

Inclusion Ireland is a national voluntary umbrella organisation working to promote the rights of people with an intellectual disability in Ireland to ensure their full and equal participation in society. Inclusion Ireland was founded in 1961 and has become the co-ordinating body for over 160 organisations providing services and supports to over 26,000 people with an intellectual disability that live in Ireland.

Inclusion Ireland provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to Government and statutory bodies, to other relevant groups as well as to the general public. Inclusion Ireland campaigns for changes in services and legislation that will improve the quality of life and participation for people with an intellectual disability in Irish life.

Promoting the Rights of People with an Intellectual Disability

Introduction

Inclusion Ireland has been contacted by many individuals and their families who have questions about the 'long stay' or 'health charges' being applied to those who use residential services.

Both of the above terms, as well as 'Charges for In-Patient Services', can be used. We will use the term 'health charges' hereafter in this booklet.

This is an information booklet to address some of the concerns raised, and to explain how the charges should be implemented.

If you have any questions arising from the issues raised in this booklet, please contact Inclusion Ireland.

November 2009

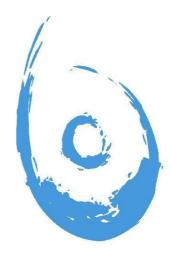
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Background

Historically, people who were in long term care were charged for staying in nursing homes and other institutions. This charge was taken directly from the social welfare payment of the individual. Most people with an intellectual disability who were in long term care at this time had no income, (apart from some who may have been receiving a pension), and therefore there was no charge levied.

This situation changed when the Disabled Persons Maintenance Allowance (DPMA) became the Disability Allowance (DA) and was transferred to the Department of Social and Family Affairs in 1996. In the years following, entitlement to DA was extended to some people with a disability in some residential services.

From January 2005 those people in institutional care that were still not entitled to a Disability Allowance became entitled to a "Personal Expenses Rate" of €35 per week. From January 2007 these people then became entitled to a full rate Disability Allowance.

All persons who are eligible for Disability Allowance are now entitled to receive it regardless of the type of residential service they receive.

Charges

From the mid 1970's people with an income resident in long stay care homes had to pay a 'health charge', which was nearly the entire income of the individual. In 2004, the Supreme Court found that there was no legal basis for these charges. Care Homes were ordered to suspend all charging between December 2004 and July 2005. New legislation was introduced in July 2005 to make charging legal. Those who were charged illegally prior to that were entitled to a repayment.

The Health (Amendment) Act 2005 and the subsequent Health (Charges for In-Patient Services) Regulations 2005 provide the legislative basis for the imposition of long stay charges. Under this legislation, charges were applied from 14th July 2005. However, some disability service providers did not recommence charging due to ambiguity on the type of residential services that could charge.

In August 2006 the HSE produced Guidelines for service providers on who to charge and how to apply these charges (see p.11 to access copies of the Guidelines). Many service providers began applying these guidelines in January 2007, and notified residents that they have to pay a 'health charge'. The Health (Charges for In-Patient Services) (Amendment) Regulations, 2008 amend the 2005 regulations and provide for an increase in the level of charges payable.

At the time of writing, the legislation provides for two different classes of person for the purpose of levying a charge.

Class 1 & Class 2

Class 1

Class 1 refers to persons in receipt of in-patient services on premises where nursing care is provided on a 24 hour basis

Class 2

Class 2 refers to persons in receipt of in-patient services where nursing care is not provided on a 24 hour basis

Level of Charge

In the case of Class 1 a weekly charge of €153.25 or the weekly income of that person less €44.70, whichever is the lesser

In the case of Class 2 a weekly charge of €114.95 or the weekly income of that person less €70.25 or 60% of the weekly income of that person, whichever is the lesser

HSE Guidelines to Service Providers

The Guidelines produced by the HSE in 2006 outline that organisations should individually assess each of its residents to determine the amount they should be charged. The maximum amounts can be reduced if for example individuals have particular socialisation expenses (cinema, recreation, sports, holidays) or other outgoings such as savings, health insurance, etc.

The service provider completes an assessment form with this information to determine the charge for each individual. Individuals or their families should ensure the service provider makes this assessment form available to them.

The Minister for Health and Children has clearly stated that "the actual charge levied will vary from person to person depending on

individual circumstances, and under the legislation the Health Service Executive can waive or reduce the charges to avoid undue financial hardship" (see page 6 for more information).

Sections 38 & 39 of the Health Act, 2004

Section 38 (formerly section 26 of the 1970 Health Act) refers to services provided on behalf of the HSE, and charges should be imposed in this instance. Large disability service providers generally fall under Section 38 and have a legal right to impose charges.

Section 39 (formerly Section 65 of the 1970 Health Act) refers to services assisted by the HSE. There is no legislative basis for the imposition of charges in this instance. Smaller disability services, or services developed since the 1970s tend to fall under Section 39 and there is no legislative basis for charges in this instance.

Appealing the amount charged

The person or their advocate may apply to the service provider to have the charge reduced or waived if they feel it is causing undue hardship and their remaining income is insufficient to meet their reasonable needs. If the person or their advocate is still dissatisfied, they can contact the relevant Appeals Officer within their HSE Local Health Office.

Many family members act as the Agent for individuals with an intellectual disability who lack the capacity to manage their money. These family members should make an arrangement with the service provider to pay the weekly charge as assessed out of the individual's Disability Allowance. Some services may ask families to transfer the agency of the Disability Allowance to the service, when

¹ *Dáil Debates*, vol. 672, no. 497 (27 January 2009)

the person goes into residential care. If the family member wishes to continue as the agent they may do so as long as the weekly charge is met. There is no legal obligation to hand over the agency to a service provider.

Will people have to pay if their only income is a social welfare payment?

Yes. However, there are a number of exemptions.

Exemptions

Under Section 4(b) (3) of the Health (Amendment) Act 2005 a charge is not payable where in-patient services concerned are provided to:

- A person under 18 years of age;
- A woman in respect of motherhood;
- A person detained involuntarily under the Mental Health Acts 1945 to 2001;
- A person who is in hospital for the care and treatment of patients with acute ailments (including psychiatric ailment), and requires medically acute care and treatment in respect of any such ailment;
- A person, who in the opinion of the HSE, has contracted Hepatitis C directly or indirectly from the use of Human Immunoglobulin Anti-D, or the receipt within the State of another blood product or a blood transfusion;
- Any person receiving services for the diagnosis and treatment of infectious diseases as prescribed under Part IV of the Health Act 1947, are excluded from charges under Health (Charges for In-Patient Services) Regulations 2005;

Reduction or Waiver of a Charge

Section 4(b)(4) of the Health (Amendment) Act 2005, provides that the HSE may reduce or waive a charge imposed on a person if it is of the opinion that, having regard to the financial circumstances of that person, it is necessary to do so in order to avoid undue financial hardship in relation to that person.

A person or their representative/advocate may make a request to the Authorised Officer as designated by senior management, to reduce or waive the charge for maintenance on financial hardship grounds. Financial Hardship needs to be demonstrated to the satisfaction of the Authorised Officer that the money remaining with the person, having taken the charge into account, is insufficient to meet their reasonable needs.

Allowable Expenses

Charges may be reduced or waived in order to avoid undue financial hardship having regard to the person's financial circumstances. The following expenses may be allowable when calculating the appropriate charge:

- Dependant child;
- Life Assurance;
- Medical Insurance;
- Medical Costs (including prescription costs);
- Rent/Mortgage Allowances;
- Loans/Repayments;
- Maintenance Payments;
- Travel Costs;
- Rehabilitative Employment Allowance;
- Other Outgoings;

Questions arising from the Charges

Health charges raise a number of important questions for people with an intellectual disability who use services as well as their families, and for the organisations who provide them with services. Below is a list of issues that have been raised:

- The charges regulations create a blanket approach to all people who require support or care. This strongly reinforces a medical model of providing services and support to people with a disability. The system of charging does not fit well with a model of flexible, supported living in the community;
- The regulations do not take cognisance of the different types
 of residential support and services available to people with
 an intellectual disability. In particular the growing number of
 people with an intellectual disability living in social housing
 and other independent living arrangements;
- 3. The amounts that are recommended for charging represent a large portion of the Disability Allowance, the only income for many people;
- 4. The regulations remove an individual's right to independently choose how their money should be spent on everyday expenses;
- 5. The guidelines recommend means testing by non-State bodies:
- 6. Despite HSE Guidelines, there is no uniform approach in how the regulations have been applied different services, different approaches;

- 7. There is little or no independent monitoring of how the charges are applied;
- 8. There is little or no accessible information for individuals and families on their right to appeal, how to reduce a charge etc;
- There is inequity created by the distinction between people in services that receive funding under different sections of the Health Act, i.e. Section 38 of the Health Act may charge under these regulations and those in Section 39 may not (see p. 4 for more details);
- 10. Services that receive funding under Section 39 of the Health Act may seek a voluntary contribution, as there is no legal basis for the imposition of charges, but at present there are no regulations governing voluntary contributions;
- 11. There is a lack of clarity among people with an intellectual disability and their families as to what the charges cover;

Inclusion Ireland's view

Inclusion Ireland supports the view that all those who have an income should be encouraged to contribute to their everyday living expenses, based on an individual assessment of their needs, as outlined in HSE Guidelines. However, despite HSE Guidelines there is no uniform approach in how the charges are applied. Inclusion Ireland endorses the Health Information and Quality Authority's National Quality Standards: Residential Services for People with Disabilities. Standard 7 is particularly relevant:

"Each individual exercises control over personal finances and is protected from financial abuse and exploitation" (see Appendix A for full criteria of Standard 7).

Any system that seeks to take a charge from individuals who use services and receive support should have the following principles applied:

- 1. Equity and fairness;
- 2. Transparency in managing or taking an individual's personal income:
- 3. Charges should not form part of core funding of services;
- 4. Charges should be individually assessed and applied by the HSE or another independent state body, not a service provider;
- Clear accessible information should be provided to those who are being charged, and/or their family or advocate, to ensure there is clarity on what is being covered by the charge;
- 6. Information on the right to appeal should be provided as well as an accessible appeals process;

<u>APPENDIX A:</u> National Quality Standards: Residential Services for People with Disabilities - Health Information and Quality Authority²

Standard 7: The Individual's Finances

Each individual exercises control over personal finances and is protected from financial abuse and exploitation.

Criteria

- 7.1 The individual controls his/her own financial affairs unless he/she wishes otherwise or where he/she lacks the capacity to do so (see Standard 11, Informed Decision Making and Consent).
- 7.2 The individual is given information, advice and support in the management of his/her own financial affairs if he/she so wishes.
- 7.3 The individual has easy access to personal monies and spends it in accordance with his/her wishes.
- 7.4 Where the individual requires assistance to manage his/her financial affairs, he/she nominates the person to be entrusted with this responsibility. The person so nominated keeps an account of all monies spent. If the person so nominated is a member of staff, he/ she accounts to the person-in-charge as well as the individual.
- 7.5 The individual does not contribute to any communal fund without his/her informed consent.
- 7.6 The individual can avail of facilities for the safe storage of his/her money and valuables.
- 7.7 Records and receipts of possessions handed over for, or withdrawn from, safekeeping are kept up to date.
- 7.8 The person-in-charge ensures that the individual has access to an advocate and/or legal advice in any situation where it appears that he/ she is subject to any form of financial abuse by a third party.

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² See <u>www.hiqa.ie</u>, or contact HIQA, Unit 1301, City Gate, Mahon, Cork for further information on the *National Quality Standards*

USEFUL LINKS

HSE information page on charges:

 http://www.hse.ie/eng/services/Find_a_Service/Older_People_ Services/Residential_Care/Long_Stay_Charges/

HSE National Guidelines for levying charges:

 http://www.hse.ie/eng/services/Find_a_Service/Older_People_ Services/Residential_Care/Long_Stay_Charges/longstaycharge sjan2009.pdf

HIQA National Quality Standards: Residential Services for People with Disabilities

http://www.hiqa.ie/functions_sh_ss_standards_residential_services disabilities.asp

Inclusion Ireland has a 'Health Charges' webpage, which contains the above information, as well as a link to the 'HSE Financial Assessment Form'. You can download information directly, or if you do not have access to the internet, please call the Inclusion Ireland office and information will be forwarded to you.

See www.inclusionireland.ie/topics_healthcharges.asp.

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The seven-year programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies across the EU-27, EFTA-EEA and EU candidate and precandidate countries.

PROGRESS mission is to strengthen the EU contribution in support of Member States' commitments and efforts to create more and better jobs and to build a more cohesive society. To that effect, PROGRESS will be instrumental in:

- providing analysis and policy advice on PROGRESS policy areas;
- monitoring and reporting on the implementation of EU legislation and policies in PROGRESS policy areas;
- promoting policy transfer, learning and support among Member States on EU objectives and priorities; and
- relaying the views of the stakeholders and the society at large.

For more information see: http://ec.europa.eu/employment_social/progress



The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.



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