



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Pre-Budget Submission 2019

Department of Health

August 2018

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

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.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.

Public Sector Duty

In its most recent strategy statement, the Department of Health notes its obligations under Section 42 of the Irish Human Rights and Equality Commission Act, 2014 and its intention to embed these across the organisation

It is particularly welcome that the Department commits to the delivery of a more responsive, integrated and person-centred social care system that supports the full and effective participation of people with disabilities in society on an equal basis with others.

This submission outlines some key actions that the Department can take to fulfil this commitment in line with its Public Sector Duty.

Health .

About this Submission

Inclusion Ireland held consultations in Cork, Tullamore & Sligo as well as an on-line survey with respondents from all 4 provinces of Ireland. People with a disability, their family members and people who work in disability all took time to complete the survey.

Inclusion Ireland is moving towards complete accessibility of its work and this document contains an easy to read summary at the start.

Easy to read summary



The Department the Health looks after the health of all the citizens in Ireland

This submission is asking the Department to look at 5 things for the Budget in 2019.



What is the Budget?

The Budget is the Government plan of how money will be spent for the coming year.

Inclusion Ireland is asking the Department to look at 5 areas



1. Health and Social Care Reform

We are asking the Department to change health services and make them better for people with disabilities and to fund Slaintecare



2. Therapy supports

We are asking the Department to employ enough staff so that people with disabilities can get the therapy supports they need like, speech and language therapy, occupational therapy and physiotherapy.



3. Personalised Budgets

We are asking for the Department to fund personalised budgets in the right way so that people can have choice and control over the services they need.



4. Safeguarding

We are asking the department to fund and implement the new recommendations of the Adult Safeguarding Bill.

This will help to keep people with disabilities safe while giving them choice and control in their lives.



5. Plan for Effective Participation

We are asking for the Department to implement the recommendations in the Plan for Effective Participation in Decision Making for People with Disabilities and Families

Introduction

All people in Ireland are impacted by our health services and due to the historical structuring of services for persons with disabilities provided under the remit of the Department of Health and the HSE, they are even more reliant on an efficient health service.

The Programme for a Partnership Government commits to “targeted improvements in public services, with a particular focus on health, education, disability, and child development and care”. Additionally, as well as the commitment to introduce personalised budgets by “devolve(ing) budgets to the person so they may shop beyond traditional service providers to better fit their needs”, there is also a commitment to “review State structures ...to respond to the introduction of personalised budgeting”. Budget 2019 provides an opportunity to advance these commitments and more.

Through our advocacy work, Inclusion Ireland hears of the daily challenges people with disabilities and their families face, particularly in the pursuit of health supports. Reform is needed to ensure that people can avail of community-based services to be included fully in society, particularly in light of the relatively recent ratification by Ireland of the UN Convention on the Rights of Persons with Disabilities.

What people said in our consultation about Health in General:

“We need good health and education services”

“It’s easy enough to get to see a GP. For everything else you are waiting for ages for appointments”.

“We need to be given more staff time in hospital to understand what is happening”

“We need more health information, about medication”

“Staff need training in easy to read- there is no easy to read information in hospitals”

There are some key areas of reform and investment that are important in order to progress the participation and inclusion as well as the provision of vital services and supports for people with disabilities.

1. Health and Social Care Reform (Sláintecare)
2. Therapy Supports
3. Personalised Budgets
4. Safeguarding
5. The Plan for Effective Participation in Decision Making for People with Disabilities and Families

1. Health and Social Care Reform

The Sláintecare report set out a vision for reform of health and social care services over the next 10 years including legislating for an entitlement to health and social care services at no or low cost and an expansion of community-based services.

Implementation of the report's recommendations has been slow. The recent appointment of an Executive Director of the Sláintecare Programme Implementation Office as well as an implementation plan are belated but nonetheless welcome developments. It is important that adequate resources are provided in Budget 2019 to staff the office and ensure implementation without further delay.

Alongside the implementation of the key reforms outlined in the Sláintecare report, Budget 2019 provides an opportunity to reform the existing spend on disability services.

Public expenditure on social care services to persons with disabilities is around €1.7 billion per year. Much of this spend is tied up in the provision of models of service where persons with disabilities have no control or say in how services and supports are delivered.

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.¹"

Government must ensure that between 8%-15% of the current HSE disability budget, which is governed by service arrangements is ring-fenced for personal and community-based models of supports.

Inclusion Ireland asks for Budget 2019, related to employment are:

1. Fund the Sláintecare implementation office to ensure that work can commence on implementing key reforms
2. Introduce the Heads of Bill for the Irish (Sláinte) Health Act as a matter of priority
3. Provide the funding recommended by the Sláintecare report to expand primary care, mental health and social care services

¹ Department of Health (2012). Value for Money and Policy Review of Disability Services in Ireland. Dublin: The Stationary Office.

- Ring-fence the €290m allocated to disability services for person-centred, community-based models of support
4. Require the HSE to ring-fence 8-15% of the disability budget for personal, community-based services or personal budgets, so that funding arrangements match policy commitments.

2. Therapy Supports

In 2015, the National Disability Authority estimated that the HSE required 550-650 additional therapists to meet the needs of children with a disability. While some therapists have been recruited, the net gain in therapist numbers has increased very little.

The consequence of the lack of therapy staff is a HSE failure to assess children in line with statutory obligations under the Disability Act and long waiting lists for therapy services. The latest available data indicates only 11% of assessments have been completed on time this year.² A number of families have had to enter the courts to compel the HSE to assess their children.

In an effort to reduce waiting lists the HSE has introduced a new standard operating procedure which means that the assessment will be more limited in nature. This is not a child-centred approach but one that is administratively centred on reducing waiting lists.

Primary care waiting lists show 575 people waiting more than 12 months for speech therapy; 2805 waiting more than 12 months for physiotherapy and 7751 waiting more than 12 months for occupational therapy³.

The waiting does not end at assessment as there are 546 people waiting for more than 12 months for speech & language treatment.

The much heralded Progressing Disability Services for Children and Young People reform program was intended to offer equality of service to children with disabilities. All children with a disability would access therapy services based upon need from a local Disability Network team. This reform program seems to be dead as not one new Disability Network team has been established in 2016 or 2017.⁴

² HSE (2018). **Performance profile, Jan-Mar 2018. Quarterly report.**

<https://www.hse.ie/eng/services/publications/performance-reports/january-to-march-quarterly-report.pdf>

³ HSE (2018). **Performance profile, Jan-Mar 2018. Quarterly report.**

<https://www.hse.ie/eng/services/publications/performance-reports/january-to-march-quarterly-report.pdf>

⁴ HSE performance reports, various years.

What people said in our consultation about Therapy Supports

"Due to lack of therapy services parents must pay on average €90-120 per therapy session. Even one session per 3 main areas (OT, SLT, Physio) is €360 per month. That's not including travel expenses, hours lost in work, or equipment"

"I (with my child) have stopped going to speech and language therapy as I cannot afford it."

(We need)" More staff for services so we don't have to pay for private"

"Access to OT, Physio and speech & language waiting lists not timely. Private services expensive".

"Public waiting lists too long so we have to pay private for all our sons therapy's. Lack of support & services a major concern"

"Occupational Therapy appointments and speech therapy are only publicly available for my daughter with ASD diagnosis. My child with dyspraxia and SPD and my other with SPD are not covered. We pay out the majority of our income in private therapies to get our children up to speed".

Inclusion Ireland asks for Budget 2019, related to therapy supports are:

1. Recruit sufficient staff to reduce the waiting times for therapeutic inputs; especially speech and language therapists.
2. Invest in Progressing Disability Services for Children and Young People program of reform.

3. Personal Budgets

Minister for State with responsibility for disability issues, Finian McGrath, launched the report of the Task force on Personalised Budgets in July 2018. Personal Budgets will enable people with disabilities to have more choice and control over the services and supports they receive in their lives.

Personal budgets will be the responsibility of the Department of Health as they will only be available to those accessing services through the HSE and HSE funded organisations. Following on from the report of the Task Force, a number of pilot projects will be rolled out across the country to ensure that personal budgets are operationalised well before they become available in a general way to people availing of supports and services. These pilot or demonstration projects are expected later this year. There are currently a number of shortcomings in the proposed demonstration projects.

- Children are excluded from the personal budget pilot projects
- Personal budgets will only be available to those who avail of HSE funded services. This is a very one dimensional approach to lifelong supports for people with disabilities if they are to be fully included in the community and in society at large.

What people said in our consultation about Personalised Budgets

"Choice is very important when it comes to money".

"Personalised budgets for children to offset lack of services and supports and help realise potential".

"Give choice and not outdated institutional services"

"I spend my money on my own activities, I have access to money in the bank when I need it and that is really important to me, many people do not have this because they are not trusted with money"

Inclusion Ireland asks for Budget 2019, related to personal budgets are:

1. Make an allocation of funding for children to participate in the pilot / demonstration projects.
2. A specific unit within the Department of Health should be funded and established to enable personal budgets to be administered and rolled out to include inter agency working so that they can be broadened beyond supports and services provided by HSE funded organisations
3. The pilot projects for personal budgets recommended by the Task Force for Personalised Budgets must identify a clear timeline and application procedure to ensure transparency and accountability within this process.
4. A timeline for the wider availability of personal budgets must be published to ensure adequate funding is made available when required without undue delay.

4. Safeguarding

Adult safeguarding has become an important policy area over the past number of years. The widely publicised case of 'Grace' and others like her as well as the findings from investigations, such as the McCoy report into Áras Attracta, illustrate the need for safeguarding of people who may be vulnerable to abuse. Ireland has a renewed responsibility to provide safeguarding laws and safeguarding monitoring under the UNCRPD. Many strands of safeguarding exist without cohesion, including the HSE safeguarding policy, the National Safeguarding Committee and the HIQA/Mental Health Commission safeguarding standards that are in development. Additionally, an Adult Safeguarding Bill, sponsored by Senator Colette Kelleher has been introduced and has received support from Government.

In Ireland, the provision of advocacy in Ireland is fragmented and without cohesion. 'A Programme for a Partnership Government' makes a commitment to establish an independent patient advocacy service, which has not been established to date. Inclusion Ireland believes that instead of an independent patient advocacy service, a National Advocacy Authority should be established that has responsibility for the development of a national advocacy strategy.

It is clear that, much like advocacy services, a national agency should be established to co-ordinate safeguarding procedures nationally and the National Adult Safeguarding Agency as envisaged by Senator Kelleher in her Bill should be resourced in Budget 2019.

Inclusion Ireland asks for Budget 2019, related to safeguarding are:

1. Fund and implement the recommendations in the Adult Safeguarding Bill
2. Fund and establish an Independent National Safeguarding Authority that can maximise efficiency in safeguarding

5. Plan for Effective Participation in Decision-Making

'Transforming Lives' is the programme to implement the changes informed by the recommendations of the Value for Money and Policy Review of Disability Services in Ireland (2012). There were several Working Groups established under a National Steering Group. Since 2015, Working Group 3 has been working on a Plan for Effective Participation in Decision Making for People with Disabilities and Families.

This plan will be published by the HSE in September and sets out what needs to happen in order for people with disabilities to be involved in a meaningful way in decisions that impact their lives directly. The plan details actions that can be taken within the HSE and Department of Health but also explains the need for interagency working. The plan details supports and strategies to improve participation of people with disabilities and at local/regional (CHO) and national level.

Inclusion Ireland asks for Budget 2019 on participation of people with disabilities in decision-making are:

1. Fund the HSE to implement Ordinary Lives in Ordinary Places, including resources for dedicated staff, implementation group, training materials and roll out.

2. Ring-fenced funding for the development of advocacy structures such as the National Platform of Self Advocates.
3. Funding for nationwide consultation forums made up of persons with disabilities.
4. Funding for nationwide consultation forums made up of family members.

Conclusion

It is clear that there are some key pieces of policy that need to be implemented by the Department of Health to drive reform and improvement in our society's vision for the provision of services and supports for people with disabilities. Resourcing and implementing Sláintecare, the recommendations in the Adult Safeguarding Bill, including a National Safeguarding Authority and the Plan for Effective Participation in Decision Making for People with Disabilities and Families will make very concrete and important changes to the choice and control people with disabilities have over their lives in line with the UNCRPD. Personalised budgets will also give people the vehicle to have the services and supports in the way that they want them.

Getting the funding right in Budget 2019 and ensuring that children are included and that there is good interagency working to deliver on personalised budgets so that services and supports can reside both inside and outside the realm of health is vital. Therapy supports need to continue to improve and personal budgets will also aid this improvement.

For Budget 2019, Inclusion Ireland asks for key changes and implementations from the Department of Health. We have an important chance to implement change, reform and shift our perspective to more interagency working and to focus more on a holistic view of disability. Now is the time to make it happen. Implementing the asks requested in this submission will be some large steps in the right direction.

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