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 coordinating 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.

These charges are now referred to as "Long-Stay Contributions" and are short for the "Resident Support Services Maintenance and Accommodation Contribution". From here on in we will use the term "contributions".

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.

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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.

Contributions

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.

From the 1st January 2017, these long-stay charges are to be replaced by Long-Stay Contributions. These contributions will go toward your accommodation and maintenance costs (food, utility bills etc.). People currently paying Long-stay Charges will now pay the same rate for the Long-Stay Contribution.

At the time of writing, the legislation provides for three different categories of payment.

Categories A,B and C

Category A

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

Category B

Category B refers to persons in receipt of in-patient services where nursing care is provided, but not on a 24 hour basis.

Category C

Category C refers to persons who receive no nursing services, in premises such as independent-living settings.

Category	Payment Rate
	In Category A a weekly charge
Category A	of €175.00 is applied, or the
	weekly income of that person
	less €33.00.
	In Category B a weekly charge
Category B	of €130.00 is applied, or the
	weekly income of that person
	less €64.00.
	In Category C a weekly charge
Category C	of €70.00 is applied, or the
	weekly income of that person
	less €118.00.

Disability Allowance (DA) as only income:

- For persons in receipt of Disability Allowance (€188.00 per week) in Category A, the most they will have to contribute is €155.00 per week.
- For persons in receipt of Disability Allowance (€188.00 per week) in Category B, the most they will have to contribute is €120.00 per week.
- For persons in receipt of Disability Allowance (€188.00 per week) in Category C, the most they will have to contribute is €70.00 per week.

Implementation of Long-Stay Contribution system

Persons who previously paid Class 1 and Class 2 Long-Stay Charges

Persons transitioning from the Long-Stay Charge system to the Long-Stay Contribution system will continue to pay the same rates until an assessment has been completed by the service provider. It is the service providers' responsibility to complete this individual assessment at the earliest opportunity. This assessment should be commenced no later than the 6th May 2017 and be completed no later than the 1st July 2017.

Persons who previously did not pay any charges

For those persons who paid no charge under the Long-Stay Charge system and who have transitioned to the Long-Stay Contribution system, an assessment must be commenced by the service provider before 6th November 2016. These assessments must be completed by 30th November 2016.

All relevant persons should be advised of any introduction of contributions along with a user guide/FAQ's in advance of any

assessments and at least 14 days in advance of the new framework coming into operation.

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 contribution 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 at the time clearly stated that "the actual contribution levied will vary from person to person depending on individual circumstances, and under the legislation the Health Service Executive can waive or reduce the contributions 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 Contributions should be imposed in this instance. Large disability service providers

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

² Section 38 Documentation

generally fall under Section 38 ² and have a legal right to impose contributions.

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

Agency Arrangements

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 contribution 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 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 contribution is met. There is no legal obligation to hand over the agency to a service provider

Appealing the amount charged

The person or their advocate may apply to the service provider to have the contribution 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.

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 contribution 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:
- If you are receiving long-term residential service from the Nursing Home Support (Fair Deal) Scheme;
- 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 Contribution

Section 4(b)(4) of the Health (Amendment) Act 2005, provides that the HSE may reduce or waive a contribution 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;
- Dependant adult;
- Life Assurance;
- Medical Insurance;
- Medical Costs (including prescription costs);
- Rent/Mortgage Allowances;
- Loans/Repayments;
- Socialisation Costs
- Maintenance Payments;
- Travel Costs;
- Rehabilitative Employment Allowance;

Questions arising from the Contributions

Long-Stay Contributions 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 contribution 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 amounts charged for Category A and B represent a large portion of the Disability Allowance, the only income for many people;
- The regulations remove an individual's right to independently choose how their money should be spent on everyday expenses;
- 4. The guidelines recommend means testing by non-State bodies;
- Despite HSE Guidelines, there is no uniform approach in how the regulations have been applied - different services, different approaches;
- 6. There is little or no independent monitoring of how the contributions are applied;
- 7. 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);

- 8. 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 contributions, but at present there are no regulations governing voluntary contributions;
- There is a lack of clarity among people with an intellectual disability and their families as to what the contributions 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, there is no independent assessment of a person's finances, and instead it is left to the service providers to calculate each person's contribution. Inclusion Ireland endorses the Health Information and Quality Authority's National Standards for Residential Services for Children and Adults with Disabilities. Under Theme 3 - Safe Services, and in particular Standard 3.1, persons are to be supported to manage their finances, protected from any mismanagement of their finances, and should expect to have proper and transparent record-keeping of their finances available to them (See Appendix A).

Any system that seeks to take a contribution 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. Contribution should not form part of core funding of services;
- Contributions 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 Standards for Residential Services for Children and Adults with Disabilities – Health Information and Quality Authority

Theme 1 - Individualised Supports and Care

<u>Standard 1.1</u> – The rights and diversity of each person is respected and promoted

1.1.2 Each person is supported to take responsibility of their own financial affairs.

Theme 3 - Safe Services

<u>Standard 3.1</u> – Each person is protected from abuse and neglect and their safety and welfare is promoted.

- 3.1.13 Information, advice and support on money management are made available.
- 3.1.14 People have easy access to personal monies and control their own financial affairs in accordance with their wishes.
- 3.1.15 Where people need support to manage their financial affairs, they nominate a person to be entrusted with this responsibility. Nominated persons keep an account of all monies spent. If nominated persons are staff members, they are accountable to the person in charge as well as the person concerned.
- 3.1.16 People do not contribute to any communal fund without their informed consent.
- 3.1.17 People can avail of facilities for the safe storage of their money and valuables.
- 3.1.18 Records and receipts of possessions handed over for, or withdrawn from, safekeeping are kept up to date.

3.1.19 The person-in-charge ensures that people have access to advocates and/or legal advice in any situation where it appears they are subject to any form of financial abuse by a third party.

USEFUL LINKS

HSE information page on contributions:

http://www.hse.ie/longstaycontributions

HSE National Guidelines for contributions:

http://www.hse.ie/eng/services/news/newsfeatures/long staycontributions/

HIQA National Quality Standards: Residential Services for People with Disabilities

http://www.hiqa.ie/media/pdfs/National Quality Standards R esidential Services People with Disabilities easy to read.pd f

How to apply for a waiver

http://www.hse.ie/eng/services/news/newsfeatures/longstaycontributions/waiversFAQs.pdf

Inclusion Ireland has a 'Health Charges' webpage, which contains the above information. 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.

http://www.inclusionireland.ie/content/page/long-staycontributions

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