



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Pre-Budget Submission 2016

*"There is a tide in the affairs of men.
Which, taken at the flood, leads on to fortune;
Omitted, all the voyage of their life
Is bound in shallows and in miseries.
On such a full sea are we now afloat,
And we must take the current when it serves,
Or lose our ventures."*

The announcement by this Government of an investment of €450 million to upgrade or invest in nursing homes and disability facilities presents a critical moment for reform.

If this moment is lost, we will embed the institutionalisation of persons with a disability for a generation.

INTRODUCTION

Programme for Government 2011-2016

"...we will move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best. Personal budgets also introduce greater transparency and efficiency in funding services."

Dept of Health Value for Money report on disability services 2012

"... those using disability services do not participate in society in any meaningful way ... have little opportunity to self determine or to live full and independent lives."

Disability supports and services are undergoing significant reform. This reform programme is about moving towards a new model of person-centred and community-based supports. Individualised supports are key top reform – a 'money follows the person' model. This Government has a small window of opportunity to initiate key reforms which would deliver meaningful change.

- Ensure between 8 – 15% of the €1.4 billion provided through HSE Service Level Arrangements (SLAs) to disability service providers is used for person-centred, individualised and community-based services. Services which do not reform should be decommissioned.
- Introduce a system of direct payments and individualised budgets where persons with a disability and family members control their own funding (money follows the person) as promised in the Programme for Government 2011-2016.
- Establish a commission to identify the costs of having a disability and make recommendations for changes to the social welfare and taxation systems.

PADDY CONNOLLY, CEO INCLUSION IRELAND

1. Ring fence percentage of the €1.4 billion disability spend for independent supported living.

According to the National Disability Authority (NDA) three quarters of the current disability spend goes on services which no longer support the policy direction the Government wishes to take.

A Value for Money (VFM) review of the disability spend stated "...those using disability services do not participate in society in any meaningful way ... have little opportunity to self determine or to live full and independent lives."

According to the HSE Service Plan 2015 five organisations control 50% of the €1.4billion – they support a small percentage of the population of persons with a disability.

In a recent letter to Minister for Health Leo Varadkar TD, 22 service providers supported a ring fencing of the disability spend stating: "We believe the individualised-supports model has the most potential for cost-effectively promoting the principles of self-direction and inclusion."

A recent analysis of HIQA inspections by 'The Irish Times' showed that only 7% of residential disability service providers are fully compliant with inspection standards.

One way to ensure greater independence and self-determination of persons with a disability is to compel service providers to provide person-centred services and supports.

The expenditure of the €450 million recently announced by the Government must be monitored to ensure it drives deinstitutionalisation and supports people to live independently with appropriate supports in the community.

2. Introduce a direct payments model

The Programme for Government 2011 committed to introducing a system of direct payments. Direct payments allow for the payment of a pocket of money to persons with a disability or families where a child has a disability based on an assessment of need.

This enables persons with a disability or family members to purchase the supports and services that they require.

This key reform would drive consumer-led provision of disability services as opposed to the current institution-led model. It requires the entry of new providers such as brokers and intermediaries who can support those who require it to manage their own budget.

It would offer more choice and flexibility to persons with a disability and family members and reform the current 'one-size-fits-all' model. It is a reform which is fundamental to recognising the right to self-determination of persons with a disability and has been in widespread use across Europe for over 30 years.

3. Commission on the Cost of Disability

Only three out of 10 adults with a disability of working age years have a job. Lack of employment opportunities mean that many people with disabilities are forced to depend on social welfare payments as their only source of income.

These payments have been reduced in recent budgets. Increases in the cost of living have further diminished the household budgets of people with disabilities. Persons with a disability are twice as likely to experience deprivation compared to the national average and deprivation rates in Irish households have more than doubled since 2007.

Official poverty statistics do not consider the costs of having a disability. These costs are substantial and have been estimated to represent 35.4%

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of disposable household income. Addressing the extra economic costs of disability is “a logical step towards alleviating elements of social exclusion for people with disability.”¹

The Government should establish a commission to identify the costs of having a disability and to make recommendations for changes to the social welfare and taxation systems.

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¹ John Cullinan, et al., 2011, ‘Estimating the extra cost of living for people with disabilities’, *Health Economics*, 20: pp. 582–599