to purpose-built accommodation.

**Festina Lente Equestrian College** (Bray) provides a 3-year accredited FÁS funded equestrian training programme for adults with an intellectual disability. The programme is run at a specific skills level and also includes a comprehensive range of personal development activities. Festina Lente Foundation is the only provider of equestrian training for people with intellectual disabilities nationally. Since 2002, Festina Lente also offers a foundation programme in the horticultural area.

### 3.3 The Study Participants

As part of this study, more than eighty letters were sent to all schools, service providers and statutory and voluntary agencies in the Bray and Wicklow area that cater in any way for young people with intellectual disabilities. The letter informed the recipients of the study and asked them for their co-operation. In particular, the recipient organisations were asked to invite the individual families with whom they were in contact to participate in the study and to get in contact with either the Bray Partnership or the consultants. This was a necessary procedure, as it was not possible to ask for any details to be passed on directly to the consultants for confidentiality reasons. Additionally, advertisements were placed in two local papers inviting families to come forward. Participation was sought from families with a child aged between 13 and 18 years and attending school, or a family member aged between 18 and 25 years and attending adult services. The purpose of seeking the co-operation of these two cohorts was that the first group provides us with information about the young people who will leave school over the next five years, while the second group provides valuable information about how those concerned have experienced the transition to adulthood over the past few years.

As a result, 25 families contacted the consultants to participate in the study. In most cases, extensive structured interviews were held with both the young person and at least one of their parents. In a few cases, interviews were only held with a parent. Considerable emphasis was placed on encouraging the young person to contribute as much as possible to the interview and to express their own concerns. The degree to which this was possible, however, depended on the degree of disability, both intellectual and physical, and in a significant number of interviews all information was provided by or mediated through the parent.

We should also highlight the considerable help and effort provided by the Bray Lakers in this process. The Bray Lakers is a personal network of the many young people and their parents who were affected by last year's failure to provide timely adult services in the Bray area, and was heavily involved in encouraging this study. Parents in contact with the Bray Lakers make up about half of our sample. Arranging contact via schools was considerably more difficult. Principals could not single out individual parents (this could have been construed as labelling) but had to send out invitations to all parents without discrimination. Returns from this process were inevitably poor, although some parents came forward from the main feeder schools.

In total, we estimate the effective sample of families interviewed to represent about one-fifth of each of the relevant cohorts of young people with intellectual disabilities in the last five years of school or in training-related adult services. As such, the results must be treated with caution: while representing a valuable source of data at a qualitative level, we cannot make precise extrapolations from the quantitative findings to the total population of people with intellectual disabilities in the Bray and Wicklow area. Nevertheless, with one important exception, the young people who participated in the study do not appear to differ systematically from those who did not. The exception is that participants in the study were clearly positioned at the more severe end of the intellectual disability spectrum.

All participants were in need of significant support both during and after school, and the study cannot therefore throw much light on the needs of those with mild intellectual disability and who are likely to find accommodation within the mainstream educational system. This, however, is in accord with the intended focus of the study, which is on the educational needs of young people with moderate to severe or profound intellectual disabilities.

### 3.3.1 Profile of the Study Participants

Tables 3.1 and 3.2 provide a brief overview of the demographic composition of the study participants.

Two thirds of study participants are male. While this is a higher share than indicated by the incidence of intellectual disability in the Bray area as a whole (Table 2.2.4, Appendix), it is nevertheless consistent with the fact that there are more males with intellectual disabilities in the area.

The study participants are well-distributed across the different age groups. All participants aged 18 years or under attend one of the Special Schools or special classes within a Secondary School, while all those aged 20 or over are in adult services. At age 19 either situation may occur, as some students stay on at school for an extra year. This situation was favoured by the difficulties encountered in placing students in adult services during 2003 and is not representative of the experience of students more generally.

In terms of the Special Schools, six of the participants currently attend Marino School, five attend St. Catherine's and one at both New Court School and St. Augustine's (Blackrock).

In terms of adult services, seven attend Sunbeam House Services and one person is at each of the following: Carmona Services (Glenageary), NTDI (Boghall Road), Enable Ireland (Dun Laoghaire), RehabCare(Bray) and Festina Lente (Bray).

All but one of the young people participating in the study live with their parents. One young adult attending training lives in a residential home during the week but stays with the family at weekends.

The tables below provide a brief overview of the degree of intellectual and physical and sensory impairment experienced by study participants. Tables 3.3 and 3.4 indicate that nearly one in two (44%) experience major difficulties in effective communication and language skills. It is worth repeating that this finding applies effectively to those with moderate, severe or profound intellectual disabilities, as the study sample only draws from this population.

Just over half of study participants (56%) also have a significant physical disability. This includes four cases of Cerebral Palsy, three cases each of Muscular Dystrophy and Down's Syndrome, two cases of Chromosome Abnormalities, and one case of West's Syndrome.

Table 3.1: Study Participants by Gender

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
Male	9	6	15	69.2	50.0	60.0
Female	4	6	10	30.8	50.0	40.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

Table 3.2: Study Participants by Age Group

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
13-16	7		7	53.8		28.0
17-19	6		6	46.2		24.0
19-22		8	8		66.7	32.0
23-25		4	4		33.3	16.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>



**Table 3.3: Ability to Communicate**

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
Not affected	3	2	5	23.1	16.7	20.0
Slightly affected	1		1	7.7	0.0	4.0
Affected	4	4	8	30.8	33.3	32.0
Strongly affected	2	2	4	15.4	16.7	16.0
Profoundly affected	3	4	7	23.1	33.3	28.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

**Table 3.4: Language Skills**

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
Not affected	1		1	7.7	0.0	4.0
Slightly affected	3	1	4	23.1	8.3	16.0
Affected	4	5	9	30.8	41.7	36.0
Strongly affected		2	2	0.0	16.7	8.0
Profoundly affected	5	4	9	38.5	33.3	36.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

**Table 3.5: Ability to use Hands and Arms**

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
Not affected	5	7	12	38.5	58.3	48.0
Slightly affected	2	3	5	15.4	25.0	20.0
Affected	3	1	4	23.1	8.3	16.0
Strongly affected	1		1	7.7	0.0	4.0
Profoundly affected	2	1	3	15.4	8.3	12.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

**Table 3.6: Ability to Move Around**

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
Not affected	4	7	11	30.8	58.3	44.0
Slightly affected	3	2	5	23.1	16.7	20.0
Affected	2	2	4	15.4	16.7	16.0
Strongly affected	2		2	15.4	0.0	8.0
Profoundly affected	2	1	3	15.4	8.3	12.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

**Table 3.7: Ability to Live Independently**

	Special School	Adult Services	Total	Special School	Adult Services	Total
				%	%	%
Not affected	2	1	3	15.4	8.3	12.0
Slightly affected		1	1	0.0	8.3	4.0
Affected	2	4	6	15.4	33.3	24.0
Strongly affected	4	3	7	30.8	25.0	28.0
Profoundly affected	5	3	8	38.5	25.0	32.0
<b>Total</b>	<b>13</b>	<b>12</b>	<b>25</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

A physical or sensory disability, even where severe, does not necessarily result in a learning disability, but certainly adds to the problems experienced. There is a question mark over the recording of cases, where both physical and intellectual disabilities are present, in the National Intellectual Disability Database (NIDD), particularly where the primary disability is deemed to be of a physical nature. The general rule with regard to the registration in the NIDD and the National Physical and Sensory Disability Database (NPSDD) is that a person should be registered in only one of the databases. However, until now the mechanisms for cross-referencing have been limited. We understand from discussions with the Health Research Board that this problem is currently being addressed. But our impressions from discussions with parents and stakeholders alike is that, until now, the lack of sufficient integration of the two databases has contributed to a situation where a person with a primary physical and/or sensory disability tends to be first and foremost assessed and provided for with regard to their medical needs, with the (further) educational needs of the young person being frequently given less attention. We will return to these questions later.

Table 3.7 shows that only one in eight of the sample is deemed by their parents to be able to live independently and that the vast majority of people with moderate to profound intellectual disabilities will need major assistance in this area. Indeed, most parents are rather protective of their children in this regard and all of the parents stated that they would like their children to stay with them for as long as they are able to care for them. Some of the young adults did indicate that they would like to achieve some independent living, pointing to potential differences here with regard to the young person's and their parents' judgement as to whether they are capable of achieving this.

While the need to enter into independent living arrangements seldom occurs at the point of reaching adulthood, parents are, nevertheless, acutely aware that they will not be able to provide for their children indefinitely and that some residential or independent living arrangements needs to be planned for long in advance. The general unavailability of suitable and high-quality supported housing is a source of major distress for many of the parents, particularly where more severe forms of intellectual disability and multiple disabilities are involved.

## 4 The Experience at School

### 4.1 What schools provide

One of the most welcome findings of this study is the positive response of young people with intellectual disabilities and their parents to their overall school experience. Nine out of ten respondents rate the support that they have been given by their (Special) school as either good or very good. The other ten per cent rate the school as reasonable, with no respondent rating their school as bad or very bad. This is a most welcome outcome and seems to acknowledge the significant changes which schools have undergone in recent years. We attach even greater importance to this overall positive response as the same respondents do not hesitate to point to a number of specific misgivings and grievances within the schools and particularly outside the school system.

At the root of this positive response is the fact that each of the schools in question are able to integrate, at least to a certain extent, the various aspects of support required by the young person. Rather than having to deal with multiple service providers, the schools provide, in general, access to a variety of services in addition to looking after educational needs, including the assessment of a student's learning ability, the allocation of educational counsellors/advisors, school transport, as well as access to speech therapy, physiotherapy, occupational therapy, and respite care, where needed. The schools thus, at least to some degree, provide a one-stop-shop for the young person and their family. This being said, the school context is not without conflicts and difficulties and we will now look at a number of areas of particular pertinence.

#### 4.1.1 Educational Assessment

All of the Special Schools undertake a formal assessment of their students at some stage. However, there are a number of misgivings with regard to these assessments:

**Timeliness.** While all of the schools undertake an assessment at the onset of schooling, annual assessments are not as common as one might assume. Seven out of twelve students currently attending school state that an assessment had been carried out within the last year (58%), three (25%) state that an assessment had been carried out within the last two years, while two parents (17%) claim that the last assessment was seven or more years ago.

**Who participates in the assessment.** The student participated in eight cases (62%), a parent in ten cases (77%), the class teacher in five cases (39%), a special education teacher in three cases (23%), the principal in four cases (31%), a psychologist in eight cases (62%) and a doctor and speech therapist in one case each (8% each). A number of parents particularly pointed out the lack of speech therapists within the context of the assessment.

**What is assessed.** A significant number of parents felt that there is an overly medical emphasis within the assessment. Particularly where students have a primary physical disability, parents strongly feel that the educational needs of their children are not given sufficient consideration.

**Informing the parents.** Many parents note that they have never been formally informed of the outcome of assessments. Communication in this regard is seen as extremely poor.

**Annual Review.** While the schools generally have a policy of annual reviews, the praxis

seems to depart somewhat from this ideal. In some cases, the annual review is an internal one, not necessarily involving the parents, or the results may not be communicated to the parents. In other cases, the school may offer reviews on demand; i.e. parents have to make a formal request for a review but are not necessarily aware of this.

**Assessment upon leaving school.** To our knowledge, none of the schools undertakes a specific multidisciplinary assessment during the last year of schooling, with the explicit aim of helping the young person and their family to make a decision about their further education.

#### 4.1.2 Person/Client-Centred Planning (PCP/CCP)

All of the Special Schools that we visited explicitly adhere to a person/client-centred planning approach (PCP/CCP) to the education of young people with learning disabilities; this takes centre stage in each school's mission statement. Central to such an approach are flexible curricula, appropriate to each individual's learning capacity, multidisciplinary assessments and a participatory approach to mapping out future learning paths. In each case, the adoption of a PCP/CCP approach marks an important development for the institution concerned. However, at times it seems that this approach remains an aspiration rather than actual praxis. This is particularly the case with respect to the participation of parents in the assessment and planning process, which is not always fully implemented. However, parent participation is becoming more frequent and both St. Catherine's and Marino are committed to further improving this.

#### 4.1.3 Speech Therapy

Table 4: Communication Needs and Provisions

	No support	Slight support	Some support	Significant support	Profound support	Total
Not affected	2	1				3
Slightly affected			1			1
Affected			1	2	1	4
Strongly affected		1		1		2
Profoundly affected			2		1	3
<b>Total</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>13</b>

Speech therapy is probably one of the most frequently required services for young people with learning disabilities, particularly where this exists alongside a physical disability. The shortfall in the number of speech therapists available in Ireland is well documented and schools are not exempt from this. The effectiveness of speech therapy increases as its availability during the formative years of life increases. Thus, comprehensive access to speech therapy is of the utmost importance to a significant number of these young people. However, Table 4.1 clearly indicates that there are shortcomings in this respect: a significant number of parents indicate that they had to put up a major fight to receive greater provision. In one case, a student identified as having a major speech impediment received 15 minutes of speech therapy per week. In other instances, students have undergone lengthy periods without access to a speech therapist and been forced to wait for extensive periods of time even after being diagnosed as needing speech therapy.

#### 4.1.4 Physiotherapy

The situation with physiotherapy is somewhat similar to that of speech therapy, albeit with fewer families involved. Nevertheless, where young people need access to physiotherapy, the level provided tends to fall far short of what is viewed as necessary. Less than half of all families in the sample are satisfied that an appropriate level of provision is available, while 5 out of 9 (56%) indicate that this is insufficient.

**Table 4.2: Physiotherapy: Needs and Provision**

	No support	Slight support	Some support	Significant support	Profound support	Total
Not affected	4					4
Slightly affected	2			1		3
Affected	1				1	2
Strongly affected			2			2
Profoundly affected					2	2
<b>Total</b>	<b>7</b>		<b>2</b>	<b>1</b>	<b>3</b>	<b>13</b>

#### 4.1.5 Transport

Transport to and from school is a major issue for the families who care for a young person with intellectual disabilities, particularly where these are severe or compounded by a physical disability. Overall, schools provide a good transport service, with students being collected from their homes and brought back where necessary. All but two families (85%) in our sample availed of some form of transport support. In one case this involved a bus pass, in all other cases, transport was provided by taxi or school buses. None of the respondents in the study expressed dissatisfaction with the services provided.

### 4.2 The big debate: Integration or Segregation?

Notwithstanding the considerable satisfaction expressed with the service which the Special Schools in the Bray and Wicklow area provide, there exists an underlying friction which few parents addressed, but which frequently came up during interviews with service providers, namely the question of whether children should be in a Special School in the first place.

The parents we consulted as part of this study clearly had a preference for their children to be in a Special School; indeed, some fought hard to have their child admitted to one of these schools in the first place. The view of the parents is generally that their child's disability, and hence their needs, are so all-encompassing that they cannot effectively be catered for within the existing mainstream schools. The Special Schools are seen to provide a 'safe haven' for children: they are less exposed to potential bullying and instead of having to fight for each individual element of their care, the school assumes a significant responsibility for the planning and implementation of the overall education and care plan.

Conversely, it is clear that an ever greater proportion of students with intellectual disabilities, and particularly physical disabilities, are being catered for within mainstream schools and that special provision, including resource teachers, is gradually improving. Indeed, many parents prefer their child to attend a mainstream school, particularly where the child has only a moderate or mild learning disability. This helps to avoid labelling, and also simplifies matters where siblings already attend an ordinary school.

One of the potentially negative effects of attending a Special School becomes apparent exactly at the time of transition to adulthood. Having attended a more sheltered environment can leave these young adults with greater difficulties in adapting to a less protective environment when entering adulthood, as this process is consequently more sudden and dramatic. The difficulties arising from this are by no means restricted to the young person, applying equally to their parents, who must quickly adapt to a situation where no-one assumes overall responsibility for the care of their children during the daytime and, as we will see in the following chapter, they frequently find themselves in a situation where they have to fight for every form of service that their child might require.

#### **4.2.1 What happens after Marino?**

While a general discussion about the merits of Special Schools or streaming is beyond the scope of this study, the different views held by some parents, on the one hand, and some institutional representatives, on the other, has led to a major conflict in the Bray area with respect to Marino School.

Marino School is established under the patronage of Enable Ireland and is a highly specialised and purpose-built school for children with mild to severe and profound physical and sensory disabilities. Together with Enable Ireland Wicklow Children's Services, the school provides a very high level of educational and other supports tailored to the individual needs of each student and parents generally hold the school in very high esteem. However, a major problem has arisen with regard to the options that are open to students once they have reached adulthood and finished their formal schooling.

When three students had reached 18 years of age during 2003, their parents were seeking a future commitment from Enable Ireland to provide a comprehensive care environment for their children. Despite years of intensive discussions between parents and the school's parent organisation, no agreement was reached.

Marino School is one of only seven schools designated by the Department of Education & Science in this category in the whole of Ireland, two of which Enable Ireland is patron of. The school is attended presently by 28 students, while Enable Ireland is catering for a total of about 160 children with physical and sensory disabilities in the Bray and Wicklow area. Thus, the vast majority of these children are attending either community pre-schools or mainstream schools. Indeed, Enable Ireland was forced to close its specialised pre-school in the area some years ago, as placements had fallen to less than three students, and parents wanted their children to attend existing schools. Now all children under five years of age are placed in mainstream schools, although it has to be added that many of these children are of average intellectual ability and the organisation therefore concentrates on their physical disabilities and the provision of adequate supports to enable them to participate fully in education.

Enable Ireland has undergone significant internal transformations over the past decade, moving towards more person-centred and individually tailored forms of support. While the parents of those children who attend Marino School see themselves as being lucky to have access to a Special School, the school's parent organisation is increasingly asking why these children cannot be supported adequately within mainstream schools. In its view, the clustering of children with multiple difficulties is itself questionable, as it arguably adds to their problems rather than solving them. As a consequence, Enable Ireland now focuses on the development of appropriate support services within existing schools, including the training and provision of support staff and the full use of Assistive Technology. With regard to educational development after leaving school, it perceives itself as forming part of a

team that can support a person-centred planning approach to meeting each person's educational needs. In fact, Enable Ireland believes that in nine out of ten cases this results in appropriate placements within existing services (predominantly Sunbeam House Services and NTDI).

Enable Ireland acknowledges that the group of young adults who will emerge from Marino School over the next two to three years will need a particularly high level of support, but strongly believes that this should be provided by appropriate facilitation within existing environments. However, the parents of the children concerned strongly disagree with this view, arguing that their children have made considerable progress on account of the good work done by Marino School and, ideally, they would have liked an adult support unit to be developed within the school itself, with an aim to providing an uninterrupted and continuous learning environment. This solution is not viewed favourably by Enable Ireland, but one cannot assume that a present service provider is automatically responsible for the further care of a young person. The planning for continuing care provision is clearly the responsibility of the regional health services and not of any one specific service provider.

After years of frustrating battles between parents and the school's parent organisation, a solution has been put forward by RehabCare, which plans to develop a high support unit for the first group of young adults who were originally due to leave Marino School during 2003. We will discuss this new undertaking in greater detail in the following chapter.

## 5 The Experience after School

Possibly the first and most important observation with regard to adult services in Bray and Wicklow are the limited choices which young people have after finishing school. In itself, this does not mean that the quality of services is poor, but that the provision of educational services for young people with intellectual disabilities is highly concentrated in two service providers: Sunbeam House Services and the National Training and Development Institute (NTDI). Other service providers are comparatively small in terms of the number of clients that they can cater for, although certain services are of a very specific nature, and thus of huge importance to the individuals concerned.

### 5.1 The main adult services providers

#### 5.1.1 Sunbeam House Services (SHS)

Sunbeam House Services is the main service provider for young adults with moderate to severe intellectual disabilities in the Bray and Wicklow area. SHS developed from the Cripples Home as far back as 1874 and today constitutes a highly professional organisation comprising a variety of services for young adults with intellectual disabilities. The core element of SHS is a training centre that provides training for a total of about 50 young people. Since 2003, training is structured over a four-year period (previously three years) and involves a set of 11 Modules, the overall objectives of which are set out in the textbox below. As more and more young adults with milder learning disabilities are entering the mainstream educational institutions, the majority of young adults attending SHS have moderate to severe learning disabilities.

The main course, “Preparation for Life”, is designed to provide the basic and practical skills and knowledge that are needed to realise each individual’s full potential in relation to work, independence and integration in the home and community. Through a Personal Outcomes approach, the course aims to support each person in their individual needs and priorities.

#### 5.1.2 National Training and Development Institute (NTDI)

NTDI forms part of the Rehab Group and is Ireland’s largest non-governmental training organisation with more than 50 purpose-built units nationwide catering for over 3,800 people each year. Historically, the organisation was primarily involved in training people with physical disabilities, but over the past few years NTDI has developed an increasing number of programmes for young people with mild and borderline learning disabilities, including two programmes for people with Asperger’s Syndrome.

In addition to a large range of specific vocational training courses, NTDI also provides a range of two-year community-based personal development and vocational exploration courses in its Bray and Arklow training centres. The focus of its training programmes can best be understood in the context of its funding structure: two-thirds of funds are provided by the Department of Enterprise & Employment. Training courses funded under this heading are exclusively job-focused and provide occupational training towards certified qualifications. The remainder of funding is provided by the Department of Health & Children. Training courses funded under this heading are person-centred in character and both the content and speed of progression is tailored to the individual needs of the



## **Programme Objectives “Preparation for Life”**

On completion of the training programme, the participants will be able to

- Demonstrate basic cooking, home maintenance, and other everyday household skills to encourage independence.
- Identify and participate in leisure time activities (with support if needed) in sports, culture, the arts, and use local community resources.
- Demonstrate the ability (with or without an advocate), to take control of their own lives.
- Use a range of skills in communication, planning, teamwork, safety, quality awareness, and hygiene.
- Identify key points that make for communication that is more effective.
- Use numbers and read signs needed for everyday use.
- Identify what makes a good worker and the kind of work he/she would like to do.
- Develop and demonstrate work related skills, e.g. time-keeping, dependability, following instructions, etc.
- Develop and demonstrate acceptable social behaviour and communications in community settings.
- Learn specific tasks related to a job.
- Assist in completing an individual vocational profile.
- Discuss and make informed choices around work, leisure, living, and other issues that are a priority to the individual person.
- Avail of a range of courses provided in the programme to meet priorities requested by individuals through Personal Outcomes.

*Sunbeam House Services – Rehabilitative Training Specification – January 2003*

participants. The provision of training for people with learning disabilities largely falls into this category.

### **Bray Services**

NTDI provides six training courses catering for 62 clients based in or managed from the Bray Centre. Clients who participate in training experience a wide range of disabilities, including learning, mental health and physical difficulties. Training courses are tailored to take into account the particular needs of individual participants. To implement this person-centred approach, each client has a personal training programme that is regularly reviewed by the client and staff team, which includes an instructor, teacher and psychologist.

A centre-based training approach is adopted by the Information Technology and Skills Foundation courses. On these courses clients attend the training centre on a daily basis and work towards nationally-recognised certification and either employment or further education. Additionally, clients on the Skills Foundation programme concentrate on social development and are encouraged to participate in community-related activities.

A more recent development has been the provision of Information Technology training to clients in their own homes. This is of particular benefit to people who are confined to their homes due to acquired disabilities such as MS or injuries sustained in road traffic accidents. Clients are provided with all of the necessary computer equipment, on loan for the duration of the course, and are regularly visited by an instructor.

Another example of an innovative training approach is that of the Employer Based Training programme. In this case a client decides on the type of training required and the instructor then develops an agreement with a local employer to deliver the training on their company premises. Clients are regularly visited by an instructor, who monitors the progress of the training programme. They also attend the training centre on a weekly basis in order to work on other areas of their training programme, which could include computer, job-seeking and personal development skills.

Finally, the Horticulture and Retail Sales programmes combine a mixture of hands-on skills acquisition in a shop and garden-centre, with classroom theory sessions and work experience with host companies.

### **Arklow Services**

NTDI provide two training programmes in Arklow, catering particularly for the South Wicklow area. This service commenced in 1996 with an aim to meeting the needs of local people, who were previously forced to travel to Bray in order to access services.

The LINK and ACCESS programmes provide training and support for people with extra support needs and a range of disabilities who may have experienced marginalisation and social exclusion in the past. Both programmes offer a holistic approach to supporting people to participate fully in their communities and to lead more fulfilling lives.

These programmes cater for 27 clients and are of a one-year and two-year duration respectively. The profile of clients includes mild learning disabilities, physical disability, hearing impairments and mental health difficulties. The aim of the courses is to increase confidence and to encourage full participation in society. Additionally NTDI trains people in a wide range of skills in order to enable progression to either higher-level training or to employment on completion of the courses

Due to the poor public transport system, NTDI provides a bus and taxi service for people who would otherwise be unable to access the service.

All of NTDI's courses provide a range of nationally-recognised certificates. They are also subject to regular quality audits by the National Accreditation Committee.

### **5.1.3 Enable Ireland**

Enable Ireland is one of the main national providers of services for people with physical disabilities and their families. The organisation was founded as Cerebral Palsy Ireland in 1948 and its residential care service in Bray, active since 1951, was one of the earliest services in the country. In the 1980s, Enable Ireland became a truly national organisation, and today it is organised through 14 regional centres that provide services for approximately 2,200 children and 200 adults.

The services provided by Enable Ireland have seen major developments in the Eastern Region over the past few years:

- Children's Services in Sandymount moved to a new location in September 2000

following the completion of an £8.4M capital project involving the building of a new school and clinic on the site in Sandymount.

- The new Enable Ireland Physiotherapy Service in County Kildare, which commenced in mid 1999, has been extended through an agreement with the HSE East Coast Area to recruit an Occupational Therapist, Speech and Language Therapist and Administrative Support Staff. This service continues to be provided on an outreach basis in Newbridge, Athy and Celbridge.
- In June 2000 Adult Services provided by Enable Ireland in Dublin were significantly boosted through the official opening of the new Dun Laoghaire Community Resource Service which will provide a range of community-based services to circa 20 adults.

However, services provided in Sandymount and Dun Laoghaire are generally not available to residents of the Bray and Wicklow area due to the regional structure of the organisation. Furthermore, as can be seen from the number of clients, Enable Ireland has a strong focus on the development of children's as opposed to adult services. With the exception of respite services, the organisation is generally not involved in the provision of residential care for adults, but focuses entirely on the provision of supports within existing services.

Overview of Children's Services	Overview of Adult Services
<p><b>Early Services (0 – 6 years)</b></p> <ul style="list-style-type: none"> <li>• Assessment and individual planning</li> <li>• Interdisciplinary team approach</li> <li>• Centre and home based programmes</li> <li>• Respite service – home based support</li> <li>• Parent and family support groups</li> </ul> <p><b>Pre-School Services (3 – 6 years)</b></p> <ul style="list-style-type: none"> <li>• Support for children attending local mainstream pre-schools</li> <li>• Enable Ireland Pre-Schools</li> <li>• Interdisciplinary team approach</li> <li>• Respite service</li> <li>• Parent and family support groups</li> </ul> <p><b>Children's and Adolescent Services (6 – 18 years)</b></p> <ul style="list-style-type: none"> <li>• Support for children attending mainstream schools</li> <li>• Enable Ireland schools (Cork, Dublin, Wicklow)</li> <li>• Interdisciplinary team approach</li> <li>• Respite service</li> <li>• Holiday breaks/summer programmes</li> <li>• Parent and family and support groups</li> </ul>	<ul style="list-style-type: none"> <li>• Person-centred training</li> <li>• Community Development Programmes</li> <li>• Access to Mainstream Adult and Further Education</li> <li>• Social and Cultural Participation</li> <li>• Respite Services</li> <li>• Supported Employment Services</li> <li>• Enterprise Employment</li> <li>• Centre Based Training</li> <li>• Day Activity Services</li> </ul> <p style="text-align: right;"><i>Enable Ireland Website, 2004</i></p>

### 5.1.4 RehabCare – New Initiative

Historically, RehabCare's primary involvement was in the field of occupational rehabilitation, both for adults who had sustained injuries and young adults with intellectual disabilities from childhood or birth. However, in a new development, RehabCare, Bray, has stepped in to develop a care plan for the young adults who attend Marino School. This plan has met the approval of the HSE East Coast Area which is providing the funds to develop the project. The project is of particular importance not only to the young adults who will be catered for through this new initiative, but also for RehabCare, as it constitutes a new departure for the organisation itself.

At first, the project will cater for three young adults from Marino School. There is a strong parental involvement from the earliest planning stages, with monthly meetings taking place, between RehabCare, the HSE East Coast Area and parents. Initial problems in finding suitable premises have now been overcome with the purchase of the Anchorage in Wicklow town. The premises are currently being modified to specification, again with the direct involvement of parents and professional care staff. From Autumn 2004 onwards, and until completion of the unit, the initiative is operating from an interim facility in Kilpeddar.

Initially, the project will work on a 5-day basis, Monday to Fridays, morning to early afternoon. The emphasis is on a person-centred approach, involving the provision of multiple aspects of care, tailored to the individual. The centre will have a one-to-one staff/client ratio. The core task of staff members is to develop and deliver an individual development plan for each young person, building on their school experience, with a multi-sensorial focus and with progressions for each individual that are appropriate to them. The emphasis of the centre is thus on a high level of personal care, with additional medical (e.g. nursing care) and specialist services (e.g. speech and language services, physiotherapy) bought in as needed.

It is hoped that the Health Services Executive will provide funding for transport (i.e. driver and support staff) to provide access to swimming and other leisure activities, as these constitute important therapeutic experiences.

While starting with three young adults, the unit could accept another one or two people within the next year, to a maximum of six clients. The emphasis is on a small and personalised environment, designed to provide a life-long service.

However, major questions remain regarding the long-term prospects of this project. For example, it is not yet known what level of medical assistance will be required over time. Secondly, while starting as a day-time facility, it is hoped to offer respite care in the near future. This effectively requires the provision of services on a 24/7 whole-time basis. From this, a further step in the long term would then be to develop the facility into a full-time residential unit, if and when parents or other relatives are no longer able to provide residential care. These long-term developments are clearly subject to funding from the HSE East Coast Area and will require considerable resources, both in terms of capital spending and ongoing staff costs. It is envisaged to undertake a review at the end of 2004 to establish the exact service needs and long-term funding requirements.

As pointed out above, the project is of considerable importance to RehabCare, as it raises many policy questions within the organisation. The project is firmly based on a social model of service provision, as opposed to a medical model, and is hoped to lead to further discussion about the development of a comprehensive, long-term and person-centred approach to the care of people with profound disabilities.

## 5.2 Access to Essential Services

Unlike the comprehensive care that is provided by Special Schools, adult services are first and foremost training providers with specialist services being provided through the Health Services Executive on the basis of individual needs. In practice, this means that either the service provider or parents must apply, and provision relies on the extent to which services are generally available in the Health Services Executive area. In the following sections, we will review the adequacy of the provision of a number of specialist services, based on the responses we received to our survey. Again, we point out the relatively small number of persons involved in the survey and the position of clients at the moderate to severe level of intellectual disability. The responses should therefore be interpreted as broadly indicative, rather than statistically representative.

### 5.2.1 Speech Therapy

Table 5.1: Communication Needs and Provision

	No support	Slight support	Some support	Significant support	Profound support	Total
Not affected	1	1				2
Slightly affected						
Affected	1	1	1	1		4
Strongly affected		1	1			2
Profoundly affected	4					4
<b>Total</b>	<b>6</b>	<b>3</b>	<b>2</b>	<b>1</b>		<b>12</b>

In our sample, ten out of twelve young people attending adult services (83%) were in need of speech therapy. Only two (20%) received speech therapy at an adequate level. In eight out of ten cases (80%), the level of provision fell short of what was deemed appropriate, and in four cases (40%) the young person had absolutely no access to speech therapy, despite being profoundly affected by speech impediments.

Some of the respondents' comments highlight the alarming shortfall in access to speech therapy in the HSE East Coast Area area: *'the level of speech therapy is totally inadequate', 'after 18 months of trying we could still get no speech therapy; we were told to get it privately', 'we were told that our son/daughter was not entitled to it and that there was a shortage of trained specialists', 'our son/daughter had no support whatsoever in coping with speech technology', 'our son/daughter received good speech therapy when in St. Catherine's, but none since entering adult services'.*

The consultants have been told that Sunbeam House Services is currently attempting to recruit a speech therapist. This would be a welcome move, as timely provision is crucial for young people's development. However, and we must also acknowledge the dearth of speech therapists throughout the country, the expansion of existing speech therapy services by the HSE East Coast Area should be a major priority for the immediate future.

## 5.2.2 Physiotherapy

Table 5.2: Physiotherapy: Needs and Provision

	No support	Slight support	Some support	Significant support	Profound support	Total
Not affected	6		1			7
Slightly affected		3				3
Affected	1					1
Strongly affected						
Profoundly affected					1	1
<b>Total</b>	<b>7</b>	<b>3</b>	<b>1</b>		<b>1</b>	<b>12</b>

Five out of twelve respondents (42%) indicated a need for physiotherapy and four of these (80%) were receiving appropriate support. Only one person with minor needs indicated that s/he did not receive any such support, thus indicating an overall satisfactory situation with regard to physiotherapy.

## 5.2.3 Occupational Therapy

Five out of twelve respondents (42%) were in need of occupational therapy. Three of these (60%) indicated mild to moderate needs but had no or only marginal access to occupational therapy. One person each who indicated slight and profound needs for occupational therapy was in receipt of same at an adequate level.

Table 5.3: Occupational Therapy: Needs and Provision

	No support	Slight support	Some support	Significant support	Profound support	Total
Not affected	7					7
Slightly affected	1		1			2
Affected	1	1				2
Strongly affected						
Profoundly affected					1	1
<b>Total</b>	<b>9</b>	<b>1</b>	<b>1</b>		<b>1</b>	<b>12</b>

## 5.2.4 Transport

Transport to and from adult services and other activities is an issue for more than half (58%) of the families in our sample. In three cases, support was provided by means of bus passes and assistance in getting on and off the bus. In four cases, it involved dedicated transport by minibus or taxi to and from the unit. At times, it has been difficult for the young person and their parents to gain access to transport: in one case, it took six months before special transport was provided, and in at least one case no support has been given, although the young person was granted special transport while attending school.

Overall, there is considerable dissatisfaction with the level of specialist transport services being provided and the existing work practices of those services which do exist.

Table 5.4: Transport: Needs and Provision

	No support	Slight support	Some support	Significant support	Profound support	Total
<b>Total</b>	<b>5</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>12</b>

### 5.2.5 Literacy

Two out of seven parents whose child attends Sunbeam House Services feel that the level of literacy teaching is insufficient compared to their son/daughter's need. In one case, this is the cumulative effect of literacy having not been provided in earlier years during school, although it is acknowledged that the literacy teaching at that school has since improved significantly. As Sunbeam House Services provides a literacy module, it may be possible to meet these clients' needs directly, by providing additional literacy classes where needed.

### 5.2.6 Jobs Coach and Employment Support Services

There are currently two employment support services for people with intellectual disabilities in the Bray and Wicklow area. The first one is the Wicklow Supported Employment Network Limited (WSEN) and the second one is Connect Employment, which is a division of Sunbeam House Services.

The **Wicklow Supported Employment Network Limited** (WSEN) operates the state funded programme of employment support services for people with disabilities within County Wicklow. WSEN works in close association with FÁS, the state agency charged with the provision of training and employment services in general. There are currently WSEN offices in Bray, Wicklow and Arklow.

WSEN is a consortium of the following organisations: the National Training and Development Institute (NTDI), the Irish Wheelchair Association, Newcastle Hospital, Festina Lente, Wicklow Trade Union Training Centre, Ardeen Cheshire Homes, Arklow Community Enterprise, and Eve Holdings & New Dawn Training Centre. There are 23 similar state-funded consortia operating throughout the country, each providing a similar service.

WSEN provides services to people who experience any form of disability and is not limited to intellectual disability. It employs a team of eight employment support specialists, providing services to over 250 participants throughout the county. It's main emphasis is on enabling people who traditionally find it very difficult to gain access to open employment to take up meaningful and well-paid mainstream work.

For a variety of complex reasons, it is not the norm for people with intellectual disabilities to take up full-time employment, but there are some instances in County Wicklow where this has happened. To this end, WSEN works closely with FÁS and Wicklow County Council to help remove the barriers to more full-time employment and other forms of social exclusion. WSEN also provides support and training to people who work very limited hours in addition to people who are in a position to take up more permanent and full-time posts.

**Connect Employment** forms part of Sunbeam House Services and provides employment services specifically to its own clients. Connect Employment does not currently form part of the WSEN.

The reasons for this are largely historical. From the viewpoint of the state-funded employment services, some of the organisations in the voluntary and particularly religious sector have, on a national basis, found it difficult to adapt to a change from the more traditional in-house holistic models of support to the more specialised mainstream model of service provision. From the viewpoint of some of the specialised disability service providers, as well as from a number of the interviewed clients, the new state-funded mainstream model of service provision lacks this holistic approach and is frequently criticised for its limited knowledge in the specific area of intellectual disabilities.

The current study focuses on the transition to adulthood. It has thus been largely concerned with the move from school to adult services and no person in the sample had already entered full-time employment. Nevertheless, some parents raised concerns with regard to (future) access to a jobs coach and employment services. This was particularly pertinent for those who did not attend Sunbeam House Services, as Connect Employment only provides services to those who previously attended Sunbeam House Services.

It is not our intention to comment here on the rights or wrongs of a particular type of employment service but, without doubt, it is somewhat irrational to operate two separate employment services within a relatively small geographical area. Additionally, both services are ultimately funded from public resources, WSEN through the Department of Enterprise, Trade & Employment, and Connect Employment through the Department of Health & Children. It thus seems obvious that some effort should be made, possibly between the HSE East Coast Area and FÁS, to put the services on a joint footing.

### **5.3 How the Families Feel about Adult Services**

#### **5.3.1 Person-Centred Planning (PCP)**

As was the case with the schools, all of the adult service providers that we visited expound a person-centred planning approach (PCP) to the further education of young people with learning disabilities. However, while training modules cover various aspects of social skills and independent living, there seems to be some dissatisfaction among parents as to the effectiveness with which this is actually being achieved.

There appear to be doubts about who is setting goals for the young adult and how the individually-tailored plan is implemented. Indeed, this issue is quite deeply rooted, raising the central issue of when a person with an intellectual disability can be deemed to be an adult.

Within the school system, no questions arise in relation to this issue: the student is a minor and the school has total responsibility for their daytime care. In contrast, those attending adult services are (at least legally) deemed to be adults, and thus service providers are not legally responsible for them to the same extent as schools. This, however, is at variance with the expectation of most of the parents that we interviewed. For them, the young person attends a special education setting precisely because they are not able to make mature decisions and to comprehend the consequences of their behaviour. In a way, many parents see adult services as an extension of the school, rather than an adult service. They also rightly point to the legal situation, which affords people with intellectual disabilities special consideration; e.g. the age for sexual consent is 18 rather than 16 years of age.

Staff members in adult services see the day-to-day decision-making of their clients as an essential part of their development of independent life skills. This difference in approach between staff and parents frequently leads to misunderstandings. For example, a number of parents point out the ease of access of their sons and daughters to chips and crisps in the canteen, and would like greater control in relation to the consumption of junk food. Staff members, by contrast, point to the various modules within their programme which deal with food, cooking and dietary issues.

Another example involves the issue of a perceived “laziness”: some parents explicitly referred to this as one aspect of their son’s or daughter’s learning disability which should be challenged more strongly. They felt that, despite the existence of timetables for



everyone, the young adults were at times being left 'hanging around', where they should be challenged and encouraged to participate more actively.

One parent explained the general need to second-guess what their son/daughter was saying by way of the following hypothetical conversation: *'Do you want to go to the moon?' – 'Yes' – 'When?' – 'Tomorrow' – 'Do you want to go to America?' – 'Yes' – 'When?' – 'Tomorrow' etc.* The parent concludes: *'Clearly, you can't take these responses as mature considerations, thus there has to be more direction given as to what to do and what not to do.'*

A similar situation arose for another parent, whose son/daughter has the habit of answering 'no' to any question that s/he is asked. Thus, when asked twice whether s/he wanted to participate in a group outing, and twice responding negatively, the young person was excluded from participation. Yet the parent knew that this led to bitter disappointment for their child.

### 5.3.2 Parent Participation

These examples may be viewed as relatively minor, but they are indicative of a whole range of situations that occur every day, where differences arise as to the extent to which young people ought to be challenged. From our experience, we believe that adult service providers cover a wide spectrum of social skills training and considerable emphasis is placed on the development of independent living skills. However, there is clearly a problem in relation to communication between service provider(s) and the parents.

This problem derives from the fact that parents are not always part of the initial assessment, nor are they invited to annual reviews, where specific goals are set for the following year, nor are parents informed – in writing – of the goals that have been set for their son/daughter. Some parents, for example, commented favourably upon the communication module in SHS, but felt that more of it would be helpful for their son/daughter. Others felt that some of the work tasks given were too repetitive and not challenging enough. Some were concerned about the lack of literacy tuition provided. In all of these cases it appears that the source of dissatisfaction lies with the planning process, suggesting that the person-centred planning approach needs to be more inclusive in relation to parents.

All too frequently, the only information that parents receive about daily activities is by asking their son/daughter *'what have you been doing today?'* and getting the response *'not much'* (a response rather typical of any young adult). It is crucial that communication between parents and service providers does not rely exclusively on mediation by the young adult themselves. It is thus to be welcomed that Sunbeam House Services, for example, held its first parent evening in Autumn 2004, and roughly half of all parents attended. The evening included a tour of the premises, a formal presentation of course content and a question-and-answer session. This is a step in the right direction, and will hopefully lead to more regular direct contact between parents and adult service providers.

### 5.3.3 Choices between Services and Localities

As is becoming apparent from the previous sections, educational services for young adults with intellectual disabilities in the Bray and Wicklow area are highly concentrated, with most young adults either attending Sunbeam House Services or the NTDI. While both organisations offer a significant range of education and training modules, it nevertheless constitutes a limited choice for the young person concerned and their parents. The choice

is limited with regard to the ethos and scale of the service providers, and with regard to the location, as most of the services are concentrated in Bray itself. Indeed, this situation is symptomatic of the situation throughout Ireland, where traditionally a highly institutionalised response to the needs of people with intellectual disabilities prevailed.

Nevertheless, times have changed and considerably greater emphasis is now placed on local, smaller, and community-based responses to the (learning) needs of those with an intellectual disability. Parents are looking for choices for their son/daughter and would like services to be close to where they are living to integrate the learning activities as closely as possible with their own daily activities and environment. The consultants therefore believe that the services in the Bray and Wicklow area are too strongly concentrated among the two major existing service providers and that, in the longer term, a more dispersed development of smaller scale projects would be welcome.

## 6 Choices about Work

This study focuses on the continuing education needs of young people with moderate and severe intellectual disabilities. It is therefore no surprise that all of the young people we interviewed remained in full-time training/education after leaving school. The term 'learning disability' is probably more appropriate to describe these young people, as it draws attention to the slower pace of the learning process and the amount of time they often need to acquire basic communication and other life skills.

Looking at all of these young people with varying degrees of intellectual disabilities, the transition to work may be said to follow two distinct pathways, at different times and for different groups of people.

The first group comprises young people, generally with mild intellectual disabilities, from New Court School or indeed any of the mainstream schools in the area, who do not want to continue in education but rather to enter paid employment. Generally, these young people will take up low-paid jobs with little job security and no career prospects. Nevertheless, they do not see themselves as 'intellectually disabled' and for this reason, and for fear of 'labelling', they tend to stay away from services targeted at supporting young people with disabilities. Assistance for this target group must therefore come via mainstream agencies, such as FÁS, the Local Employment Service or other job search agencies.

The second group comprises those who, having completed school, continue their training in adult services. Depending on where they have received their education (mainly the NTDI and Sunbeam House Services), this group is likely to have moderate to severe learning disabilities and almost all need some sort of assistance to enter gainful employment.

A few observations may usefully be made in relation to this latter group. Firstly, a significant proportion of those coming from adult services do not enter the open labour market, as they require some sort of sheltered work environment, either in the form of sheltered employment or in the form of a protected position through the Employment Support Scheme. It is crucial that the person has access to continued personal supports through dedicated staff.

Secondly, it is important that the needs of this group are clearly identified and registered with the National Intellectual Disability Database. Failure in forward planning for this group frequently leads to situations where young people spend extra years in adult services. There is nothing wrong with planning a longer stay in adult services if a tailored progression plan for a given individual explicitly envisages this, but it should not happen simply 'because there is nowhere else to go'. In such a situation, the prolonged stay in adult services will serve little purpose and is likely to prevent the vacation of places for incoming trainees.

Thirdly, there is a tendency for these young people to enter part-time employment. This may be acceptable if it coincides with the preferences of the young person concerned, but more frequently it is driven by the fear of losing Disability Allowance. There is therefore an urgent need to review the current system of entitlements, above all in order to avoid creating benefit traps, but also to set the level of entitlements to meet the real costs of independent living.

## **7 Addressing Future Learning Needs**

A number of issues have emerged from this study that are central to the development of a meaningful continuing education environment for young people with intellectual disabilities. While these issues have been identified on the basis of consultations in the Bray and Wicklow area, it is clear that they are of national relevance, being indicative of the crossroads at which these services find themselves at this point in time.

### **7.1 A Legal Right to Basic Education**

The first and most profound issue relates to the concepts of continuing education and lifelong learning itself. As we suggested in the opening chapter, for most of the readers of this report the concept of 'lifelong learning' will be a familiar one, associated with a second chance to finish basic educational qualifications or to reach the Leaving Certificate, or perhaps to attend Third Level education after having previously worked or raised children in the home. All of these examples of lifelong learning share an underlying assumption that ongoing education is not a luxury, but is increasingly necessary in order to advance in a rapidly changing world.

For people with intellectual disabilities the situation couldn't be more different: at the milder and even moderate end of learning disability, it may involve a number of extra years of person-centred education, after which time the client may, possibly with further assistance, participate in other mainstream education environments. At the severe to profound level of disability, by contrast, lifelong learning frequently involves the most basic life skills and communication abilities and it may take them a whole lifetime to master these. While the Irish state is beginning to provide the wider society with a growing choice of lifelong learning opportunities, it effectively denies this most basic right to continuing education and lifelong learning to those with severe and profound intellectual disabilities. While the new Disability Bill, passed during 2004, provides for future independent assessment of needs, it also makes the provision of services conditional upon the resources available, and no person can legally enforce adequate provision, even where their needs have been independently assessed. The legally enforceable right to basic education beyond the age of 18 for people with learning disabilities remains a central issue in Ireland.

### **7.2 A Person-centred Planning Approach**

Education has undergone huge changes over the past decades, particularly with regard to the education of young people with intellectual disabilities. As one interviewee pointed out, as little as thirty years ago, children with intellectual disabilities were effectively hidden from society, cared for in closed institutions with no prospects of ever entering open society. In fact, the legacy of these attitudes means that many people – individuals who are not known to service providers or to the state authorities – register in their thirties for day care or residential care services, as their carers are no longer able to provide for them. However, the number of people who fall within this category is steadily declining as most younger people with intellectual disabilities are now known to the authorities.

Today, children with intellectual disabilities can not only avail of early childhood interventions and, in the case of moderate to profound disabilities, special schools, but a significant number of them will subsequently enter ordinary schools and participate in mainstream society from an early age onwards.

Possibly one of the greatest changes in addressing the learning needs of people with intellectual disabilities over recent years is the widespread acceptance of a person-centred planning approach as a key educational principal. All of the special schools and the main adult services providers in the study area have made the person-centred planning approach the linchpin of their service development. Indeed, one could say that the PCP approach to education provision meets with far more acceptance within this sector than within the mainstream education sector, where education remains organised around narrowly-defined academic curricula. This is most likely due to the greater flexibility needed to respond to the needs of people with (intellectual) disabilities.

Despite the widespread acceptance of a person-centred learning approach, current practice nevertheless diverges from these generally expressed aspirations. For example:

- Multi-disciplinary assessments are generally the norm, but are still not always comprehensive enough with regard to the individuals involved. Specialists (e.g. speech therapists and psychologists) do not always participate, even where they are involved in actual care.
- Conversely, in the case of severe to profound physical and sensory disabilities, there is a tendency for assessments to be medically-orientated with insufficient attention paid to educational needs.
- Parental participation is still evolving and is far from routine. Nevertheless, we understand from our interviews with educational institutions that this is currently being addressed with a view to achieving more regular participation by parents in the assessment and planning process.

We may therefore conclude that a person-centred planning approach has become the educational paradigm *within* the educational establishments. However, major questions need to be asked with regard to the overall responsibility for the comprehensive application of a person-centred planning approach to the continuing education needs of young people with intellectual disabilities.

### 7.3 Inter-departmental Co-ordination and Overall Responsibility

It is generally the practice that schools invite the main service providers during the last year before the transition. However, this liaison seems to be predominantly based on bilateral relationships between schools and service providers and, as a consequence, beset with major difficulties:

- Firstly, the question arises as to who is ultimately responsible. While some schools invite certain service providers, it is not guaranteed that every young person (and their family) will be fully informed in advance about their options upon completion of schooling.
- Secondly, there is clear evidence that the strongest relationships have developed between the main special schools and the main adult services provider(s), with the result that young people are often not fully informed about the range of options available to them. There is little evidence of any pathways being proposed as an option to young people with intellectual disabilities, exploring for example how participation in mainstream education might be pursued. The emphasis is, instead, on matching individuals to existing institutional environments, rather than the identification of the specific needs of a person to pursue a path of their choice. This is clearly the very antithesis to a person-centred approach to planning.

- Thirdly, the identification of future learning goals, and the specific support needs that arise from that, should be assessed independently of what is immediately on offer. The ultimate responsibility for assessment, planning and implementation should lie neither with schools nor with individual service providers.
- Fourthly, good bilateral relationships between the main schools and the main service providers are no substitute for the independent forward planning of the HSE East Coast Area and the Department of Health & Children as the ultimate funding provider. The transition crisis of 2003 was not due to a lack of communication between St. Catherine's Special School and Sunbeam House Services. Both organisations were in full contact about the pending transitions. The crisis originated with the lack of adequate and robust planning on the part of the HSE East Coast Area which failed to secure the timely funding from the Department of Health & Children to provide the places required. A contingency plan should have been in place to deal with a significant funding shortfall. Of course, the crisis also originated with the Department of Health & Children itself, which refused to provide the necessary funds in time.

#### 7.4 Towards a new organisational approach?

While there is evidence that a person-centred planning approach is gradually becoming more prevalent within each of the *individual* institutions, special schools and adult service providers alike, this approach is remarkably absent from the transition process as a whole. The current process of transition for young adults with intellectual disabilities from school to an adult learning environment is marked by an institutionalised approach where the individual has to fit into a narrow range of existing institutional 'options', with little choices given to the individual concerned.

A person-centred planning approach to the educational needs of young adults with learning difficulties requires a *comprehensive* and *independent* process of assessment, planning, implementation and review, not unlike the APIR approach currently being implemented in the UK (see Section 2.4). Such an approach would involve, for example, the assignment of an independent advocate to each person registered with a learning disability and in need of special support, some years prior to the transition. The specific task of their advocate would be to ensure an effective team approach is applied to the young person's education planning, which involves both the person concerned and his/her parents, all educational and medical personnel involved as well as the different departmental and agency responsibilities.

There is some scope under the newly developing disability legislation for this to happen, but this is likely to take a considerable amount of time. **Until independent advocates are allocated under the new disability legislation, it is absolutely essential that the Regional Health Authorities assume overall responsibility for the advocacy process.**

#### 7.5 Responsibilities of the Health Services Executive

We welcome in this respect the recent publication of an Advocacy Framework for the Eastern Region by the HSE Eastern Region. This publication states that *modern health care is accepting of the participation of health service users and holds person-centredness as one of its core principles. Therefore it is imperative that health service users be empowered and facilitated to access the services and entitlements they require.* The publication sets out the advocacy principles as follows (slightly abbreviated):

## Common Advocacy Principles

Effective advocacy requires that

- the person advocated for is fully informed of the options available to them;
- the person advocated for is fully involved in the decisions that affect them;
- the advocate be independent from any conflict of interest that should compromise the advocacy;
- the advocate be faithful to the person's best interests and take into account their wishes;
- the advocate defend the rights, dignity and well-being of the person being advocated for;
- is expected to be enabling of the person doing as much of their own advocacy as possible.
- the advocacy that people need be available in amounts sufficient to defend the person's interests, resources permitting;
- the advocate make additional reasonable efforts to secure as beneficial outcomes for the person as may be possible at a given moment.

*Advocacy Framework for the Eastern Region – HSE Eastern Region, 2004*

Based on the extensive consultation undertaken in the context of this study, and measured against their own advocacy framework, there are a number of issues that the HSE East Coast Area urgently needs to address:

1. Until independent advocates are appointed, the HSE East Coast Area should allocate a designated advocate within its own staff who can act as a "one-stop-shop" for young people with disabilities and their families. The families should be formally notified of this appointment and told how the person can be contacted.
2. The (interim) advocate should be appointed at the latest when the student is about 12 years of age. Their role is a proactive one, involving liaison with the school to ensure that agreement is reached over who supports the young person with learning difficulties and how it is organised.
3. In the context of the transition to adulthood this means that the advocate should arrange at least one visit to each family where a child is reaching age 18 over the next twelve months. This means an average of about twenty to thirty visits per annum in the HSE East Coast Area, including children with moderate to severe intellectual disabilities and those with multiple disabilities.
4. The main role of this meeting is to inform the young person and their family about the options available to them. This includes all of the adult service providers, mainstream education providers, work options etc., including access to various supports such as speech, physiotherapy, occupational therapy, transport, personal attendants, job coaches, etc., what the entitlements are with regard to each service and benefits, direct payment options and how these supports and benefits can be applied for.

5. The (interim) advocate is responsible for ensuring that a multidisciplinary assessment is undertaken *prior to leaving school* in order to identify the wishes and abilities of the young person with regard to their future educational path. The purpose of this assessment is to identify the specific needs of the person in the context of their preferred options for further education. It is essential that this assessment be undertaken *prior* to the transition and not, as is currently the practice of adult service providers *after* a decision on the post-school placement has been made.
6. Once a decision has been made by the young person and their family as to what educational path they would like to pursue, it is the task of the Regional Health Authority (HSE East Coast Area) to ensure that the necessary funding and other supporting arrangements are made in a timely manner.
7. The (interim) advocate should ensure that other support arrangements not directly provided by the educational institution or adult service provider (e.g. speech therapy, physiotherapy or occupational therapy, personal assistant, job coach etc.) are in place. It is not acceptable that parents should have to fight for each of these services, once they have been determined necessary at the time of the independent assessment.
8. It is the role of the (interim) advocate to ensure that regular (annual) review meetings are carried out (usually by the service provider), that these adhere to set standards (to be identified by the Regional Health Authority), and that any new arrangements that may be necessary in relation to support services or structures are implemented.
9. It is the role of the (interim) advocate to ensure that the current service provider makes appropriate submissions to the National Intellectual Disability Database, so that service needs for the next five years may be adequately estimated, providing a reliable basis for the Regional Health Authority's planning and resource allocation process.



## 8 Recommendations

### 8.1 General Recommendations

#### Recommendation 1:

The proposed disability legislation has to become more explicit about who has the **ultimate** responsibility for the Needs Assessment and Personal Advocacy Service for persons with intellectual disabilities before and after reaching adulthood.

#### Recommendation 2:

The Health Services Executives must be explicitly given the overall responsibility for ensuring a person-centred approach to continued education and adult services in advance of the transition to adulthood.

#### Recommendation 3:

Even when passed, the *Comhairle (Amendment) Bill, 2004*, does generally not foresee a personal advocacy service for persons under the age of 18. The Health Services Executives thus must have the overall responsibility for ensuring a person-centred approach in the transition from school to adult services.

#### Recommendation 4:

Immediate tasks following from the Health Services Executive's overall responsibility for the carrying out of a needs assessment and (interim) advocacy role involve:

- advance visits to **each** family approaching the transition before the young person leaves school, providing a "one-stop-shop" approach to service provision,
- ensuring that special educational needs are comprehensively assessed prior to leaving school, through a multi-disciplinary assessment involving all relevant personnel and the parents,
- the provision of comprehensive information about all educational options available to the young person,
- the provision of comprehensive information in relation to the young person's and the family's entitlements to benefits and services,
- ensuring that an appropriate package of educational placement and complementary services (therapies, personal assistant, assistive technology, resource teacher, job coach etc.) be put into place for each young person with intellectual disabilities upon leaving school.

#### Recommendation 5:

A review should be undertaken by the HSE of the effectiveness of use of the National Intellectual Disability Database for service planning. Shortcomings with regard to timeliness, comprehensiveness of registration, consideration of people with primary physical and sensory disabilities and the ability at central and regional level to handle the data on a day-to-day basis need to be identified and addressed.

## 8.2 Recommendations for the Health Services Executive - East Coast Area

### Recommendation 6:

To effectively fulfil its advocacy role, the HSE- East Coast Area urgently needs to strengthen its disability services, particularly with regard to sufficient staffing to accommodate the tasks under Recommendation 4.

### Recommendation 7:

The HSE East Coast Area should underwrite the long-term development of the RehabCare initiative for young people with multiple profound disabilities. In the short term, this involves the provision of day care for three to six young adults. In the medium term, it will require the development of the facility into respite care and, ultimately, a long-term residential care centre tailored to the individual needs of the group of young adults concerned.

### Recommendation 8:

Speech therapy services in the Bray and Wicklow area are in urgent need of improvement, preferably via the immediate appointment of an additional speech therapist. If Sunbeam House Services manages to employ a speech therapist, it is important that this appointment be supplemental to existing posts.

### Recommendation 9:

Adult services in the Bray and Wicklow area are overly concentrated in two large-scale service providers, Sunbeam House Services and NTDI. In the view of the consultants, it would be preferable in the medium term if a larger choice were available between service providers. This would also facilitate the development of a more spatially dispersed network of services and local availability throughout the county.

### Recommendation 10:

Young people with mild intellectual disabilities have nowhere to go in the Bray area for their leisure activities. They urgently need an appropriate meeting place which is (i) centrally located, (ii) easily accessible by public transport, (iii) not designated as a service for people with disability and yet, in a discreet way, supported through staff that have the capacity to deliver services specific to this target group.

### Recommendation 11:

Bray Lakers fulfils an important role in the provision of leisure facilitation for children and adults with mild, moderate and severe learning disabilities together with children and adults on the Autistic Spectrum - autism, Asperger's Syndrome etc., as well as providing a valuable source of information and support for parents. It is important that the services they provide are placed on more secure footing by facilitating the purchase of premises from where Bray Lakers can continue to deliver its services.

**Recommendation 12:**

The HSE East Coast Area, in co-operation with FÁS, should review the effective working of the two employment services in its catchment area so as to guarantee that every person with an intellectual disability has adequate access to meet their needs.

**8.3 Recommendations for the Bray Partnership**

**Recommendation 13:**

Bray Partnership, in association with the Disability Cluster Group, should publish a guide which outlines the rights, benefits and options which young adults have upon leaving school within the Bray and Wicklow area. Consideration may also be given to have such information regularly been updated and posted on the Web.

## Appendix

### Selected Tables for the HSE Eastern Region and Bray Area

The authors would like to acknowledge the support of Steve Barron of the Health Research Board for extracting the data from the 2003 National Intellectual Disability Database

#### Note:

For convenience, the tables in the appendix are numbered according to the table numbers in the **2003 Annual Report of the National intellectual Disability Database Committee**

**Table 2.2.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.**  
Age, gender and degree of intellectual disability.

**Numbers**

Age Group	Not Verified			Mild			Moderate			Severe			Profound			All Levels		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	130	184	314	3	8	11	13	22	35	2	9	11	1	0	1	149	223	372
5-9	36	64	100	48	68	116	50	114	164	37	47	84	15	17	32	186	310	496
10-14	24	29	53	117	175	292	106	140	246	39	51	90	7	8	15	293	403	696
15-19	11	9	20	199	373	572	124	187	311	29	55	84	11	15	26	374	639	1013
20-34	35	36	71	416	491	907	439	537	976	146	215	361	39	37	76	1075	1316	2391
35-54	39	40	79	383	477	860	545	528	1073	235	206	441	66	98	164	1268	1349	2617
55 & over	25	19	44	183	95	278	302	177	479	117	43	160	16	12	28	643	346	989
<b>All ages</b>	<b>300</b>	<b>381</b>	<b>681</b>	<b>1349</b>	<b>1687</b>	<b>3036</b>	<b>1579</b>	<b>1705</b>	<b>3284</b>	<b>605</b>	<b>626</b>	<b>1231</b>	<b>155</b>	<b>187</b>	<b>342</b>	<b>3988</b>	<b>4586</b>	<b>8574</b>

**Table 2.2.2 Intellectual Disability Database, Bray Area 2003.**  
Age, gender and degree of intellectual disability.

**Numbers**

Age Group	Not Verified			Mild			Moderate			Severe			Profound			All Levels		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	27	18	45	3	1	4	1	1	2	2	1	3	0	0	0	33	21	54
5-9	14	9	23	6	7	13	13	10	23	5	5	10	2	2	4	40	33	73
10-14	4	4	8	7	4	11	10	15	25	9	6	15	0	0	0	30	29	59
15-19	5	6	11	6	2	8	17	13	30	11	7	18	2	0	2	41	28	69
20-34	10	17	27	66	64	130	59	44	103	36	17	53	3	3	6	174	145	319
35-54	15	14	29	77	53	130	76	57	133	23	20	43	1	2	3	192	146	338
55 & over	3	3	6	14	28	42	50	36	86	10	11	21	0	0	0	77	78	155
<b>All ages</b>	<b>78</b>	<b>71</b>	<b>149</b>	<b>179</b>	<b>159</b>	<b>338</b>	<b>226</b>	<b>176</b>	<b>402</b>	<b>96</b>	<b>67</b>	<b>163</b>	<b>8</b>	<b>7</b>	<b>15</b>	<b>587</b>	<b>480</b>	<b>1067</b>

**Table 2.2.3 Intellectual Disability Database, Health Services Executive Eastern Region 2003.**  
Age, gender and degree of intellectual disability.

Prevalence Rates																		
Age Group	Not Verified			Mild			Moderate			Severe			Profound			All Levels		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	3.9	2.6	3.2	0.2	0.1	0.1	0.5	0.3	0.4	0.2	0.0	0.1	0.0	0.0	0.0	4.7	3.0	3.8
5-9	1.5	0.8	1.1	1.6	1.0	1.3	2.7	1.1	1.8	1.1	0.8	0.9	0.4	0.3	0.4	7.2	4.1	5.6
10-14	0.6	0.5	0.6	3.8	2.4	3.1	3.0	2.2	2.6	1.1	0.8	1.0	0.2	0.1	0.2	8.7	6.1	7.4
15-19	0.2	0.2	0.2	7.1	3.7	5.3	3.6	2.3	2.9	1.0	0.5	0.8	0.3	0.2	0.2	12.1	6.9	9.5
20-34	0.2	0.2	0.2	2.5	2.2	2.3	2.7	2.3	2.5	1.1	0.8	0.9	0.2	0.2	0.2	6.6	5.6	6.1
35-54	0.2	0.2	0.2	2.5	2.1	2.3	2.8	3.0	2.9	1.1	1.3	1.2	0.5	0.4	0.4	7.1	7.1	7.1
55 & over	0.1	0.2	0.2	0.7	1.6	1.1	1.2	2.7	1.9	0.3	1.0	0.6	0.1	0.1	0.1	2.4	5.6	3.9
All ages	0.5	0.4	0.5	2.4	2.0	2.2	2.4	2.3	2.3	0.9	0.9	0.9	0.3	0.2	0.2	6.4	5.8	6.1

**Table 2.2.4 Intellectual Disability Database, Bray Area 2003.**  
Age, gender and degree of intellectual disability.

Prevalence Rates																		
Age Group	Not Verified			Mild			Moderate			Severe			Profound			All Levels		
	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total	Females	Males	Total
0-4	4.6	6.3	5.5	0.3	0.7	0.5	0.3	0.2	0.2	0.3	0.5	0.4	0.0	0.0	0.0	5.3	7.7	6.6
5-9	2.3	3.3	2.9	1.8	1.4	1.6	2.6	3.1	2.9	1.3	1.2	1.2	0.5	0.5	0.5	8.5	9.6	9.1
10-14	0.9	0.9	0.9	0.9	1.6	1.3	3.5	2.3	2.9	1.4	2.1	1.7	0.0	0.0	0.0	6.8	7.0	6.9
15-19	1.4	1.1	1.3	0.5	1.4	0.9	3.1	3.9	3.5	1.7	2.5	2.1	0.0	0.5	0.2	6.6	9.4	8.0
20-34	1.4	0.8	1.1	5.2	5.4	5.3	3.5	4.9	4.2	1.4	3.0	2.2	0.2	0.2	0.2	11.7	14.4	13.0
35-54	0.9	1.0	0.9	3.3	5.0	4.2	3.6	5.0	4.3	1.3	1.5	1.4	0.1	0.1	0.1	9.2	12.5	10.9
55 & over	0.3	0.3	0.3	2.5	1.5	2.0	3.2	5.3	4.2	1.0	1.1	1.0	0.0	0.0	0.0	7.0	8.1	7.5
All ages	1.3	1.4	1.4	2.9	3.3	3.1	3.2	4.2	3.7	1.2	1.8	1.5	0.1	0.1	0.1	8.6	10.9	9.7

**Table 3.2.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.**

**Summary of service provision in 2003 by degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Receiving 5- or 7- day residential services	5	12	17	39	394	433	100	2016	2116	144	2422	2566
Resident in a psychiatric hospital	0	3	3	0	67	67	0	195	195	0	265	265
Receiving residential support services only	2	0	2	0	6	6	0	7	7	2	13	15
Receiving no service	3	1	4	5	22	27	2	12	14	10	35	45
No service requirements in 2003	52	110	162	57	698	755	30	324	354	139	1132	1271
<b>Total</b>	<b>483</b>	<b>198</b>	<b>681</b>	<b>886</b>	<b>2150</b>	<b>3036</b>	<b>1016</b>	<b>3841</b>	<b>4857</b>	<b>2385</b>	<b>6189</b>	<b>8574</b>

**Table 3.2.2 Intellectual Disability Database, Bray Area 2003.**

**Summary of service provision in 2003 by degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Receiving day services	76	37	113	29	147	176	112	129	241	217	313	530
Receiving 5- or 7- day residential services	1	7	8	0	75	75	8	303	311	9	385	394
Resident in a psychiatric hospital	0	0	0	0	0	0	0	1	1	0	1	1
Receiving residential support services only	0	0	0	0	0	0	0	3	3	0	3	3
Receiving no service	0	0	0	0	3	3	0	0	0	0	3	3
No service requirements in 2003	9	19	28	3	81	84	5	19	24	17	119	136
<b>Total</b>	<b>86</b>	<b>63</b>	<b>149</b>	<b>32</b>	<b>306</b>	<b>338</b>	<b>125</b>	<b>455</b>	<b>580</b>	<b>243</b>	<b>824</b>	<b>1067</b>

Table 3.7.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Principal day service, degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	24	0	24	3	11	14	4	10	14	31	21	52
Home help	0	0	0	0	1	1	0	0	0	0	1	1
Early services	218	0	218	12	0	12	18	0	18	248	0	248
Mainstream pre-school	34	0	34	11	1	12	6	3	9	51	4	55
Special pre-school for intellectual disability	57	0	57	16	0	16	41	6	47	114	6	120
Child education and development centre	9	0	9	0	0	0	132	42	174	141	42	183
Mainstream school	24	0	24	66	8	74	33	1	34	123	9	132
Resource/visiting teacher	20	0	20	0	1	1	1	0	1	21	1	22
Special class - primary level	1	2	3	148	36	184	18	1	19	167	39	206
Special class - secondary level	2	0	2	20	14	34	5	0	5	27	14	41
Special school	25	0	25	524	71	595	676	19	695	1225	90	1315
Special vocational training centre	0	12	12	5	131	136	8	229	237	13	372	385
Activation centre	0	22	22	1	160	161	4	1465	1469	5	1647	1652
Programme for the older person	0	2	2	0	33	33	0	116	116	0	151	151
Special high-support day service	3	1	4	4	13	17	10	65	75	17	79	96
Special intensive day service	1	0	1	5	4	9	10	44	54	16	48	64
Sheltered work centre	0	30	30	0	416	416	2	940	942	2	1386	1388
Sheltered employment centre	0	6	6	0	32	32	0	23	23	0	61	61
Multidisciplinary support service	6	4	10	1	45	46	6	150	156	13	199	212
Centre-based day respite service	0	0	0	0	0	0	0	0	0	0	0	0
Day respite in the home	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	1	0	1	1	15	16	1	41	42	3	56	59
Enclave within open employment	0	0	0	0	2	2	0	2	2	0	4	4
Supported employment	0	7	7	1	299	300	0	212	212	1	518	519
Open employment	0	1	1	0	28	28	0	6	6	0	35	35
Generic vocational training	0	0	0	6	62	68	0	23	23	6	85	91
Generic day services	0	0	0	0	17	17	0	40	40	0	57	57
<b>Total</b>	<b>425</b>	<b>87</b>	<b>512</b>	<b>824</b>	<b>1400</b>	<b>2224</b>	<b>975</b>	<b>3438</b>	<b>4413</b>	<b>2224</b>	<b>4925</b>	<b>7149</b>



**Table 3.7.2 Intellectual Disability Database, Bray Area 2003.**

**Principal day service, degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	1	0	1	0	2	2	0	0	0	1	2	3
Home help	0	0	0	0	0	0	0	0	0	0	0	0
Early services	32	0	32	3	0	3	1	0	1	36	0	36
Mainstream pre-school	10	0	10	1	0	1	0	0	0	11	0	11
Special pre-school for intellectual disability	12	0	12	9	0	9	14	0	14	35	0	35
Child education and development centre	1	0	1	0	0	0	2	1	3	3	1	4
Mainstream school	10	0	10	8	0	8	11	0	11	29	0	29
Resource/visiting teacher	1	0	1	0	0	0	0	0	0	1	0	1
Special class - primary level	0	0	0	1	1	2	9	0	9	10	1	11
Special class - secondary level	1	0	1	1	0	1	0	0	0	2	0	2
Special school	8	0	8	4	0	4	80	4	84	92	4	96
Special vocational training centre	0	5	5	1	22	23	2	29	31	3	56	59
Activation centre	0	17	17	0	32	32	0	130	130	0	179	179
Programme for the older person	0	0	0	0	5	5	0	9	9	0	14	14
Special high-support day service	0	0	0	0	12	12	0	36	36	0	48	48
Special intensive day service	0	0	0	0	0	0	0	4	4	0	4	4
Sheltered work centre	0	22	22	0	61	61	0	125	125	0	208	208
Sheltered employment centre	0	0	0	0	3	3	0	2	2	0	5	5
Multidisciplinary support service	0	0	0	0	4	4	0	30	30	0	34	34
Centre-based day respite service	0	0	0	0	0	0	0	0	0	0	0	0
Day respite in the home	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	1	0	1	0	1	1	0	7	7	1	8	9
Enclave within open employment	0	0	0	0	0	0	0	0	0	0	0	0
Supported employment	0	0	0	0	40	40	0	15	15	0	55	55
Open employment	0	0	0	0	2	2	0	0	0	0	2	2
Generic vocational training	0	0	0	1	30	31	0	21	21	1	51	52
Generic day services	0	0	0	0	7	7	0	19	19	0	26	26
<b>Total</b>	<b>77</b>	<b>44</b>	<b>121</b>	<b>29</b>	<b>222</b>	<b>251</b>	<b>119</b>	<b>432</b>	<b>551</b>	<b>225</b>	<b>698</b>	<b>923</b>

Table 3.8.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Overall level of residential service provision in 2003, degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
5-day community group home	1	2	3	25	21	46	2	67	69	28	90	118
7-day (48-week) community group home	0	0	0	1	45	46	9	158	167	10	203	213
7-day (52-week) community group home	2	4	6	10	187	197	18	445	463	30	636	666
5-day residential centre	0	0	0	1	4	5	10	49	59	11	53	64
7-day (48-week) residential centre	0	0	0	1	30	31	18	218	236	19	248	267
7-day (52-week) residential centre	1	3	4	1	80	81	21	877	898	23	960	983
Nursing home	0	1	1	0	2	2	0	10	10	0	13	13
Psychiatric hospital	0	3	3	0	67	67	0	195	195	0	265	265
Intensive placement (challenging behaviour)	0	0	0	0	19	19	2	107	109	2	126	128
Intensive placement (profound or multiple disability)	1	1	2	0	2	2	17	75	92	18	78	96
Other full-time residential place	0	1	1	0	3	3	2	4	6	2	8	10
Occupying a residential support place	0	0	0	0	1	1	1	6	7	1	7	8
Holiday residential placement	0	1	1	5	51	56	0	80	80	5	132	137
Crisis or planned respite	33	9	42	47	193	240	429	716	1145	509	918	1427
Occasional respite with host family	1	0	1	0	1	1	12	8	20	13	9	22
Overnight respite in the home	0	0	0	0	0	0	1	0	1	1	0	1
Shared care or guardianship	0	0	0	0	1	1	0	1	1	0	2	2
Regular part-time care (2/3 days per week)	2	0	2	0	1	1	5	23	28	7	24	31
Regular part-time care (every weekend)	0	0	0	0	0	0	0	0	0	0	0	0
Regular part-time care (alternate weeks)	0	0	0	0	1	1	0	6	6	0	7	7
Other residential service	1	0	1	1	0	1	1	1	2	3	1	4
Foster care and boarding-out arrangements	8	0	8	21	9	30	13	2	15	42	11	53
Living semi-independently	0	2	2	0	54	54	0	8	8	0	64	64
Living independently	0	6	6	1	72	73	0	15	15	1	93	94

**Table 3.8.2 Intellectual Disability Database, Bray Area 2003.**

**Overall level of residential service provision in 2003, degree of intellectual disability and age group.**

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
5-day community group home	0	0	0	8	0	8	15	23	38	23	23	46
7-day (48-week) community group home	0	0	0	7	3	10	16	26	42	23	29	52
7-day (52-week) community group home	1	3	4	32	2	34	47	85	132	80	90	170
5-day residential centre	0	0	0	1	0	1	3	4	7	4	4	8
7-day (48-week) residential centre	0	0	0	5	0	5	57	62	119	62	62	124
7-day (52-week) residential centre	0	3	3	12	1	13	132	148	280	144	152	296
Nursing home	0	1	1	1	0	1	5	7	12	6	8	14
Psychiatric hospital	0	0	0	0	0	0	1	1	2	1	1	2
Intensive placement (challenging behaviour)	0	0	0	9	0	9	5	14	19	14	14	28
Intensive placement (profound or multiple disability)	0	0	0	0	2	2	22	24	46	22	26	48
Other full-time residential place	0	0	0	0	0	0	1	1	2	1	1	2
Occupying a residential support place												
Holiday residential placement	0	1	1	0	8	8	0	33	33	0	42	42
Crisis or planned respite	21	4	25	11	26	37	82	78	160	114	108	222
Occasional respite with host family												
Overnight respite in the home												
Shared care or guardianship												
Regular part-time care (2/3 days per week)												
Regular part-time care (every weekend)												
Regular part-time care (alternate weeks)												
Other residential service												
Foster care and boarding-out arrangements	1	0	1	1	1	2	3	1	4	5	2	7
Living semi-independently	0	1	1	0	21	21	0	2	2	0	24	24
Living independently	0	4	4	0	10	10	0	1	1	0	15	15

Table 3.9.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Overall level of day service provision in 2003, degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	60	0	60	19	38	57	189	145	334	268	183	451
Home help	3	0	3	1	1	2	1	1	2	5	2	7
Early services	321	0	321	29	0	29	74	0	74	424	0	424
Mainstream pre-school	58	0	58	13	1	14	10	3	13	81	4	85
Special pre-school	65	0	65	16	0	16	42	6	48	123	6	129
Child education and development centre	9	0	9	0	0	0	150	42	192	159	42	201
Mainstream school	24	0	24	66	8	74	34	1	35	124	9	133
Resource/visiting teacher	38	0	38	2	1	3	10	0	10	50	1	51
Special class - primary	2	2	4	149	36	185	18	1	19	169	39	208
Special class - secondary	2	0	2	20	14	34	5	0	5	27	14	41
Special school	27	0	27	524	71	595	677	19	696	1228	90	1318
Special vocational training	0	12	12	36	149	185	12	246	258	48	407	455
Activation centre	0	23	23	1	201	202	4	1510	1514	5	1734	1739
Programme for the older person	0	2	2	0	43	43	0	139	139	0	184	184
High-support day service	3	1	4	5	13	18	10	69	79	18	83	101
Intensive day service	1	0	1	5	4	9	10	48	58	16	52	68
Sheltered work	0	30	30	0	465	465	2	989	991	2	1484	1486
Sheltered employment	0	6	6	0	34	34	0	23	23	0	63	63
Multidisciplinary support service	33	14	47	266	661	927	645	2427	3072	944	3102	4046
Centre-based day respite programme	1	0	1	2	13	15	22	85	107	25	98	123
Day respite in the home	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	1	0	1	1	21	22	3	54	57	5	75	80
Enclave within open employment	0	0	0	0	3	3	0	4	4	0	7	7
Supported employment	0	7	7	1	390	391	0	324	324	1	721	722
Open employment	0	1	1	0	32	32	0	6	6	0	39	39
Generic vocational training	0	0	0	6	85	91	0	37	37	6	122	128
Generic day services	0	0	0	0	27	27	1	50	51	1	77	78

**Table 3.9.2 Intellectual Disability Database, Bray Area 2003.**

Overall level of day service provision in 2003, degree of intellectual disability and age group.

	Not Verified			Mild			Moderate, Severe & Profound			All Levels		
	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages	18 and under	19 and over	All ages
Home support	1	0	1	0	2	2	0	0	0	1	2	3
Home help	0	0	0	1	0	1	1	0	1	2	0	2
Early services	32	0	32	3	0	3	1	0	1	36	0	36
Mainstream pre-school	10	0	10	1	0	1	0	0	0	11	0	11
Special pre-school	12	0	12	9	0	9	14	0	14	35	0	35
Child education and development centre	1	0	1	0	0	0	20	1	21	21	1	22
Mainstream school	10	0	10	8	0	8	11	0	11	29	0	29
Resource/visiting teacher	6	0	6	0	0	0	8	0	8	14	0	14
Special class - primary	0	0	0	1	1	2	9	0	9	10	1	11
Special class - secondary	1	0	1	1	0	1	0	0	0	2	0	2
Special school	8	0	8	4	0	4	80	4	84	92	4	96
Special vocational training	0	5	5	1	36	37	2	34	36	3	75	78
Activation centre	0	17	17	0	42	42	0	138	138	0	197	197
Programme for the older person	0	0	0	0	8	8	0	14	14	0	22	22
High-support day service	0	0	0	0	12	12	0	39	39	0	51	51
Intensive day service	0	0	0	0	0	0	0	4	4	0	4	4
Sheltered work	0	22	22	0	75	75	0	135	135	0	232	232
Sheltered employment	0	0	0	0	4	4	0	2	2	0	6	6
Multidisciplinary support service	0	0	0	0	4	4	0	30	30	0	34	34
Centre-based day respite programme												
Day respite in the home												
Other day service	1	0	1	0	3	3	2	8	10	3	11	14
Enclave within open employment												
Supported employment	0	0	0	0	68	68	0	27	27	0	95	95
Open employment	0	0	0	0	2	2	0	0	0	0	2	2
Generic vocational training	0	0	0	1	51	52	0	35	35	1	86	87
Generic day services	0	0	0	0	12	12	0	21	21	0	33	33

Table 4.5.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Future full-time residential service requirements of individuals receiving no residential service in 2003.

	No service - requires residential service				Receives residential support only - requires residential service				Receives day service - requires residential service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
5-day community group home	0	0	1	1	0	0	0	0	3	23	55	81	3	23	56	82
7-day (48-week) community group home	0	0	1	1	0	2	0	2	3	14	52	69	3	16	53	72
7-day (52-week) community group home	0	6	3	9	0	0	2	2	4	74	232	310	4	80	237	321
5-day residential centre	0	0	0	0	0	0	0	0	0	0	4	4	0	0	4	4
7-day (48-week) residential centre	0	0	0	0	0	0	0	0	0	1	18	19	0	1	18	19
7-day (52-week) residential centre	0	0	0	0	0	0	0	0	0	9	54	63	0	9	54	63
Nursing home	0	2	0	2	0	0	0	0	1	0	5	6	1	2	3	8
Psychiatric hospital	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Intensive placement (challenging behaviour)	0	0	1	1	0	0	0	0	0	3	20	23	0	3	21	24
Intensive placement (profound or multiple disability)	0	0	0	0	0	0	0	0	0	3	30	33	0	3	30	33
<b>All services</b>	<b>0</b>	<b>8</b>	<b>6</b>	<b>14</b>	<b>0</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>11</b>	<b>127</b>	<b>470</b>	<b>608</b>	<b>11</b>	<b>137</b>	<b>478</b>	<b>626</b>

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**Table 4.5.2 Intellectual Disability Database, Bray Area 2003.**

**Future full-time residential service requirements of individuals receiving no residential service in 2003.**

	No service - requires residential service				Receives residential support only - requires residential service				Receives day service - requires residential service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
5-day community group home	0	0	0	0	0	0	0	0	3	14	30	47	3	14	30	47
7-day (48-week) community group home	0	0	0	0	0	0	0	0	1	3	5	9	1	3	5	9
7-day (52-week) community group home	0	1	0	1	0	0	2	2	3	10	12	25	3	11	14	28
5-day residential centre	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1	1
7-day (48-week) residential centre																
7-day (52-week) residential centre	0	0	0	0	0	0	0	0	0	0	14	14	0	0	14	14
Nursing home	0	0	0	0	0	0	0	0	1	0	0	1	1	0	0	1
Psychiatric hospital																
Intensive placement (challenging behaviour)	0	0	0	0	0	0	0	0	0	1	0	1	0	1	0	1
Intensive placement (profound or multiple disability)	0	0	0	0	0	0	0	0	0	1	4	5	0	1	4	5
<b>All services</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>2</b>	<b>8</b>	<b>29</b>	<b>66</b>	<b>103</b>	<b>8</b>	<b>30</b>	<b>68</b>	<b>106</b>

Table 4.6.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Future day service requirements of individuals receiving no day service in 2003.

	No service - requires day service				Receives residential support only - requires day service				Receives residential service only - requires day service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Home support	0	0	0	0	1	0	0	1	0	0	0	0	1	0	0	1
Home help	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Early services	1	0	1	2	0	0	0	0	0	0	0	0	1	0	1	2
Mainstream pre-school	1	0	0	1	0	0	0	0	0	0	0	0	1	0	0	1
Special pre-school	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Child education and development centre	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Mainstream school	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Resource/visiting teacher	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class - primary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special class - secondary	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Special school	1	0	0	1	0	0	0	0	0	0	5	5	1	0	5	6
Special vocational training	0	5	1	6	0	1	0	1	0	1	0	1	0	7	1	8
Activation centre	1	4	5	10	0	0	1	1	0	1	6	7	1	5	12	18
Programme for the older person	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Special high-support day service	0	0	1	1	0	0	1	1	0	0	1	1	0	0	3	3
Special intensive day service	0	0	1	1	0	0	0	0	0	0	0	0	0	0	1	1
Sheltered work centre	0	1	3	4	0	2	0	2	0	2	0	2	0	5	3	8
Sheltered employment centre	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Multidisciplinary support services	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Centre-based day respite service	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other day service	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Enclave within open employment	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Supported employment	0	8	0	8	0	0	0	0	0	0	0	0	0	8	0	8
Open employment	0	2	0	2	0	0	0	0	0	0	0	0	0	2	0	2
Generic vocational training	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	1
Generic day services	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
<b>All services</b>	<b>4</b>	<b>22</b>	<b>14</b>	<b>39</b>	<b>1</b>	<b>3</b>	<b>2</b>	<b>6</b>	<b>0</b>	<b>4</b>	<b>12</b>	<b>16</b>	<b>5</b>	<b>29</b>	<b>28</b>	<b>62</b>



Table 4.6.2 Intellectual Disability Database, Bray Area 2003.

Future day service requirements of individuals receiving no day service in 2003.

	No or minimal service - requires day service				Receives residential support only - requires day service				Receives residential service only - requires day service				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Home support																
Home help																
Early services																
Mainstream pre-school																
Special pre-school																
Child education and development centre																
Mainstream school																
Resource/visiting teacher																
Special class - primary																
Special class - secondary																
Special school					1								1			
Special vocational training																
Activation centre			1												1	
Programme for the older person																
Special high-support day service					1								1			
Special intensive day service																
Sheltered work centre																
Sheltered employment centre		1												1		
Multidisciplinary support services																
Centre-based day respite service																
Other day service																
Enclave within open employment																
Supported employment		1												1		
Open employment																
Generic vocational training																
Generic day services																
<b>All services</b>		2	1		2								2	2	1	5

Table 4.7.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Future residential support service requirements of individuals receiving no residential support services in 2003.

	No service – requires residential support				Receives day service – requires residential support				Receives residential service – requires residential support				Receives residential and day services – requires residential support				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Foster care and boarding-out	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2	0	0	2	2
Living independently	0	0	0	0	0	10	2	12	0	0	0	0	0	2	0	2	0	12	2	14
Living semi-independently	0	4	0	4	7	43	11	61	0	0	0	0	0	17	7	24	7	64	18	89
Holiday residential placement	0	0	0	0	1	6	21	28	0	0	0	0	0	0	7	7	1	6	28	35
Crisis or planned respite	0	0	1	1	9	53	130	192	0	0	0	0	0	0	1	1	9	53	132	194
Occasional respite care with host family	0	0	0	0	0	0	6	6	0	0	0	0	0	0	0	0	0	0	6	6
Occasional respite in the home	0	0	0	0	0	0	2	2	0	0	0	0	0	0	0	0	0	0	2	2
Shared care or guardianship	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Regular part-time care (2/3 days per week)	0	0	0	0	1	0	2	3	0	0	0	0	0	0	0	0	1	0	2	3
Regular part-time care (every weekend)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Regular part-time care (alternate weeks)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other residential service	0	0	0	0	0	0	1	1	0	0	0	0	0	1	2	3	0	1	3	4
<b>All services</b>	<b>0</b>	<b>4</b>	<b>1</b>	<b>5</b>	<b>18</b>	<b>112</b>	<b>175</b>	<b>305</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>20</b>	<b>19</b>	<b>39</b>	<b>18</b>	<b>136</b>	<b>195</b>	<b>349</b>

Table 4.7.2 Intellectual Disability Database, Bray Area 2003.

Future residential support service requirements of individuals receiving no residential support services in 2003.

	No service – requires residential support				Receives day service – requires residential support				Receives residential service – requires residential support				Receives residential and day services – requires residential support				Overall need			
	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All	NV	Mild	MSP	All
Foster care and boarding-out																				
Living independently													1		1		1		1	
Living semi-independently		1		1	4	14	1	19					4	1	5	4	19	2	25	
Holiday residential placement					1			1								1			1	
Crisis or planned respite					6	9	8	23								6	9	8	23	
Occasional respite care with host family																				
Occasional respite in the home																				
Shared care or guardianship																				
Regular part-time care (2/3 days per week)																				
Regular part-time care (every weekend)																				
Regular part-time care (alternate weeks)																				
Other residential service													1	1	2	0	1	1	2	
<b>All services</b>		<b>1</b>		<b>1</b>	<b>11</b>	<b>23</b>	<b>9</b>	<b>43</b>					<b>6</b>	<b>2</b>	<b>8</b>	<b>11</b>	<b>30</b>	<b>11</b>	<b>52</b>	

Table 4.12.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Pattern of movement of individuals from existing day service to future day service 2004-2008.

Day service in 2003:	Day service required in the period 2004-2008																											
	HS	HH	ES	MPS	SPSC	EDC	MS	RT	SCP	SCS	SS	SVT	AC	POP	SHS	SI	SWC	SEC	MSS	DR	DRH	OT	E	SE	OE	GVT	GD	All
Home support (HS)	0	0	0	6	4	2	0	0	0	0	1	0	0	0	1	1	2	0	0	0	0	0	0	2	0	0	0	19
Home help (HH)	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Early services (ES)	0	0	21	78	41	7	20	0	3	0	27	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	197
Mainstream pre-school (MPS)	0	0	0	2	0	0	23	0	7	0	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	36
Special pre-school (SPS)	0	0	10	5	2	7	6	0	4	0	58	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	92
Child education & develop. centre (CEDC)	3	0	0	0	0	10	0	0	0	0	6	0	53	0	5	2	0	0	0	1	0	0	0	0	0	0	0	80
Mainstream school (MS)	0	0	0	1	0	0	0	0	3	7	15	6	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	34
Resource/visiting teacher (RT)	0	0	0	6	2	1	1	0	1	0	9	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	20
Special class – primary (SCP)	0	0	0	0	0	0	0	0	0	127	10	0	0	0	1	1	0	0	0	0	0	0	0	1	0	1	0	141
Special class – secondary (SCS)	0	0	0	0	0	0	0	0	0	1	1	10	13	0	0	0	0	0	0	0	0	0	0	0	0	1	0	26
Special school (SS)	21	0	0	0	0	0	0	1	0	0	33	365	86	0	8	1	48	0	1	0	0	1	0	22	21	0	0	608
Special vocational training (SVT)	2	0	0	0	0	0	0	0	0	0	0	8	11	1	3	3	65	0	1	0	0	0	0	124	0	1	0	219
Activation centre (AC)	3	0	0	0	0	0	0	0	0	0	0	6	223	197	60	168	28	1	0	0	0	0	0	57	0	1	1	745
Programme for the older person (POP)	0	0	0	0	0	0	0	0	0	0	0	1	6	51	1	3	0	0	0	0	0	0	0	0	0	0	0	62
Special high-support service (SHS)	0	0	0	0	0	0	0	0	0	0	0	4	2	4	5	14	1	0	0	0	0	1	0	2	0	1	0	34
Special intensive service (SI)	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	6	1	0	0	0	0	0	0	0	0	0	0	9
Sheltered work centre (SWC)	4	0	0	0	0	0	0	0	0	0	0	9	92	104	10	10	181	1	2	0	0	0	9	163	4	4	0	593
Sheltered employment centre (SEC)	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	1	1	0	0	0	0	0	9	0	0	0	13
Multidisciplinary support services (MSS)	1	0	0	0	0	1	0	0	0	0	1	3	12	43	20	10	3	0	11	0	0	0	0	7	0	1	0	113
Centre-based day respite service (DR)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Day respite in the home (DRH)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Other day service (OT)	0	0	0	0	1	0	0	0	0	0	0	0	5	9	1	1	1	0	0	0	0	0	0	1	0	0	0	19
Enclave with open employment (E)	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Supported employment (SE)	1	0	0	0	0	0	0	0	0	0	0	2	5	11	2	0	4	1	0	0	0	2	0	26	4	0	1	59
Open employment (OE)	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	2	0	0	0	3
Generic vocational training (GVT)	0	0	0	0	0	0	0	0	0	0	0	1	2	1	0	0	6	1	0	0	0	0	0	21	26	0	0	58
Generic day service (GD)	0	0	0	0	0	0	0	0	0	0	0	1	2	0	2	0	3	0	0	0	0	0	0	7	0	0	0	15
All services	36	0	31	98	50	28	50	1	18	135	165	416	514	423	120	220	345	5	15	1	0	4	9	444	55	12	2	3197

The abbreviations in the third row of the table refer to the programme descriptions outlined in column one.  
The shaded area of the table represents existing services that require no alteration or enhancement.

Table 4.12.2 Intellectual Disability Database, Bray Area 2003.

Pattern of movement of individuals from existing day service to future day service 2004-2008.

Day service required in the period 2004-2008																													
Day service in 2003:	HS	HH	ES	MPS	SPS	CEDC	MS	RT	SCP	SCS	SS	SVT	AC	POP	SHS	SI	SWC	SEC	MSS	DR	DRH	OT	E	SE	OE	GVT	GD	All	
Home support (HS)																													
Home help (HH)																													
Early services (ES)				7	19		1		2																			29	
Mainstream pre-school (MPS)				1			4																					5	
Special pre-school (SPS)							1		2		23																	26	
Child education & develop. centre (CEDC)							1																					1	
Mainstream school (MS)				1					1																			2	
Resource/visiting teacher (RT)									1																			1	
Special class – primary (SCP)										6	1																	7	
Special class – secondary (SCS)																													
Special school (SS)											1	20	9									1						31	
Special vocational training (SVT)												2	2		2	1	11								13			31	
Activation centre (AC)												2	31	11	7	4		1							8		1	65	
Programme for the older person (POP)														1	3	1												5	
Special high-support service (SHS)														2	4	1	6	1				1			2		1	18	
Special intensive service (SI)																													
Sheltered work centre (SWC)												1	22	17			33	1						9	32	1	4	120	
Sheltered employment centre (SEC)																													
Multidisciplinary support services (MSS)														2	24	2									1			29	
Centre-based day respite service (DR)																													
Day respite in the home (DRH)																													
Other day service (OT)					1									3	4													8	
Enclave with open employment (E)																													
Supported employment (SE)																	1								5	2		8	
Open employment (OE)																													
Generic vocational training (GVT)														2	1		6	1							15			25	
Generic day service (GD)														2		2									5			9	
All services				9	20		1	6		6	6	25	25	76	64	15	11	52	3				2	9	81	3	5	1	420

The abbreviations in the third row of the table refer to the programme descriptions outlined in column one.  
The shaded area of the table represents existing services that require no alteration or enhancement.

Table 4.19.1 Intellectual Disability Database, Health Services Executive Eastern Region 2003.

Pattern of day service provision required 2004-2008.

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-) /Excess (+) of places arising from demand
Home support	1	0	0	36	0	-37
Home help	0	0	0	0	0	0
Early services	2	0	0	31	0	-33
Mainstream pre-school	1	0	0	98	36	-63
Special pre-school	1	0	0	50	92	41
Child education and development centre	0	0	0	28	80	52
Mainstream school	0	0	0	50	34	-16
Resource/visiting teacher	0	0	0	1	0	-1
Special class - primary	0	0	0	18	141	123
Special class - secondary	0	0	0	135	26	-109
Special school	6	0	0	165	608	437
Special vocational training	8	1	0	416	219	-206
Activation centre	18	5	2	514	745	206
Programme for the older person	1	4	0	423	62	-366
Special high-support day service	3	19	2	120	34	-110
Special intensive day service	1	9	0	220	9	-221
Sheltered work centre	8	0	0	345	593	240
Sheltered employment centre	1	1	0	5	13	6
Multidisciplinary support services	0	0	0	15	0	-15
Centre-based day respite service	0	1	0	1	0	-2
Day respite in the home	0	0	0	0	0	0
Other day service	0	0	0	4	19	15
Enclave within open employment	0	0	0	9	1	-8
Supported employment	8	0	0	444	59	-393
Open employment	2	0	0	55	3	-54
Generic vocational training	1	0	0	12	58	45
Generic day services	0	2	0	2	15	11
<b>All Services</b>	<b>62</b>	<b>42</b>	<b>4</b>	<b>3197</b>	<b>2847</b>	<b>-458</b>

Table 4.19.2 Intellectual Disability Database, Bray Area 2003.

Pattern of day service provision required 2004-2008.

	New services required by people without day services	New services required by people transferring from psychiatric hospitals	Service changes required by people within psychiatric hospitals	Service changes required by people receiving day services	Places vacated by people receiving day services	Shortfall (-)/
Home support	0	0	0	0	0	0
Home help	0	0	0	0	0	0
Early services	0	0	0	0	0	0
Mainstream pre-school	0	0	0	9	5	-4
Special pre-school	0	0	0	20	26	6
Child education and development centre	0	0	0	1	1	0
Mainstream school	0	0	0	6	2	-4
Resource/visiting teacher	0	0	0	0	0	0
Special class - primary	0	0	0	6	7	1
Special class - secondary	0	0	0	6	0	-6
Special school	1	0	0	25	31	5
Special vocational training	0	0	0	25	31	6
Activation centre	1	0	0	76	65	-12
Programme for the older person	1	0	0	64	5	-60
Special high-support day service	0	1	0	15	18	2
Special intensive day service	0	0	0	11	0	-11
Sheltered work centre	0	0	0	52	120	68
Sheltered employment centre	1	0	0	3	0	-4
Multidisciplinary support services	0	0	0	0	0	0
Centre-based day respite service	0	0	0	0	0	0
Day respite in the home	0	0	0	0	0	0
Other day service	0	0	0	2	8	6
Enclave within open employment	0	0	0	9	0	-9
Supported employment	1	0	0	81	8	-74
Open employment	0	0	0	3	0	-3
Generic vocational training	0	0	0	5	25	20
Generic day services	0	0	0	1	9	8
<b>All Services</b>	<b>5</b>	<b>1</b>	<b>0</b>	<b>420</b>	<b>361</b>	<b>-65</b>