

National Association for People with an Intellectual Disability

Pre-Budget Submission 2018

Department of Social Protection

July 2017

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 persons 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 persons 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.

Introduction

The Programme for Partnership Government commits to

- Eliminate any persisting discrimination on the nine grounds, including disability,
- Equality of opportunity,
- Supporting persons with disabilities in maximising their potential,
- Removing barriers which impact on access to services, education, work or healthcare,
- Targeted improvements in welfare.

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 and to make long-lasting and structural reforms.

Public Sector Duty

In the most recent strategy statement, the Department of Social Protection states that it is required to have regard to its public sector duty in all its 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.

Of importance in fulfilling its public sector duty, the Department of Social Protection must do more to improve the accessibility of services and information. Information should be a minimum of Plain English and ideally in easy-to-read and other accessible formats.

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

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



1. An Equal & Just Society

Inclusion Ireland believes in a fair and more equal distribution of resources and that poverty and social exclusion among persons with intellectual disabilities needs urgent addressing. Budget 2018 can address this through a cost of disability payment and associated reforms.

Cost of Disability

Economic costs associated with having a disability mean that persons with disabilities are more likely to experience poverty and social exclusion than others.

Persons with disabilities are at an increased risk of poverty. Consistent poverty among persons with disabilities is at 22.4% compared to 8.7% among the general population¹ and more than half of adults with a disability experienced multiple quality of life challenges – more than any other societal group².

Persons with disabilities are less likely to attend further education or be in employment. If they do have a job, they are likely to have lower earnings.

Coupled with lower incomes, persons with disabilities face extra costs, and this is estimated at €207-€276 per week³.

These costs may be specialist disability aids, home adaptations, higher energy costs or an increased need for taxis due to inadequate public transport. It may be in the form of higher insurance costs or VAT or as a result of requiring specialised clothing or footwear.

Although VAT refunds can be made on some aids and appliances used by people with disabilities, some goods and services remain beyond reach because of up-front expense or do not qualify for refunds. In Budget 2018 should reform the classification of 'luxuries' that are in reality medically needed.

Addressing cost of disability should focus on the tandem approach of increasing income as well as reducing costs.

¹ The Survey on Income and Living Conditions 2015

² Department of Social Protection and the ESRI report entitled 'Social Risk and Social Class Patterns in Poverty and Quality of Life in Ireland'

³ Cullinan, J. & Lyons, S. (2015)

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on cost of disability;

"The expense of buying 2 tickets for events, additional parking costs, petrol .. (there is) definitely an additional cost for socialising & going out with peers"

"All items eligible for vat back on medical grounds should not have any vat applied them in the first place as they are necessities."

"No rural transport means a min €10 taxi to the closest bus."

"Once an item is deemed special needs it doubles in price, especially sensory equipment".

Inclusion Ireland asks for Budget 2018 on cost of disability;

- •New National Action Plan for Social Inclusion must include measures to address cost of disability.
- •Department of Social Protection should sponsor research into the extra costs for persons with disabilities in Ireland and how these can best be addressed.
- •An individually assessed cost of disability payment should be introduced to offset the additional costs associated with having a disability.
- •VAT and other taxation should be equality-proofed.

2. Participation & Decision-Making

Advocacy is crucial for the enjoyment of rights by persons with disabilities. A broad range of advocacy supports is required. Budget 2018 can address this through investment in advocacy services

Investment in Advocacy

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. Instead of an independent patient advocacy service, Inclusion Ireland believes that a National Advocacy Authority should be established that has responsibility for coordination and oversight of all forms of advocacy services. Advocacy will also be particularly important in light of the Assisted Decision-Making Act and proposed Safeguarding legislation.

The National Advocacy Authority would develop a National Advocacy Strategy to analyse the advocacy need for persons with disabilities and would co-ordinate the advocacy requirements for children and adults with disabilities.

The current National Advocacy Service (NAS) that provides a representative advocacy service to persons with disabilities falls far short of the Personal Advocacy Service (PAS) that was provided for under the Citizens Information Act 2007. NAS does not sufficiently meet the need for advocacy with advocates possessing no statutory powers, long waiting lists reported and the exclusion of children with disabilities from the remit of NAS. The NAS is also under resourced in comparison with the population of adults with disabilities. There is 35 advocates and a budget of $\mathfrak{T}_3,103,045^4$ equating to 1 advocate for every 15,000 people in the adult population who have a disability.

The PAS should be introduced without any further delay.

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⁴ 2015 Annual report

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on advocacy;

"There are not enough advocates. In some areas there are long waiting lists"

"(Advocacy service) should include a national, independent key working service, independent of any other services"

"Only advocate I have now is my parents... not right"

"I am part of an advocacy group in Cork and I take part in meetings. I think it is important to voice your needs and wants. These services should be set up."

Inclusion Ireland asks for Budget 2018 on advocacy:

- The Personal Advocacy Service, as provided for under the Citizens Information Act 2007, should be commenced immediately.
- An independent National Advocacy Authority (NAA) should be established by the Department of Social Protection.
- The NAA should develop a national advocacy strategy for persons with a disability.
- The NAA should be resourced to fund self-advocacy initiatives in readiness for ratification of the United Nations Convention on the Rights of Persons with Disabilities.

3. A Life in the Community

Persons with intellectual disabilities should be engaged in all areas of society including the workforce. Budget 2018 is an important opportunity for making key reforms.

Employment

Employment is a gateway to citizenship and persons with disabilities experience many barriers in accessing employment including financial barriers, negative societal attitudes, environmental barriers, the education system and lack of opportunity.

Employment rates for persons with disabilities are extremely low and while 2/3 people of the general population are working, almost 2/3 persons with disabilities are not⁵. Persons with intellectual disabilities of working age fare worse with 83% not in employment⁶. Targeted measures are required to ensure those who may have higher support needs to obtain and retain employment.

Reasonable accommodation is required for people with disabilities to get and keep jobs and is required under our equality legislation and the yet to be ratified United Nations Convention on the Rights of Persons with Disabilities.

The 'Reasonable Accommodation Fund for Persons with Disabilities' set up to provide grants for employers has been utilised poorly in recent years with the amount spent decreasing annually from €112,017 in 2013 to €77,822 in 2016 and just €30,044 so far in 2017⁷. No Employee retention grants have been drawn down in 6 years. Greater public awareness of this fund and also the Employer Disability Information for Ireland resource is required in order to promote reasonable accommodation.

The "Make Work Pay for People with Disabilities" report includes welcome moves to dispense with the requirement that work is of a 'rehabilitative nature', to allowing a fast-track return to Disability Allowance or Medical Card for individuals who leave work, for allowing retention of Free Travel Pass for a period and raising the Medical Card earnings disregard. Budget 2018 must prioritise these measures.

⁶ Census 2011

⁵ Census 2016

⁷ Finian McGrath Parliamentary Question 27072/17

The Department of Social Protection is a key player in the Comprehensive Employment Strategy for People with Disabilities. Progress is behind schedule and three actions are needed to take place in order for the strategy to work⁸ – More engagement with persons with a disability, fulfilling a commitment to a 6% quota for the employment of persons with a disability in the public service and a public awareness campaign aimed at breaking down barriers, and highlighting the real contribution persons with a disability can make.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on employment;

"At the moment there is no support or prospect of work for my son."

"Depending on each individual and their needs - part time work is a must. A purpose to get up every day and feel needed."

"Government needs to show much flexibility & vision. It is not about employment but employment with quality of life, living wages & mixed employment."

"(my) child with a memory processing disorder and dyslexia would benefit greatly with a job to build his self esteem and could hold a job if supported."

Inclusion Ireland asks for Budget 2018 on employment;

- Increased promotion and advertisement of the Reasonable Accommodation Fund and Employer Disability Information support service.
- A commitment of resources required to implement the recommendations of 'Make Work Pay' and the Comprehensive Employment Strategy.
- A strategy for increasing the public sector employment rate to 6%.

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⁸ According to First Report of the Chair of the Implementation Group – March 2017

4. Social Protection Payments Reform

There is what has been described as "almost an automatic rejection" of social protection payments⁹.

In 2016 there were 28,696 Disability Allowance applications, 16,669 were awarded and 12,027 were disallowed (42%) and of the 4,285 appeals, 66% were appealed successfully. This is a worrying statistic due to the fact that appeals take 14.6 weeks for summary decisions and 20.1 weeks for an oral hearing¹⁰

The quality of first instance decision-making in 2016 regarding disability allowance, invalidity pension and carer's allowance was so poor that over 50% of these decisions were overturned on appeal, either wholly, partially or by a revised initial decision. In January 2017¹¹ it was reported that 80% of Domiciliary Care Allowance (DCA) applications that were rejected were later granted the payment on appeal.

These significant number of apparently incorrect decisions coupled with the extensive waiting period meant that families were often left in financially precarious position as a result of the poor decision-making within the Department of Social Protection.

During Inclusion Ireland Consultation for Budget 2018, we received the following feedback on Social Protection Payments Reform;

"Appeal took 18 months. This caused extreme hardship & overwhelming anxiety"

"Appeals are very stressful and unfair"

"You should be allowed ANYONE attend with you (at an appeal)"

"Everyone who is turned down is going to appeal because it is known that they were turning everyone down."

⁹ Catherine Murphy TD – KFM 30.06.17

¹⁰ Minister Leo Varadkar Parliamentary Question 14973/17

¹¹ Irish Examiner, Monday, January 23, 2017

Inclusion Ireland asks on Social Protection Payments Reform;

- Resource allocation for additional Deciding and Appeals Officers within the Department.
- Resource allocation to allow for training on eligibility criteria and their application in decision-making to disability, domiciliary and carer's allowance.
- Take steps to improve the accessibility of applications in line with meeting the public-sector duty.
- Provide reasonable accommodation and easy-to-read information for and during the appeals processes.

Conclusion

The Department of Social Protection is a key player in promotion of equality for persons with disabilities and can take some measures in Budget 2018 towards that end.

At a minimum, the Department must improve the application processes. It is unacceptable that individuals who rely on social protection should wait up to 20 weeks for an appeal. It is an indictment of the process that two out of three of those appeals are successful. Correct decisions should be made first time and if there is a persistent and consistent reason for wrongful refusal (e.g. lack of information) there is a responsibility on the Department to ensure that the process is made clearer and more accessible.

Getting and keeping a job can be important to moving out of consistent poverty. The commitments in Make Work Pay and the Comprehensive Employment Strategy must be resourced. Disabled people were less likely to get a job and more likely to leave than non-disabled people during recession and recovery years¹². As we enter a period of sustained recovery and approaching full employment we cannot leave persons with disabilities behind.

Measures relating to reasonable accommodation will help but are not enough. The cost of disability can make taking up employment prohibitive but must be addressed for all persons with disabilities be they in the labour force or not.

Finally, independent advocacy is required to support persons with disabilities as citizens. It is essential that the Department of Social Protection delivers on its decade-old commitment to a Personal Advocacy service and a National Advocacy Authority to co-ordinate this essential service.

For further information contact Sarah Lennon, Campaigns & Policy Lead, Inclusion Ireland. 01 855 98 91 / sarah@inclusionireland.ie

¹² NDA (2017). Employment transitions research