



INCLUSION IRELAND

National Association for People with an Intellectual Disability

**Pre-Budget
Submission 2018**

Department of Health

August 2017

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

The Programme for Partnership Government commits to:

- Eliminate any persisting discrimination on the nine grounds,
- Equality of opportunity,
- Supporting persons with disabilities in maximising their potential,
- Removing barriers which impact on access to services, education, work or healthcare,
- Introducing personalised budgets to provide an individual with more control in accessing services greater independence and choice,
- Move persons with disabilities out of congregated settings to enable them live independently and be included in the community.

Inclusion Ireland believes that persons with disabilities should live self-determined lives and Budget 2018 provides an opportunity to reform traditional services and systems, to create a more equal & just society, to encourage participation and decision-making, and to develop pathways into a life in the community.

2.1 Public Sector Duty

Government Departments are required to have regard to the public sector duty in all activities as provided for by Section 42 of the Irish Human Rights and Equality Commission Act, 2014.

Inclusion Ireland would encourage the Department to ensure that all decisions made for Budget 2018 are in line with this duty by being proactive in promoting equality, ensuring human rights are realised and eliminating discrimination.

The Department has acknowledged its responsibility to ensure that the principles of the Public Sector Duty in relation to human rights and equality are embedded across the work of the Department¹.

The Department gives the example of its "commitment to the creation of a more responsive, integrated and people-centred social care system which (amongst other things) supports the full and effective participation of people with disabilities in society on an equal basis with others, in accordance with the United Nations Convention on the Rights of Persons with Disabilities"².

Budget 2018 offers the Department the opportunity to pursue this aspiration and Inclusion Ireland's pre-budget submissions to all departments are categorised into 4 headings aimed at promoting equality for persons with disabilities (i) An Equal & Just Society (ii) Participation and Decision-Making, (iii) A life in the Community and (iv) Reform

2.2 Consultation

In preparing our pre-budget submission Inclusion Ireland conducted regional focus groups across Ireland in Cork, Donegal, Sligo and Tullamore as well as an on-line survey. Men and women with disabilities, family supporters and people employed in disability-related services took part.

¹ Department of Health Statement of Strategy 2016 – 2019

² Ibid Objective 1, Pg7

An Equal and Just Society

- Disability Act & therapies

Participation & Decision-Making

- Assisted Decision-Making
- Participation of People with Disabilities in Decision-Making

A Life in the Community

- Housing

Reform

- Ring-Fenced Budgets
- Personal Budgets

3. Priorities for Budget 2018

- Implement the outstanding aspects of the Disability Act as an interim measure with a view to reforming the Act and providing new rights based legislation in line with the CRPD.
- Ensure the Decision Support Service is funded, branded and launched through Budget 2018 as a standalone service and is adequately staffed to carry out its myriad functions including public awareness.
- Ensure individual reviews of wards of court are carried out to ascertain loss to funds and identify support needs.
- Provide funding for advocacy structures and processes so that people with disabilities are involved in decision making
- Provide ring-fenced funding to protect people with disabilities from homelessness and to support those living in inappropriate accommodation to have a home of their own
- Ring-fence a portion of the health spend on disability services for individualised and community-based models of support and implement a time line for the roll out of personal budgets

3.1 Disability Act Reform

A key provision of the Disability Act is the right to an Assessment of Need for health and education and a related Service Statement. The assessment of need and corresponding services are seen as essential for the development of children with disabilities.

Assessments are carried out by HSE officers as provided for in Part 2 of the Act. However, Part 2 has not been fully implemented since only children born after 01 June 2002 are entitled to apply for an assessment. The Act was to be commenced for those children aged 5-18 years in tandem with the implementation of the EPSEN Act 2004 but to date the commencement orders for people born before 2002 have not been signed.

The Act sets out a legal timeframe that assessments start within 3 months and be completed within another 3 months, however in 2016 just under 24% of assessments met the timeframes and significant regional disparities in meeting targets were revealed.³

³ CHO 9 completed 5.9% within timeline; CHO 2 completed 82% HSE Performance Reports 2016

In 2013, the average time for an assessment was 9 months; it now stands at 11 months. There has also been an increase in new applicants rising from 4908 in 2014 to 5992 in 2016 while at the same time compliance plummeted from 39% to just below 24% for 2016, with Dublin North only assessing 3.1% of children within the 6-month timeframe in 2016⁴.

Inclusion Ireland has been concerned for some time with the degree to which parents and family members have to fundraise and use their family income to secure therapy services that should be available through the public system.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on the Disability Act

"Multi-disciplinary services don't exist for over 18yrs, especially in community."

"Assessments are useless unless the follow on supports advised need to be available within a reasonable time frame."

"Assessment of need does not provide access to therapy and intervention. It provides for an assessment and blocks up clinical hours providing assessments."

Inclusion Ireland asks for Budget 2018 on the Disability Act

- Fully commence the Disability Act 2005 to include all persons with a disability regardless of age,
- Prioritise the reduction of waiting lists for assessments,
- Conduct a review of the Disability Act with a view to new rights-based legislation to reflect UNCRPD,

⁴ Health Service Management Data Reports and Performance Reports 2016

- Improve provision of therapists through increased recruitment and mandatory cover for maternity leave, illness or leave of absence.

3.2 Assisted Decision-Making

The Assisted Decision-Making (Capacity) Act 2015 was enacted at the end of 2015. Full commencement is the next critical step to ensure that individuals with disabilities have the support to exercise decision-making and choice in their lives.

The recruitment process for the Director of the Decision Support Service (DSS) is underway and should be concluded but it is essential that s/he is given adequate resources to execute his/her functions including promoting public awareness, to provide information, to supervise compliance by decision-making assistants, co-decision-makers, decision-making representatives and attorneys and carrying out investigations.

The Decision Support Service (DSS) was situated within the Mental Health Commission (MHC) and this was an important process while the DSS was being established as many of the functions of the MHC and DSS are similar and the rights-based approach of the MHC was preferable to the more adversarial courts system that had been proposed.

It is now essential that the DSS should become an independent body in its own right. There is potential for a DSS to perform a function with mooted Safeguarding Legislation as well as any national advocacy service that is established.

The DSS should also stand alone in order to reflect the 'disability neutral' nature of the law.

The National Disability Inclusion Strategy commits to the establishment of the DSS in 2017 and to commencing the Assisted Decision-Making (Capacity) Act, developing the associated Codes of Practice and providing training in early 2018.

Part 6 of the Assisted Decision-Making Act involves a review of people who are currently Wards of Court. A report of the Public Accounts Committee⁵ found that some Wards of Court's individual funds were severely depleted in value during the financial downturn and recommended contingency plans for

⁵ Public Accounts Committee Report on the Wards of Court July 2015

those with depleting funds. Budget 2018 should provide resources for the review of wards on an individual basis and necessary financial, health and social care supports as required.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on Assisted Decision-Making

"We need this now to help people understand the law."

"Decisions are being made without us!"

"Training is essential. Everyone needs to be made aware this is the future."

"We have learned today that it has been set up. We feel there is more advertising this as many people do not know that this act is in place."

"This has been a long time coming and the office should be (there) for help and advice."

Inclusion Ireland asks for Budget 2018 on Assisted Decision-Making

- The Decision Support Service is funded, branded and launched through Budget 2018 as a standalone service,
- The Decision Support Service is adequately staffed to carry out its myriad functions,
- A programme of information, public awareness and training is carried out by the Decision-Support Service in early 2018,
- Individual reviews of wards of court are carried out to ascertain loss to funds and identify support needs.

3.3 Participation of People with Disabilities 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, including Working Group 3 in the area of people with disabilities & community involvement.

In 2015, Working Group 3 began work on a plan called 'Ordinary Lives in Ordinary Places' for effective participation in decision-making for people with disabilities and families. This plan will shortly be published by the HSE 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.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on participation on decision-making;

"People need training in how to participate effectively in policy making".

"We do not have enough say in the policies that are been passed by our politician".

"I have no CONTROL over my life."

"This needs to happen now. We need to be central in all processes and decisions to ensure our rights and wants are being respected".

"Important that people with disabilities are represented by people with disabilities".

Inclusion Ireland asks for Budget 2018 on participation of people with disabilities in decision-making

- General funding allocated to the HSE and government departments to implement Ordinary Lives in Ordinary Places, including resources for dedicated staff, training materials and roll out
- Ring-fenced funding for development of advocacy structures
- Funding for nationwide consultation forums made up of persons with disabilities.
- Funding for nationwide consultation forums made up of family members.

3.4 Housing

Ireland has indicated an intention to close all large institutions of ten or more persons as established in the "A Time to Move On" report.

Department of Housing, Planning, Community and Local Government made €10 million available to purchase houses to move people out of institutions in 2016. Only €2 million of this fund was drawn down.

To assist with transitioning people out of congregated settings into ordinary homes a Service Reform Fund has been established. The fund has €27m available to services over a 3-year period. Despite being announced in June 2015⁶, no money has been allocated from this fund as of May 2017.

Despite significant funds being made available to move people out of institutions in 2016, less people moved than in 2015 when dedicated funds were not available. In 2016, only 52 people moved to community settings.

For people with disabilities living at home with relatives, there are also challenges and blocks to finding a home. In 2015, there were 4,039 people with intellectual disabilities aged over 35 living at home with aging parents. Of this number 734 were aged over 55 and living at home with their parents⁷. Due to the social housing shortage and private housing shortage in general, many of these people have little hope of owning or living in their

⁶ Lynch welcomes collaboration with The Atlantic Philanthropies on service reform fund, press release, June 16th 2015, available at www.merrionstreet.ie

⁷ Annual Report of the National Intellectual Disability Database Committee 2015, Doyle, A & Carew, A., Health Research Board, 2016.

own home. They are often the forgotten group because they are currently cared for by family member.

Homelessness has soared in Ireland in recent years. People with disabilities are more likely to experience homelessness than non-disabled people. While people with a disability constitute around 13% of the population as a whole, 42% of the homeless population had one or more disabilities in 2011⁸. This is an extremely worrying statistic and impacts on children and those with high medical needs the most.

Similarly, those with the highest level of support needs often need adaptations to make their homes comfortable and safe. According to Citizens Information services, housing adaptation grants are available up to €30,000 for existing homes and up to €14,500 for new builds. These grants are means tested and often do not cover the cost of what a person truly needs to fulfil their potential but the bare minimum to get by.

From our advocacy work, we have found that in different areas of the country, it can be much harder to secure the grant than other areas and in some areas it is practically impossible to secure any grant at all; the money just isn't available in the Local Authority.

⁸ Census 2011.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on participation on housing

"There isn't enough support for this. I was looking for support to help with cooking on a budget, routine planning etc. and couldn't get it."

"We have an ageing intellectual disability population, and their parents are ageing."

"People should have the right to live where ever they want. They should have support to develop life and social skills so they don't get isolated and depressed."

"There is no reason why people with disabilities should be forced to live with parents or non-relatives and are not entitled to their own home and own place."

"At the moment unfortunately we are building small institutions in community and causing more isolation instead of inclusion everyone is entitled to a home not a house. I feel we should support people to live in their home as much as possible with the required supports."

"I find it difficult to live with five people, I would like to move out and get a house of my own."

Inclusion Ireland asks for Budget 2018 on housing

- The service reform fund budget of €27 million, which was promised in 2015, must be allocated,
- Funding needs to be made available for persons with disabilities who currently live within family homes and are in need of independent living arrangements but are currently outside the service provision system,

- New ring-fenced funding must be made available to protect children with disabilities and specific medical needs from homelessness,
- Ring-fenced funding for housing adaptation grants needs to be available and equitable across all counties in Ireland.

3.5 Ring-fenced budgets

Public expenditure on social care services to persons with disabilities is around €1.6 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."

Government must ensure that between 8%-15% of the current HSE disability budget, which is governed by service-level agreements (SLAs), is ring-fenced for individualised and community-based models of supports.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on ring-fenced budgets

"Disability supports should be considered as being "above politics" and a Core Social Policy of the State."

"I think funding is given to certain services and we never see what it is used for."

"There should be choice given to the individual and if that is the choice the money should be given to the individual."

"Choice is the key thing."

Inclusion Ireland asks for Budget 2018 on ring-fenced budgets

- A commitment to ring-fence a percentage of the health budget for individualised services or personal budgets.

3.6 Personal Budgets

Personal budgets are seen as one tool to enable choice and control for persons with disabilities in their lives. In October 2016, The Minister for Disabilities established a Taskforce to make recommendations on a personalised budgets model which will give persons with disabilities more control in accessing health-funded personal social services.

The Taskforce is due to report to the Minister by end of 2017 and Budget 2018 should include a commitment to ring-fence a percentage of the health budget for personal or individualised budgets.

The system of personalised budgets that are introduced should not be limited to any category of individual e.g. school-leavers, and should also lay out how a cross-departmental approach will be taken to the roll-out of personal budgets i.e. beyond Department of Health spend alone.

The commitments in the National Disability Inclusion Strategy relating to personal budgets are loose, simply stating that “the Personalised Budgeting Task Force will report to the Government by Q4 2017 and its recommendations will be considered by Government in line with the commitment in the Programme for Partnership Government.”

The Programme for Partnership Government speaks of devolving “budgets to the person so they may shop beyond traditional service providers to better fit their needs”.

Simply put, a more robust commitment to a system of personal budgets must be announced and resourced in Budget 2018 with clear time scales for individuals who wish to avail of the option.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on personal budgets

"People should be empowered to decide the type of support they want. We should be active participants in our support."

"Personal budgets recognise individual rights."

"A system of personalised budgets should be established with an independent commissioning body established."

"Everyone should have personal budget and be a consumer to decide what service to go for and not that this is the only service available."

Inclusion Ireland asks for Budget 2018 on personal budgets

- A commitment to ring-fence a percentage of the health budget for personal or individualised budgets,
- An action-plan for the involvement of all departments in personal budgets,
- A timescale for the roll out of the option of personal budgets to all people with disability.

For further information, contact:

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