



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

# **Pre-Budget Submission 2020**

## **Department of Employment Affairs & Social Protection**

June 2020

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Ireland plain English guidelines**

# Easy to read summary



The Department of Employment Affairs & Social Protection looks after employment supports, people's social welfare and how included they are in society.



## 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:



### 1. Jobs

Put in place the supports that people need to get a job, keep a job and progress in their workplace.



### 2. Cost of Disability

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 with disabilities.



### 3. Social Welfare Applications happen

Speed up applications and to make sure there are less refusals and appeals of applications.



### 4. Advocacy

Put a plan in place for advocacy along with colleagues from the Department of Justice

### 5. Public Sector Duty

Make sure that all decisions made for Budget 2020 promote equality and human rights and prevent discrimination



# About Inclusion Ireland

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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.

## About this submission

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Inclusion Ireland consulted with people across Ireland in the preparation of this submission. People with a disability, family members and people who work in disability all took part in our consultations.

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

## Introduction

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The Programme for Partnership Government makes commitments to eliminate discrimination, provide equality of opportunity, support persons with disabilities in maximising their potential, remove barriers which impact on access to services, education, work or healthcare, and target improvements in welfare.

Inclusion Ireland believes that persons with disabilities should live self-determined lives and Budget 2020 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 5 areas of reform for Budget 2020 that fall within the remit of the Department of Employment Affairs and Social Protection:

1. Employment
2. Cost of Disability
3. Social Protection Application reform
4. Advocacy
5. Public Sector Duty

# 1. Employment

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

People with disabilities experience multiple barriers to accessing employment, including financial barriers, negative societal attitudes, environmental barriers, the education system and lack of opportunity.

Just 36% of people with disabilities of working age and 17% of people with an intellectual disability are in employment<sup>1</sup> and this indicates a societal problem that needs urgent addressing using a range of strategies.

## **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. According to the DEASP, 5% of employees of the Department were persons with disabilities as of the end of 2018.<sup>2</sup>

While this is a positive step towards achieving the 6% target, it's important also to know what positions and grades they occupy so as to ascertain whether persons with intellectual disabilities are advancing in the workplace. The DEASP should progress work with the NDA on developing a way of reporting on this that respects the privacy of employees.

## **Employment supports**

Finding employment is only one part of the process, workplace supports are crucial to sustaining employment over the medium and long term.

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<sup>1</sup> CSO (2017). Census 2016

<sup>2</sup> DEASP consultative committee communication as of 31.12.18

The Comprehensive Employment Strategy for People with Disabilities (CES) notes that some people with disabilities may require a high level of support to obtain and retain employment. Recent research by Inclusion Ireland indicates that those with complex needs can obtain and keep a job, with the right supports.<sup>3</sup> A job coach can be one such support.

The Comprehensive Employment Strategy also sets out the value of individualised support from a job coach in supporting people with intellectual disabilities to find and keep jobs. A job coach, as described by the CES, works to prepare a person for employment, makes links with employers, and supports the person in the workplace in settling in and managing tasks.<sup>4</sup>

Job coaches are currently available through the Employability programme. However, from our advocacy work, Inclusion Ireland is aware of people with intellectual disabilities who have not been able to access Employability supports because they are not 'job ready'.

The recently launched Ability Programme funds projects that are aimed at supporting young people with disabilities who are not currently job ready through the provision of a range of person-centred supports.

The projects should be evaluated to assess what has worked and what hasn't and those projects that have demonstrated positive outcomes for people with intellectual disabilities should be mainstreamed.

It is important that the pilot projects are not an end in themselves but translate into real jobs for persons with intellectual disabilities, with good support when transitioning into the open labour market.

## **Reasonable accommodation**

The prioritisation of reasonable accommodation measures is necessary for persons with disabilities to get and keep jobs and is required under law.<sup>5</sup> The 'Reasonable Accommodation Fund' for People with Disabilities is designed to support persons with disabilities to access further training and employment opportunities. It is a demand led scheme and is not advertised widely and therefore demand has been almost non-existent.

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<sup>3</sup> Magee, C., Murphy, T., Turley, M., Feely, M., García Iriarte, E., McConkey, R. and Inclusion Ireland (2019). 19 Stories of Social Inclusion – Ireland: Stories of belonging, contributing and connecting. <http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1673/19-stories-socialinclusion-ireland.pdf>

<sup>4</sup> Government of Ireland (2015). Comprehensive Employment Strategy for People with Disabilities 2015-2024

<sup>5</sup> Employment Equality Acts & United Nations Convention on the Rights of Persons with Disabilities.

A mere €1200 was spent on employee retention grants as part of the Fund in 2018, with zero expenditure on this in the previous two years.<sup>6</sup>

Inclusion Ireland understands that the Department is currently reviewing the Reasonable Accommodation Fund with a view to making it more effective. Following the review, the department should allocate funding to advertise the scheme in order to raise public, employer and employee awareness of the supports available.

***What people said in our consultation about employment:***

“There is no on the job support for my son. He has very high support needs but would be well capable of a few hours of work per week. It is the support for this that is missing”.

“Employers need disability awareness training so that they can support people with disabilities in their jobs.”

“People with disabilities need to be given the opportunities to work so that they can get work experience. A lot of people never get that chance”

“A rights-based approach may ensure more actual paid jobs and protection of jobs when issues arise”

“I want to get paid for work, I want an 'outside' job”

“We want 'outside' work in town. We want the government to provide us with someone who will help us to get jobs”.

**Inclusion Ireland asks for Budget 2020**

1. Work with the National Disability Authority to get accurate figures relating to public sector employment rates and the grades at which people are employed.
2. Ring-fence the money used for the “Ability Programme” to ensure that those pilot projects that worked well are sustainable.
3. Use the good practice and learning from evaluation of the “Ability Programme” and apply through INTREO offices
4. Fund the recruitment of job coaches for Intreo offices to provide ‘on the job’ support to enable those with high support needs to obtain and maintain employment

<sup>6</sup> <https://www.kildarestreet.com/wrans/?id=2019-01-15a.2953&s=%22reasonable+accommodation+fund%22#g2954.g>

5. Invest in an advertising campaign for the 'Reasonable Accommodation Fund' to ensure that employers and people with disabilities are aware of the support available

## 2. Cost of disability

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The UNCRPD, is clear on the need to eradicate poverty for persons with disabilities. Article 28, which is concerned with an adequate standard of living and social protection, requires States to "ensure access by persons with disabilities...to social protection programmes and poverty reduction programmes".

Research on minimum incomes indicates that current social welfare rates and minimum wages are not sufficient to provide a minimum essential standard of living for some sectors of the population. For example, a single adult of working age, living alone in an urban area and on social welfare supports would require an additional €42.39 and a person working and earning minimum wage would require an additional €129.36 to have an adequate income. Their counterpart in a rural area would require an additional €81.07 or €32.31, respectively.<sup>7</sup>

In Ireland, people with disabilities are more than three times as likely to experience consistent poverty as the general population.<sup>8</sup> Persons with a disability experience much higher rates of deprivation which means they go without some of the basic necessities for living.<sup>9</sup>

While the MESL and SILC work provide valuable indications of income adequacy and poverty, neither take into account the extra costs experienced by people with disabilities. The ESRI has 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.<sup>10</sup>

People with intellectual 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

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<sup>7</sup> [https://www.budgeting.ie/download/pdf/mesl\\_2019\\_update\\_report.pdf](https://www.budgeting.ie/download/pdf/mesl_2019_update_report.pdf)

<sup>8</sup> In 2017, 24% of people with disabilities experienced consistent poverty as compared with 6.7% of the general population.

<sup>9</sup> CSO (2019). SILC 2017.

<sup>10</sup> ESRI (2018). <https://www.esri.ie/news/irelands-deprivation-gap-is-large-and-increased-over-time>

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 week<sup>11</sup>.

Specific measures to address the cost of disability are necessary in order to reduce poverty among persons with disabilities and these measures must assess and address the extra costs that people face as well as increasing income.

Inclusion Ireland welcomed the commitment towards research on cost of disability given by Minister Regina Doherty in 2018 and the publication of a tender for this research in early 2019. It is hoped that this research will help 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.

However, a report published by Indecon/the NDA in 2004 found sufficient evidence for the introduction of a cost of disability payment. It is important that following the publication of the next report, that action is taken and that the recommendations from the report are implemented.

Inclusion Ireland believes that a cost of disability payment should be available to all eligible 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.

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<sup>11</sup> Cullinan, J., Gannon, B. and Lyons, S. (2008) Estimating the Economic Cost of Disability in Ireland. ESRI

### ***What people said in our consultation on cost of disability:***

"It has cost me my career as I now cannot work"

"People with disabilities experience disadvantage due to additional costs associated with many aspects of life: housing (accessibility, location, size), transport, supports (personal assistance, communication, sensory), dietary (cost of food/supplements), sensory (equipment and therapeutic interventions) and therapy provision inadequately provided by public system"

"Additional costs for clothing/shoes that fit specifications of medical equipment"

"I have to buy adult wipes for changing my daughter...These cost €16 per week. I buy disposable incontinence sheets for under her wheelchair and our couch. They are €10 per week. Then there is the extra cost of our bins because of the weight of nappies".

"A lot of things are expensive for people with disabilities, people need more money to cover costs "

### **Inclusion Ireland asks for Budget 2020:**

1. Include specific, measureable and time bound targets aimed at addressing poverty among people with disabilities in the forthcoming National Action Plan on Social Inclusion.
2. Introduce an individually assessed, non-means tested cost of disability payment to offset the additional costs associated with having a disability.

## **3. Social protection payments waiting times**

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

Applicants for Carers Allowance waited an average of 16 weeks for an initial decision and 24.3 weeks for the outcome of an appeal in 2018.<sup>12</sup> Disability Allowance has the highest number of appeals of any scheme at 5,200<sup>13</sup> in 2018 with 64% of appeals allowed or partially allowed. Coupled with the high rate of appeals, the extensive waiting time of 17.1 weeks for a review of Disability Allowance<sup>14</sup>, means that people who require social protection payments are placed in a potentially vulnerable position financially. These figures represent, not an ineligibility of applicants, but an inaccessible system.

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 obliged to "provide accessible information to persons with disabilities" and all departments have committed to provide public sector information in easy to understand formats as part of the National Disability Inclusion Strategy.

An issue with the Disability Allowance application form is that there is little guidance on how to complete the form for persons with intellectual disabilities, with many questions focused on physical or mental health needs.

A more accessible and relevant application process is needed with guidance for individuals with intellectual disabilities, similar to the UK Department of Work and Pensions Capability for Work questionnaire which describes the support needs people with intellectual disabilities may have, such as learning simple or complex tasks, starting or completing tasks, coping with small changes to your routine, getting about, coping with social engagement, making yourself understood, awareness of danger and so on.<sup>15</sup>

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 processes and forms and to work towards easy to read materials for people with intellectual disabilities.

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<sup>12</sup> Minister Regina Doherty. Tuesday, 26 March 2019. Response to PQ [13221/19]

<sup>13</sup> Ibid

<sup>14</sup> Minister Regina Doherty. Thursday, 28 February 2019. Response to PQ [10121/19]

<sup>15</sup> UK Dept of Work and Pensions, Capability for work questionnaire – Mental, cognitive and intellectual capabilities

### ***What people said in our consultation on social protection applications:***

“5 months for carers benefit and 6 months for Domiciliary Care Allowance. Absolute disgrace”.

“It is humiliating – unnecessarily long forms, delayed decisions and requires an immense amount of time”

“Not flexible or quick enough. We got reviewed and reduced our payments wrongly. Took 9 months to follow up appeal and get it reversed and only happened so quickly because we spent a lot of time making calls and eventually got a person to deal with”

“DCA is a soul destroying form and process. Thoughts of a review equally so”

“I assist families to apply for relevant benefits and allowances. waiting times are frustrating but so is parents having to highlight their child’s needs and their deficits over and over again”.

### **Inclusion Ireland asks for Budget 2020:**

1. Allocate additional Deciding and Appeals Officers within the Department to reduce waiting times for applications and appeals
2. Develop easy to read guides to filling in application forms.
3. 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.

## Advocacy

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Advocacy, self-advocacy and representation is essential for the realisation of the rights of disabled people. The Committee of the UN Convention on the Rights of Persons with Disabilities has recognised that “the effective and meaningful participation of persons with disabilities, through their representative organisations, is ...at the heart of the Convention”.<sup>16</sup>

State support for advocacy is crucial to successful advocacy. The UNCRPD Committee also recommended States parties “prioritizing resources to

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<sup>16</sup> General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention\*

organisations of persons with disabilities that focus primarily on advocacy for disability rights”.

In an Irish context, advocacy is required for ensuring the success of the Assisted Decision-Making Act 2015 as well as the proposed adult safeguarding legislation. Advocacy can be an essential tool in preventing abuse and getting the voices of marginalised people into decision-making structures.

Inclusion Ireland has highlighted concerns about the National Advocacy Service (NAS) for many years. NAS does not have statutory powers, there are too few advocates resulting in long waiting lists. Furthermore, there is no national, statutory service providing advocacy for children.

While the imminent delivery of the independent patient advocacy service, is welcome, it will represent yet another strand of advocacy that must be connected by a strategic approach.

Inclusion Ireland has consistently criticised the fragmented nature of advocacy provision and called for a cohesive strategy.

The seminal document on advocacy ‘Jigsaw of Advocacy’ recognises that there are 5 distinct models of advocacy, namely;

- Self-advocacy covering both general self-advocacy and group advocacy for people with disabilities
- Peer advocacy covering family and community advocacy
- Personal / professional advocacy covering legal advocacy, patient advocacy
- Citizen advocacy
- Public policy advocacy

Safeguarding Ireland recently<sup>17</sup> identified illustrative examples of organisations delivering or supporting these models of advocacy. There is no consistent source of core funding for these organisations with the Department of Employment Affairs and Social Protection, HSE, Department of Health and the Department of Rural and Community Development (through the Scheme to Support National Organisations) all among the funders.

Inclusion Ireland is concerned that the spreading of advocacy across multiple Government Departments, dilutes the value placed on it and possibly threatens the work. Core funding cuts have also been made to umbrella organisations funded through the HSE as a result of the Value

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<sup>17</sup> Independent Advocacy in Ireland Current Context and Future Challenge

Improvement Programme and recent reports that the Irish Deaf Society were refused funding because their work related “in the main to advocacy, training and development<sup>18</sup> all lend themselves to a risk to advocacy.

Inclusion Ireland is calling for the Department of Employment Affairs and Social Protection as the lead department in advocacy provision and the Department of Justice as the department responsible for working towards an equal and inclusive society<sup>19</sup> to work together to ensure an advocacy strategy is developed and implemented.

A National Advocacy Authority should be established that has responsibility for the development of the national advocacy strategy.

***What people said in our consultation on advocacy:***

“Advocacy for families is virtually non-existent. This is essential for younger people with disabilities”

“We need Inclusion Ireland around to fight for the UNCRPD to be brought into law”

“Inclusion Ireland is the only organisation that represents people with intellectual disabilities in Ireland. We need it to stay”.

“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.”

“Our child has no voice. As his parents, we have come to realise that we have no voice, in spite of all our shouting. Our child has no power. We have no power. Advocacy for our child is not a charity issue; it is a justice issue. Advocacy from Inclusion Ireland for our young, intellectually disabled, non-verbal autistic son is essential”.

**Inclusion Ireland asks for Budget 2020**

1. Establish a National Advocacy Authority (NAA) (working with the Department of Justice)

<sup>18</sup> <https://www.irishtimes.com/news/social-affairs/irish-deaf-society-on-brink-of-closure-due-to-lack-of-funds-1.3822021>

<sup>19</sup> Department of Justice Strategy Statement 2016-2019

2. Consultation with disabled people and others on a national advocacy strategy
3. As part of that strategy, the department should become the source of core funding for all advocacy organisations.

## 4. Public Sector Duty

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In its 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. The development of a new departmental strategy this year provides the department with an opportunity to further develop and progress its commitments under the Duty.

Inclusion Ireland would encourage the Department to ensure that all decisions made for Budget 2020 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 inclusive and Inclusion Ireland welcomes the announcement by the Department that it is planning training on disability awareness to staff.<sup>20</sup> As the public facing aspect of the Departments work, it is particularly important that the Intreo service fulfils its Public Sector Duty obligations.

### **Inclusion Ireland asks for Budget 2020**

1. Progress and build on previous PSD commitments in the departments new strategy statement to be developed
2. Report on progress in forthcoming annual report for 2018
3. Examine the Intreo service and how could be improved for people with disabilities
4. Carry out audit of the Intreo service to examine how the service might be improved for people with disabilities

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<sup>20</sup> Communicated at DEASP disability consultative forum, May 2019.

# Conclusion

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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 4 months for an appeal and it is an indictment of the process that almost two thirds 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 a greater effort must be made to implement those actions aimed at supporting those with higher support needs who want to take up employment.

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.

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