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information for all

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Developments in Disability Policy and Services

Introduction

In *Relate*, we aim to include information on developments in disability policy and services. The last detailed update on such developments was in the May 2003 issue. The revised Disability Bill has still not been published – the target date is now September 2004. The legislation on special needs education has been passed and is described below. A review of the Disabled Person's Housing Grant has been undertaken by the Department of the Environment and a report is expected shortly. The National Disability Authority is continuing its work on standards for services and has recently published a report "Disability and the Cost of Living". This report examines the extra costs of disability and the NDA argues that a Cost of Disability payment should be introduced to compensate for these extra costs. Further information on standards and on the report can be accessed at www.nda.ie. More information on disability is available since the publication of a number of reports from the National Intellectual Disability Database.

National Intellectual Disability Database

The 2003 Annual Report of the National Intellectual Disability Database (NIDD) was published in June 2004. (The reports for 2001 and 2002 were also published in the past year). The objective of the NIDD is to ensure that accurate information is available about the needs of people with intellectual disabilities. Services are planned and co-ordinated on the basis of this information.

The 2003 Report shows, among other things, that 25,557 people are registered on the NIDD – this means that there are almost seven people with intellectual disabilities out of every 1,000 of the population. There has been a significant increase in recent years in the number of adults



aged 35 years and over with a moderate, severe, or profound intellectual disability and a corresponding ageing of their carers. This means that there is increased demand for residential services.

People who need services

The vast majority of the people on the NIDD (92%) are receiving services; 8,092 are receiving full-time residential services; 15,335 are attending day services. There are 2,284 people with intellectual disabilities who are either without any services or without a major element of service and have identified needs in the period 2004-2008. There are 1,776 people who need a residential service between 2004 and 2008 and 546 people who need day services. 1,637 need residential support services, such as respite services. 11,135 of the people who already have services need those services enhanced or changed to adequately meet their needs. There are 356 people who do not have any services at present and who will need services before 2008.

In May 2003, there were 438 people with intellectual disabilities living in psychiatric hospitals or units.

The National Intellectual Disability Database has been in existence since 1995. The information for the database is collated by the ten health boards and managed nationally by the Health Research Board. The full report is available on its website: www.hrb.ie

Education For Persons With Special Educational Needs Act 2004

The Education for Persons with Special Needs Act has been passed. It started out as the Education for Persons with Disabilities Bill 2003. The original Bill was described in the September 2003 issue of Relate. A substantial number of amendments, including the change of name, were made as it went through the Oireachtas. The following is a summary of the main points of the Act.

The 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,
- ◆ to establish the National Council for Special Education (this Council has already been set up and the Act will give it a statutory basis)
- ◆ to confer certain functions on health boards in relation to the education of people with special educational needs
- ◆ to establish an independent appeals system – the Special Education Appeals Board.

Special educational needs

You are a person with special educational needs if there is a restriction in your capacity to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in you learning differently from people who do not have the condition.

The Act states that the policy is to educate children with special needs (up to age 18) in an “inclusive environment” with children who do not have special needs unless this would be inconsistent with the best interests of the child or the effective provision of education to the other children.

Assessment of needs of children

The Act provides that the assessment of a child’s educational needs may be started in a number of ways. It may be started by the parents, the health board, the school principal or the National Council for Special Education (NCSE).

The parents’ consent is required for assessments ordered by the health board or NCSE. If the parents refuse to give consent, the health board or NCSE may ask the Circuit Court to dispense with consent. The Circuit Court may dispense with the consent if it considers that it would be in the best interests of the child to do so.

The parents may appeal to the Appeals Board against an assessment on the ground that it was not carried out in accordance with the required standards. Such an appeal must be heard within two months.

Health board

If the health board considers that a child who is not at school may have special educational needs, it may order an assessment of the child. In practice, this is mainly aimed at pre-school children but it could also apply to children who are of school age but are being educated at home.

Parents

If the parents consider that the child may have special educational needs they may ask the health board (if the child is not at school) or the NCSE to have an assessment done. The health board or NCSE must have the assessment started within one month of this request. Either may refuse to have an assessment carried out if they consider that there are not grounds to support the view that the child has special educational needs or if a similar assessment has been carried out in the previous year. The parents may appeal such a refusal to the Appeals Board who must give a decision on the appeal within six weeks.

Child at school

The school principal may, after consulting the parents, arrange for the assessment of a child who is not benefiting from the regular education programme in the school. This assessment must be started no later than one month after the principal decides it is necessary and must be completed within three months. If the assessment establishes that the child has special educational needs, the principal must organise the preparation of an education plan for the child within one month.

If the NCSE considers that a child who is at school may have special educational needs, it may order an assessment.

Education Plan

An education plan is drawn up following the assessment and is based on the needs identified in the assessment. When preparing the education plan, the principal must consult the parents and the special educational needs organiser and must facilitate the involvement of the parents in drawing up the plan. The National Council for Special Education will prepare guidelines on education plans. When the education plan is prepared, it must be given to the parents and the special educational needs organiser (who will be employed by the NCSE). If the principal thinks that preparing such a plan will not meet the child's educational needs, the NCSE may be asked to

prepare a plan. If the NCSE refuses to do this, the principal or the parents may appeal to the Appeals Board. The Appeals Board will have the power to order the NCSE to prepare a plan.

If the plan is being drawn up by the NCSE, the main person involved will be the special needs educational organiser. The organiser may convene a team to help devise the plan – this team must include the parents if they wish to be included and may include the child, the principal and teachers in the relevant school, a psychologist.

The education plan must include

- ◆ the nature and degree of the child's abilities, skills and talents
- ◆ the nature and degree of the child's special educational needs and how those needs affect his or her educational development
- ◆ the present level of educational performance of the child
- ◆ the special education and related support services to be provided to the child to enable the child to benefit from education and to participate in the life of the school
- ◆ where appropriate, the special education and related support services to be provided to the child to enable the child to effectively make the transition from primary school education to post-primary school education, and
- ◆ the goals which the child is to achieve over a period of up to 12 months.

The principal of the school will be responsible for implementing the education plan and the school "shall be provided with the necessary moneys and support services".

If the child is transferring to another school, the principals of the two schools must consult in order to ensure that the second school is in a position to implement the plan.

The education plan must be reviewed regularly – at least once a year – to see if the child is reaching the specified goals and changes may be made if the plan is not effective. There are provisions for the parents to seek a review of the education plan and they may appeal to the Appeals Board if they are not satisfied.

Parents may appeal to the Appeals Board against various aspects of the education plan including;

- ◆ any statement or description in it of their child's special educational needs
- ◆ any other statement or description which they consider to be incorrect or inadequate to meet the child's special educational needs
- ◆ the failure of the school or health board to implement any part of the plan.

The Appeals Board must make a decision on any such appeal within 2 months of receiving it.

As the child approaches adulthood and, in particular in the year before reaching 18, the education plan must take into account the provisions which may need to be made to help the child continue education or training on becoming an adult. The child's and the parents' wishes in this respect must be taken into account.

Who provides the services

At present, health boards are responsible for providing services to pre-school children and for speech and language therapy services generally while the Department of Education and Science is responsible for providing educational services to school-going children. The Act broadly proposes to continue this arrangement – the NCSE will take over the Department's role. The health board 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 board and the NCSE may ask each other to provide certain services. If there is a dispute between the health board 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.

The health boards and the NCSE will have liaison officers to ensure that the two work in a co-ordinated and consistent way in providing services.

Schools

The NCSE will have the power to designate the school which the child with special needs is to attend and that school must admit the child. When making such a designation, the Council must take into account the needs of the child, the parents' wishes and the capacity of the school to accommodate the child. The school's Board of Management may appeal to the Appeals

Board against any such designation or against any recommendation which the Council may have made about additional resources to be allocated because of the designation. The burden of proof will be on the Board of Management to show that they do not have the resources to meet the needs of the child concerned.

The Board of Management will be obliged to keep parents informed of the child's needs and how the child is progressing. Schools will be obliged to provide integrated education as far as possible, to cooperate with the NCSE and to promote awareness among pupils and staff of the needs of children with special educational needs.

Implementation

The Act has been passed but the required orders to bring it, or parts of it, into effect have not yet been made. When the NCSE is established on a statutory basis, 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.

The Special Education Appeals Board

The Special Education Appeals Board will be a statutory independent board. It will have procedures to ensure that the parties can be helped to reach agreement through mediation. If a hearing is necessary, it must be conducted as informally as possible. The Act sets out time limits for the making of decisions by the Board – generally the decision must be made within two months.

Advocacy Service for People with Disabilities

Comhairle has published "Developing an Advocacy Service for People with Disabilities" which was commissioned from Goodbody Economic Consultants. The Disability Bill 2001 included provision for the establishment by Comhairle of advocacy services for people with disabilities, including a Personal Advocacy Service. In this context, Comhairle commissioned this study to:

- ◆ Identify and examine the components of an Advocacy Service for and on behalf of people with disabilities that would best fit and could be applied in Ireland

- ◆ Set out a strategic framework for establishing and developing such a service
- ◆ Estimate the cost of developing the service
- ◆ Identify funding and accountability structures which would guarantee the independence of the service, and
- ◆ Set out a five-year programme to implement the strategic framework identified.

Volume 1 of the report reviews the concept of advocacy, provides an overview of the policy context within which advocacy services are to be developed, profiles the population of people with disabilities, outlines the current institutional environment in Ireland and the results of a consultation exercise, reviews the international experience of advocacy and sets out proposals for the developing of advocacy services in Ireland. Volume 2 presents the research papers on the seven countries which were examined for the purposes of the report.

The main recommendations set out in the report are:

- ◆ A coherent advocacy service should be developed to incorporate a Personal Advocacy Service (PAS), a Support Programme for the Community and Voluntary Sector and a Community Visitors Programme
- ◆ These services should be supported by research, standard setting and educational and training activities
- ◆ The Personal Advocacy Service should be set up on a paid professional basis to deal with critical and complex advocacy issues only. It should focus on advocacy in relation to assessments of need, access to services, complaint mechanisms, and delivery and operation of services. It should be a case-based service targeting the most vulnerable cases
- ◆ The Community Visitors Programme should focus on inspection of residential institutions for people with cognitive disability. It should be set up on a volunteer basis, and overseen by a central and regional support structure
- ◆ The Support Programme for the Community and Voluntary Sector should be focused on the provision of individual advocacy services, employing a range of advocacy delivery models. Representative rather than service delivery organisations should be accorded priority in

funding. Organisations providing advocacy services to rural dwellers should also be accorded some priority. Citizens Information Centres/Citizens Information Services bodies should be encouraged to play a part in the delivery of individual advocacy services in the community

- ◆ These services should be phased in – the Programme of Support for the Community and Voluntary sector should be initiated two years before the commencement of the PAS
- ◆ Comhairle should hold the budgets for the above programmes. It should also have an overall lead role in monitoring the development of these and other services and advising the Government on resource organisation. The estimated cost of the services, when fully operational, is €5.1m annually
- ◆ Existing funding of advocacy from other sources should be continued and there should be renewed efforts on the part of service providers to put customer service mechanisms in place.

The Minister for Social and Family Affairs has said that she intends to publish a Comhairle (Amendment) Bill in 2004 to provide for the introduction of a personal advocacy service for people with disabilities. The main function of the personal advocate will be to help, support and represent the person with a disability in applying for and obtaining a social service and also in pursuing any right of review or appeal in connection with that service.

The report is available at: www.comhairle.ie

Mental Health

The Report of the Inspector of Mental Hospitals for the year 2002 has been published. The report shows that the number of patients in in-patient psychiatric facilities is declining and also that about 11% of all admissions are involuntary. The new procedures for dealing with involuntary admissions which are set out in the Mental Health Act 2001 are still not in effect. The expert group on mental health policy was set up in 2003. The Inspector of Mental Hospitals has issued "Guidelines on Good Practice and Quality Assurance in Mental Health Services" to all providers of mental health services. The new Inspector of Mental Health Services has been appointed. The report is available at www.doh.ie/publications/inspect02.html

Reorganisation of health services

The Health (Amendment) Act 2004 is the first of two pieces of legislation to implement the new structures for delivery of health services. The main elements of this re-organisation are:

- ◆ the abolition of the health boards and the Eastern Regional Health Authority
- ◆ the establishment of the Health Services Executive (HSE) as the overall national body for delivery of health services
- ◆ the establishment of the Health Information and Quality Authority (HIQA) to ensure that safety and quality of care is promoted throughout the system
- ◆ the transfer of the functions of a number of existing agencies to the HSE, the HIQA and the Department of Health and Children.

The interim Health Services Executive was established in March 2004 by the Interim Health Services Executive (Establishment) Order 2004 (S.I. No. 90 of 2004). The interim HSE's remit is to draw up a plan for:

- ◆ the establishment of a unified management structure for the proposed new HSE,
- ◆ the integration of the existing health board structures into the new HSE
- ◆ the streamlining of other statutory bodies which it is proposed to incorporate in the new structure
- ◆ the establishment of regional boundaries for the delivery of primary, community and continuing care services
- ◆ the establishment of procedures to develop a national service plan for the delivery of health services
- ◆ the establishment of appropriate structures and procedures to ensure the proper governance and accountability arrangements for the proposed HSE, and
- ◆ the appointment of a chief executive officer.

The Health (Amendment) Act 2004 ends the membership of the various health boards and the Eastern Regional Health Authority and deals with the administrative arrangements which result from this. The health board management and staff structure remain in place for the present. There are no

members of health boards and the decisions which used to be made by the boards are now being made by their Chief Executive Officers and the Minister for Health and Children. The Act came into effect on 15 June 2004.

The second Bill will be introduced later this year and will provide for the establishment of the HSE and the HIQA. It will also provide for a statutory complaints system. It is expected that all of this will be in effect by January 2005.

It is expected that the HSE will be organised on a regional basis and that there will be arrangements to allow for local representatives (members of local authorities) to raise local issues of concern. Similar arrangements will be made for professionals such as doctors and nurses. Most health boards have set up consumer panels to facilitate community participation in decisions about the delivery of services and two have set up advisory panels for older people and their carers. It is planned to include provisions for such panels in the legislation which will be introduced later this year.

The interim HSE is at: Block 4, Floor 3, Irish Life Mall, Talbot Street, Dublin 1. Tel: 01 865 6968

Information on developments in the implementation of the changes is available at: www.healthreform.ie

Rural Social Scheme

The Rural Social Scheme was announced in the Budget of December 2003. It is being implemented from July 2004. The scheme aims to provide part-time community work for 2,500 farmers and fishermen or their spouses. The work will involve providing services to rural communities. It is broadly similar to the Community Employment scheme in terms of who qualifies, the hours to be worked and the payments which are made but it does not include any training element. It is an income maintenance and community enhancement scheme and is not designed to get people back into the full-time work force.

The sort of projects which may be included under the scheme are:

- ◆ Maintaining and enhancing waymarked ways, agreed walks and bog roads
- ◆ Energy conservation work for older people and the less well off
- ◆ Village and countryside enhancement projects
- ◆ Social care and care of older people, community care for pre-school and after-school groups
- ◆ Environmental maintenance work
- ◆ Maintenance and caretaking of community and sporting facilities
- ◆ Projects relating to not-for-profit cultural and heritage centres.

In order to be eligible for the scheme, you must be getting Farm Assist, or you must have a herd number and be getting Unemployment Assistance, Disability Allowance or Unemployment Benefit or be on a Community Employment scheme (CE). Transfers from CE will only be accepted during the first 12 months.

If you get a place on the scheme, you may work on it for one year. After that, you may be eligible again but this depends on the number of places in your

area. You will have to work 19.5 hours a week and the time will be arranged to suit your farming and fishing requirements. The payments will be:

Single person	€159.20
Person with Adult Dependent	€248.60
Child Dependent	€16.80 (or €8.40 if you are entitled to the half rate only – this arises if your spouse has income)

Initially, the scheme will be delivered by the following groups but it is expected that it will become available in other areas at a later stage:

Mayo	South-West Mayo Development
Donegal	Inishowen Rural Development
Galway	Galway Rural Development
Cavan/Monaghan	Cavan/Monaghan Rural Development
Leitrim & N. Roscommon	Arigna Catchment Area Community Development
Cork & part Kerry	I.R.D. Duhallow
Wexford	W.O.R.D. (Wexford)
Gaeltachts and Islands	M.F.G./Údarás na Gaeltachta

Further information is available at: www.pobail.ie

Rent Supplement recipients

Changes were made to the rules on Rent Supplement earlier this year and the Minister for Social and Family Affairs expressed concerns that the housing needs of Rent Supplement recipients were not being adequately addressed – see Relate, January 2004. New proposals to meet the long term housing needs of Rent Supplement recipients have now been announced. The new arrangements mean that local authorities will gradually assume responsibility for meeting the long-term housing needs of those who have been dependent on Rent Supplement for 18 months or longer (about 19,000 people).

The new arrangements will start from September of this year in a number of areas – Dublin, Galway and Limerick Cities, South Dublin, Donegal, and Offaly / Westmeath County Councils and Drogheda Town Council. They should be in operation in all areas by September 2005. An assessment of housing assistance needs and possible accommodation-based options of people who have been receiving Rent Supplement for 18 months or more will be completed by March 2005.

The new arrangements will involve the local authorities in making accommodation arrangements

instead of paying a Rent Supplement. A variety of accommodation arrangements will be put in place. These could include specifically built premises, existing properties which are rented to Rent Supplement recipients, new developments under public private partnerships which could be financed, developed and operated on a long-term basis exclusively for households designated by local authorities.

The Rent Supplement will continue to be available as short term support.

Affordable Housing

Increased income limits for Shared Ownership and Affordable Housing have been announced. They are effective from 13 July 2004.

The maximum loan for a local authority house purchase has been increased from €130,000 to €165,000. The income eligibility limits for Affordable Housing and the Shared Ownership scheme are now €36,800 for a one income household and €92,000 for a two income household (two and a half time one income and once the second income). Further information is available at www.environ.ie

New Committees and Working Groups

Consumer Strategy Group

The Minister for Enterprise, Trade and Employment has appointed a consumer strategy group to advise on the development of a national consumer policy. The consumer Advisory Council has been stood down. The new group is expected to report before the end of the year. The terms of reference of the group are to advise and make recommendations for the development of a national consumer policy strategy which will:

- ◆ provide consumers with the knowledge, information and confidence to be demanding of quality, service and value
- ◆ ensure consumers are well informed of their rights and have effective and speedy means of redress in the event that those rights are denied
- ◆ give consumers a powerful voice and effective representation and input in the development of policy proposals at national and local level
- ◆ ensure the views of consumers are heard and taken into account in national debate on relevant business, trade and social policy issues
- ◆ promote among product and service providers best practice in the delivery of quality customer service and value for money and an appreciation of the contribution satisfied consumers make to the growth and development of business.

Regulation of Auctioneers

A working group to review the regulatory arrangements for the auctioneering industry has been established by the Minister for Justice, Equality and Law Reform. The group has been asked to make

specific recommendations on:

- ◆ The qualification requirements (if any) necessary or desirable for acting as an Auctioneer or Property Letting Agent
- ◆ The need for the introduction of a code of ethics and professional standards for the auctioneering profession and for property letting agents
- ◆ The need for an appropriate body to regulate the professional conduct of auctioneers/property letting agents
- ◆ The desirability of establishing a system to facilitate the investigation of complaints in relation to auctioneering/property letting transactions.

The legislation governing auctioneers sets out the licensing requirements and deals with, among other things, how auctioneers must deal with clients' money, fees and accounts generally. This legislation is the Auctioneers and House Agents Act 1947 as amended in 1967 and 1973. Auctioneers must have a licence – this is obtained by applying to the District Court for a certificate of qualification and then to the Revenue Commissioners for an auctioneer's license. Any person may object at the District Court stage.

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