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Pobail agus Rialtais Áitiúil
Department of Housing, Planning,
Community and Local Government

INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Health

On homecare services in Ireland

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**This document is written in font 12 Verdana in line with Inclusion
Ireland plain English guidelines.**

1. About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

Inclusion Ireland welcomes the review of home care services being undertaken by the HSE. Homecare is one of the range of supports that can play a key role in supporting people to live in their own homes in the community and to remain in their own homes as they age, alongside the provision of Assistive Technology, Personal Assistance and a personal budget.

Currently, homecare is accessed mainly by older people. However, there is potential for homecare to be a valuable support across the lifespan for people with disabilities, acquired disabilities, those recovering from illness or injury or any person requiring support to live an independent life.

3. Current context

Homecare supports are currently provided by the HSE through the home help service and home care packages. Homecare supports were cut as part of austerity measures over the past number of years, from 12.3m hours to 54,736 people in 2007 to 10.5m hours to 47,891 people in 2015¹.

¹ Slaintecare report 2017

Though people with disabilities are eligible to apply for homecare, in reality few people with disabilities are actually accessing these supports. There are over 28,000 people registered with the National Intellectual Disability Database (NIDD). However, only 210 people with disabilities received home support and only 28 received home help services in 2016².

The Department of Health recognises that the demand for homecare supports is currently outstripping supply. Given that Ireland has an ageing population, demand for homecare supports is likely to increase in the future.

There is a strong link between ageing and disability. Among people in their twenties, less than 10% have a disability. The likelihood of having a disability increases with age and is over 20% by age 60. From age 70 on, rates increase more sharply with 75% of all women aged 85 and over having a disability³.

In keeping with general population trends, people with intellectual disabilities are also living longer. While this is good news, it has an impact on policy and service provision. As they age, people with disabilities are more likely to experience vision and mobility challenges, a higher prevalence rate for falls, and an increased risk of dementia among people with Down Syndrome. Future planning needs to take into account this growing population of people with disabilities and their support needs.

4. Improving homecare services

- **Provide a statutory right to a range of supports and services**

The Disability Act 2005 provides for an assessment of need and a service statement. However, it has not been fully commenced so only those born after 1st June 2002 have a right to an assessment under the Act. The Disability Act also provides no corresponding right to receive the services and supports identified in an assessment.

The Department of Health are seeking the views of stakeholders on whether there should be a statutory right to homecare services. It is the

² Health Research Board (2017). Report of the National Intellectual Disability Database 2016

³ CSO. Census 2011.

view of Inclusion Ireland that persons with disabilities should have a statutory right to whatever services and supports are identified through an assessment of need process, including homecare supports or other supports such as Personal Assistance or Assistive Technology.

- **Increase the accessibility of services to people with disabilities**

The low number of people with disabilities accessing homecare supports, as evidenced by the NIDD would appear to indicate that people with disabilities experience barriers to accessing these supports.

All health and social care supports should be available consistently across the country. Clear and accessible information on services and supports available, eligibility and how to apply should be available in a variety of formats.

- **Increase the quality of services**

Health and social care services and supports should be person-centred and underpinned by a rights and equality approach. Homecare services, like all public services, should meet their Public Sector Duty, in line with the Irish Human Rights and Equality Act 2015. This means they must actively promote equality and rights and eliminate discrimination.

Those working in homecare, like all other services, should have the appropriate education, training and skills to carry out their duties effectively. Home Care Assistants should be trained to the appropriate skill level prior to recruitment, particularly where they are recruited to assist persons with specific care needs such as Alzheimer's disease or autism. Similarly, service management must also be qualified in the area of care provision so that they are aware of the support needs of individuals and should include social care and psychology graduates as well as those with medical backgrounds.

Homecare services should be regulated and inspected by a statutory body such as Hiqa, to ensure persons using the service are treated with dignity and respect, their rights are upheld, their independence and choice is promoted and the quality of the service is assured.

Persons with disabilities should be able to exercise choice and control over the homecare supports they require, and should be able to access them within a personal budget.

Services provided should be in line with the requirements of the Assisted Decision Making (Capacity) Act 2015 and the HSE's safeguarding policy. Where a person wishes to make a complaint about the service they are receiving, they should have access to independent advocacy and a clear and accessible complaints procedure.

- **Involve people with disabilities in planning, design and evaluation of services**

Persons with disabilities should be involved in the planning, design, monitoring and evaluation of services and supports they access. They should be involved in decisions that affect their lives. It is important in consultations such as these, that persons with disabilities are supported to express their views and provided with accessible information and materials in order to do so.

Easy to read versions of consultation papers should be made available. Easy to read documents include the use of images to support written text, and should be proofread by people with disabilities to ensure it can be understood. Easy to read documents are also usually accredited with The European Easy-to-Read logo after being proofread.

During Inclusion Ireland's consultation on homecare, we received the following feedback from people with intellectual disabilities:

- Make sure there are enough staff resources available to support people
- People should have a choice in who provides the homecare help
- Homecare packages should be part of a person's individual funding
- Homecare support should work well with other aspects of a person's life, for example making sure they can still participate in the community

5. Key recommendations

- Provide a statutory right to homecare supports in the context of a statutory right to a basket of health and social care supports
- Ensure homecare is available to people across the lifespan where a need for support to live independently has been identified
- Ensure the provision of homecare is in line with relevant policies such as the Assisted Decision Making (capacity) Act 2015, HSE safeguarding policies, the Public Sector Duty, advocacy and complaints policies and the recommendations of the Taskforce on Personalised Budgets.
- Ensure home care workers and management have the appropriate skills and training to perform the duties of their roles effectively
- Provide accessible information on accessing homecare supports and ensure consistent availability nationally
- Implement regulation of homecare services in line with international best practice
- Carry out a review of the Disability Act 2005.

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