



INCLUSION IRELAND

National Association for People with an Intellectual Disability

**Pre-Budget
Submission 2019**

**Department of Employment
Affairs & Social Protection**

July 2018

**This document is written in font 12 Verdana in line with Inclusion
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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 the most recent strategy statement, the Department of Social Protection notes its obligations under 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 2019 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 become accessible and Inclusion Ireland welcomes the announcement by the Department that it will work with the National Adult Literacy Agency to ensure staff members are trained in plain English.

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 of Employment Affairs & Social Protection is a very important government department.

The Department looks after people's social welfare and how included they are in society.

This submission is asking the Department to look at 4 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 4 areas



1. Jobs

We are asking the Department to put in place the supports that people need to get a job, travel to work, keep a job and progress in their workplace.



2. Cost of Disability

We are asking the Department to see that people with disabilities can have less money and extra costs than people without a disability. We are asking for a payment for people and for research into ways to bring costs down.



3. Changing the way Social Welfare Applications happen

We are asking for the Department to speed up applications and to make sure there are less refusals and appeals of applications.



4. Advocacy

We are asking for the Department to put a plan in place for advocacy and to give advocates more powers to do their job.

Introduction

In the Programme for Partnership Government, there is a commitment 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,
- Targeted improvements in welfare

Inclusion Ireland believes that persons with disabilities should live self-determined lives and Budget 2019 provides an opportunity to create a more equal & just society and to develop pathways into a life in the community for people with a disability.

Inclusion Ireland has identified 4 areas of reform for Budget 2019 that fall within the remit of the Department of Employment Affairs and Social Protection.

Budget 2019

1. Employment for people with disabilities
2. Cost of Disability
3. Social Protection Application reform
4. Advocacy

1. Employment

Article 27 of the United Nations Convention on the Rights of Persons with Disabilities affirms the right of “persons with disabilities to work, on an equal basis with others”.

Ireland must ensure that the barriers that some persons with disabilities have in accessing employment such as financial barriers, negative societal attitudes, environmental barriers, the education system and lack of opportunity are removed.

As Ireland moves towards full employment and the live register is at its lowest since July 2008¹, we know that this does not show the entire picture. Just 36% of people with disabilities of working age and 17% of people with an intellectual disability are in employment² and this indicates a societal problem that needs urgent addressing using many strategies.

Targeted measures are required to ensure those who may have higher support needs to obtain and retain employment.

- a) Reasonable Accommodation
- b) Early engagement across all disability schemes
- c) Public Sector Employment
- d) Transport for work

Reasonable Accommodation

The prioritisation of reasonable accommodation measures is necessary for persons with disabilities to get and keep jobs and is required under law.³

The ‘Reasonable Accommodation Fund’ for People with Disabilities is a demand-led scheme and part of the Comprehensive Employment Strategy for People with Disabilities⁴. The fund is designed to support persons with disabilities to access further training and employment opportunities but it has been very under-utilised in recent years with the amount spent decreasing annually. In 2013 there was a drawdown of €112,017, while in 2016 it was only €77,822 and so far in 2018 just €55,009 has been spent⁵.

¹ <https://www.rte.ie/news/business/2018/0608/969118-live-register-figures/>

² Census 2016

³ Employment Equality Acts & United Nations Convention on the Rights of Persons with Disabilities.

⁴ Action 3.2

⁵ Minister Doherty, Written Answer [25834/18]

No 'Employee Retention Grants' have been drawn down in 7 years and it is unclear what is being done to raise public, employer and employee awareness of both this fund and the Reasonable Accommodation Fund.

Because the scheme is demand-led, it does not encourage pro-activity on the part of employers and it is not advertised widely.

Early engagement across all disability schemes:

As noted in the survey of Disability Allowance recipients⁶ many persons with a disability want to work and are willing to engage in finding work, however as already mentioned less than 17% of persons with intellectual disabilities are in employment.

Finding employment is only one part of the process, workplace supports are crucial to sustaining employment and personal assistance and training support on an ongoing basis if required would all be beneficial to persons with intellectual disabilities being in a position to sustain employment for the medium and long term.

Measures such as the recently announced "Ability Programme" are important measures aimed at bringing young persons with disabilities between the ages of 15 and 29 closer to the labour market and it is essential that this project focuses on both employee and employer development.

It is important that these pilot projects are not an end in itself and that this programme translates into real jobs for persons with disabilities, with good support when transitioning into the open labour market. A programme of support and development that can be replicated and sustained over the medium to long term with progression to real jobs at a pace that can be individualised would be important.

Public Sector Employment

The National Disability Inclusion Strategy includes a target to increase the public sector employment target of persons with disabilities from 3% to 6% by 2024. Part 5 of the Disability Act 2005 sets out the legal obligations of public service bodies including to meet a target of 3% of employees with disabilities, the Disability Act should be amended to include this improved target, rather than just a notional target.

The National Disability Authority publishes an annual report on public sector compliance and unfortunately, recent figures are not available, with

⁶ Department of Social Protection Report on Disability Allowance Survey 2015

the last report published in 2017, relating to 2015 figures. That report showed that at the end of 2015, public bodies reported that 3.6% of staff employed in the public sector are persons with disabilities, a 0.1% increase on the previous year. At that pace, it would be 2041 before the 2024 target was met.

Funding must be made available to promote employment among public bodies but additionally, the National Disability Authority must publish up-to-date figures of not only those in employment, but what positions and grade they occupy so as to ascertain whether persons with disabilities are advancing in the workplace.

Transport for work

Access to good transport links is essential to accessing and maintaining employment and persons with disabilities require physically accessible transport options.

The experience of persons with disabilities can vary widely in a rural environment with many living in rural areas having no access to transport at all.

This difficult situation was compounded when two grants (the Motorised Transport Grant and the Mobility Allowance) which supported those with disability to travel were closed in 2013. A replacement was promised but this grant has still not arrived. Disappointingly, Minister McGrath has confirmed that although a memorandum was brought to Government for proposals for a new Transport Support Payment Scheme, it was decided to withdraw the memorandum from the Cabinet agenda on 8th May 2018.

This disappointment comes 5 years after the two previous grants were closed and the failure to replace the grants in that time period is exacerbating the difficulties that disabled persons have in accessing work.

What people said in our consultation about employment:

"The biggest barrier is attitude of employer, employees and society".

"Work place supports are vital, at least for the 1st year of employment and perhaps reduced after that but perhaps available at a distance ongoing"

"For people who were working, on the job support at the start was very important. But once you've learned the job you don't need it anymore."

"I only ever got jobs no one else wanted"

"There should be more options to work flexible and part time hours to enable employees time to attend medical, support, therapies etc and receive social welfare support for days not worked. Additional supports may be required around transport, Access, technology etc"

"Lots of chances to do work experience but no employment. Employers are not skilled or aware of disability and use it as an excuse."

"We want the government to expect more of us in work. We need to be trusted to try."

"I am working 2 days per week. It is difficult to get a job. I would like more workdays. I would like to work 5 days per week. I am working towards an apartment."

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

1. Actively promote and advertise the 'Reasonable Accommodation Fund' and 'Employee Retention Grant' and invest in an advertising campaign for both.
2. Ring-fence the money used for the "Ability Programme" to ensure that the pilot projects are sustainable.
3. Use the good practice and learning made from the "Ability Programme" and apply through INTREO offices.
4. Work with the National Disability Authority to get accurate figures relating to public sector employment and progression.
5. Publish a public-sector employment plan to accelerate the numbers employed in the public service who have a disability.
6. Commit the resources required to implement the recommendations of 'Make Work Pay' and the Comprehensive Employment Strategy.
7. To open up employment options, publish and enact the Transport Support Scheme.

2. Cost of Disability

The UNCRPD, is clear on the need to eradicate poverty for persons with disabilities in order for the full enjoyment of their human rights and fundamental freedoms to be realised.

In the Convention preamble, the fact that the majority of persons with disabilities live in conditions of poverty is highlighted and States parties are urged to work towards the eradication of poverty.

Article 28, which is concerned with the an adequate standard of living and social protection required States to “ensure access by persons with disabilities . . . to social protection programmes and poverty reduction programmes”

In Ireland, persons with disabilities are more than three times as likely to experience poverty and deprivation as the general population⁷.

According to the ESRI persons with a disability experience much higher rates of deprivation which means they go without some of the basic necessities for living. The ESRI has also said that “policies that reduce poverty among the general population do not adequately address deprivation experienced by vulnerable groups” and targeted interventions are needed in households where there is a disabled person.

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.

Persons with disabilities also face additional costs such as specialist disability aids, home adaptations, higher energy costs or an increased need for taxis due to inadequate public transport and these costs are estimated as being between €207-€276 per week⁸.

Specific measures to address cost of disability are necessary in order to reduce poverty among persons with disabilities and these measures must not address increasing income alone but must also assess and address the cost of disability.

⁷ In 2016, 26% of people with disabilities were at risk of poverty as compared with 8% of the general population..

⁸ Cullinan, J., Gannon, B. and Lyons, S. (2008) Estimating the Economic Cost of Disability in Ireland. ESRI

Cost of disability payment

A report published by the National Disability Authority found sufficient evidence for the introduction of a cost of disability payment.

Inclusion Ireland believes that this payment should be available to all persons with a disability, not just those in receipt of a social protection payment in acknowledgment of the extra costs accrued by those who have a job.

An individually assessed, non-means tested benefit payment, similar in nature to the Personal Independence Payment in the UK should be introduced to support mobility and daily living.

Extra Costs

Inclusion Ireland acknowledges that it is not possible to alleviate the cost of disability through social protection payment alone and that it is necessary to examine the extra costs experienced by persons with disabilities.

In the UK, the 'Extra Costs Commission' was established to examine the issue of the cost of disability and found that the costs were multi-faceted and that cross-departmental policy making was required. The Commission also made recommendations about areas in which regulators and government should intervene where features of markets result in unfair extra costs for disabled persons .

Similar research is needed to order to determine what the drivers of extra costs are for persons with disabilities in an Irish context and how the extra costs can be addressed.

What people said in our consultation on cost of disability:

"Car insurance is more expensive for people with disabilities"

"(There are) hidden and pervasive costs, for example meds are higher costs as child cannot take tablets but only more expensive liquid meds"

"Everything costs more if you say special needs"

"My son lives at home on €198 per week. While this is not a bad weekly income it will not support him to ever move out on his own or pay bills. Unless he lives at home for ever he will have no disposable income"

"(I have a) food sensitivity to 12 different foods, so my diet costs are more . . . there should be a diet allowance option to people diagnosed with a food problem"

"I have a profound Intellectual Disability and severe autism. I have incontinence problems and the associated costs in clothing and washing, laundry could be what a family of 6 have and I'm only one person".

"I am under 16 and cannot use public transport alone . . . My nearest primary care centre is 1 mile out of town and situated on a large hill. The nearest bus stop is one mile away in each direction the only option is to get a taxi".

Inclusion Ireland asks for Budget 2019, related to cost of disability are:

1. Introduce an individually assessed / non-means tested cost of disability payment to offset the additional costs associated with having a disability.
2. Include specific, measureable and time bound targets aimed at addressing poverty among people with disabilities in the revised National Action Plan on Social Inclusion.
3. Sponsor research through a Cost of Disability Commission into the extra costs for persons with disabilities in Ireland and how these can best be addressed

3. Social Protection Applications Reform

Inclusion Ireland has, through its advocacy work, learned of what people describe as an "almost an automatic rejection" of Social Protection payments.

Disability Allowance has the highest number of appeals of any scheme at 5,077⁹ with 73% of appeals allowed or partially allowed. These figures represent, not an ineligibility of applicants, but an inaccessible system. Coupled with the high rate of appeals, the extensive waiting time of 17.8 weeks for a review of Disability Allowance, means that people who require social protection payments are placed in a potentially vulnerable position financially.

The Department's statement of strategy includes a commitment to ensure speedy access to accurate decisions, payments and reviews for all schemes and services, which are clearly communicated to the client. Under Article 4 of the UNCRPD, States Parties are generally obliged to "provide accessible information to persons with disabilities" and the recent announcement that The National Adult Literacy Agency Organisation (NALA) has won the tender for the provision of plain English writing, editing and training services is welcome news.

The next steps in ensuring that people with disabilities can apply for social protection payments is to consult with people with disabilities on the accessibility of process and forms and to work towards easy to read materials for people with intellectual disabilities.

Additionally, an investment in deciding officers and appeals officers should be made, to improve the 4-month waiting time for appeals to be heard.

⁹ Social Welfare Appeals Office Annual Report 2017

What people said in our consultation on social protection applications:

"There is no guide to filling out the Disability Allowance form. Even though my son's application was approved first time it took 16 weeks."

"Domiciliary Care Allowance application a horrendous experience, diagnosis for multidisciplinary team not even entertained in some cases.. very unfair.. and very personal info at some strangers desk.."

"Very long drawn out process. Everything is a red tape battle."

"Up to a year waiting for a payment entitled to. Refused at first and granted on appeal. Very upsetting and stressful experience"

"I can't understand the letters that come in the post". They need to be easy to read and there needs to be someone I can go and talk to if I get stuck or don't understand something"

Inclusion Ireland asks for Budget 2019, related to social protection applications reform are:

1. Allocate additional Deciding and Appeals Officers within the Department.
2. Allocate resources to consult with people with disabilities on their experiences of social protection payment applications and to road-test any new forms or processes.
3. Develop easy to read guides to filling in application forms.

4. Advocacy

Advocacy is an essential tool for the support of people with disabilities and will form an essential component of the Assisted Decision-Making Act 2015 once commenced as well as the proposed adult safeguarding legislation.

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.

As an interim measure, the Personal Advocacy Service (PAS) that was provided for under the Citizens Information Act 2007 should be commenced without delay. Ireland's only statutory advocacy service is the National Advocacy Service (NAS) that provides a representative advocacy service to adults with disabilities.

The NAS service falls far short of the Personal Advocacy Service (PAS) that was provided for under the Citizens Information Act. National Advocates have no statutory powers, there are too few advocates with long waiting lists reported and the exclusion of children with disabilities from the remit of NAS means there is no national, statutory service providing advocacy for children.

What people said in our consultation on advocacy:

"Advocacy for families is virtually nonexistent. This is essential for younger people with disabilities"

"We don't know enough about advocacy outside of disability services, it would be nice if NAS came and explained what they do to us. We have been told they don't have enough funding to do that"

"There needs to be more advocates. In my area there was no advocate for months. Even now (and the person is good) they only take on the most needy cases".

"Prior to my son being 18 there was no advocacy service for him at all."

"As I am just under 16 the NAS national advocacy service say they don't have the capacity to take cases on for my age group".

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

1. The Personal Advocacy Service, as provided for under the Citizens Information Act 2007, should be commenced immediately.
2. Provide funding for a National Advocacy Service specifically for children.
3. An independent National Advocacy Authority (NAA) should be established by the Department of Social Protection.
4. The NAA should develop a national advocacy strategy for persons with a disability.

Conclusion

The Department of Social Protection is a key player in the promotion of equality and social inclusion for persons with disabilities, however there are clear areas in which the Department can improve on its support for people with disabilities.

At a minimum, the Department must improve the procedures relating to social protection payments. It is unacceptable that individuals who are reliant on social protection payments should wait over 4 months for an appeal and it is an indictment of the process that almost $\frac{3}{4}$ of those appeals are successful.

Employment opportunities, retention of employment and career progression are essential to moving persons with disabilities out of the consistent poverty trap that they persistently remain in. The commitments in Make Work Pay and the Comprehensive Employment Strategy are important and must be delivered on.

The cost of disability can make taking up employment prohibitive and must be addressed for all people with disabilities be they in the labour force or not and measures must be taken to address the cost.

Finally, independent advocacy is required to support people 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 support.

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