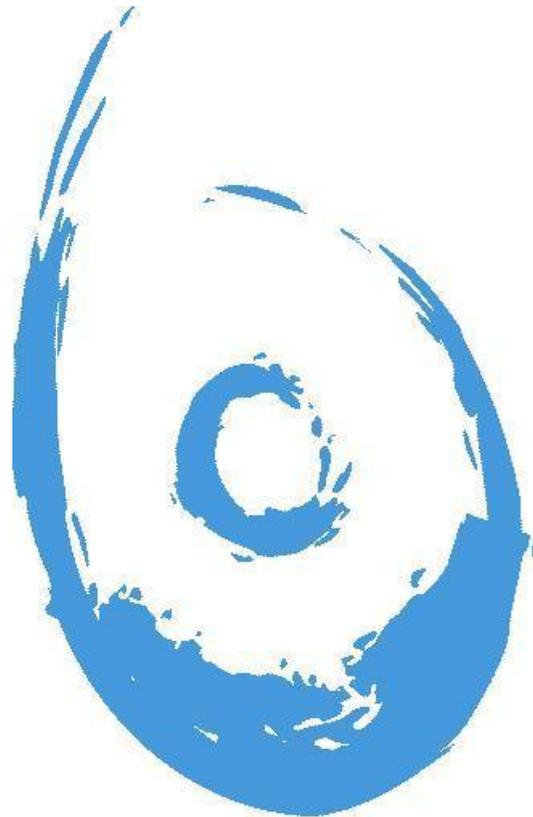


Inclusion Ireland – Budget 2014



**Pre-Budget Submission to the
Department of Social Protection
- June 2013**

Introduction

Inclusion Ireland is the national organisation advocating for the rights of people with an intellectual disability in Ireland. The vision of Inclusion Ireland is of a society where people with an intellectual disability live and participate in the community with equal rights as citizens. The mission of Inclusion Ireland is to ensure that people with an intellectual disability have their voices heard, and are supported to lead independent and fulfilled lives.

People with a disability and their families are extremely vulnerable to reductions in social welfare payments. The Survey on Income and Living Conditions (SILC) in Ireland (2010) recorded that four out of ten people with a disability experienced increased deprivation. Where the principal economic status of the head of household was defined as unable to work due to illness or disability, the deprivation rate was 66%. Deprivation was measured by not being able to do at least two of the following things: heat their home; buy a warm coat or new clothes or not able to eat meat or fish at least every second day. The true poverty rate experienced by people with a disability is likely to be more severe when the cost of disability is considered.

The cuts to income supports since 2009 have had a major, cumulative effect on the quality of life of people with an intellectual disability and their families. These cuts have included reductions in basic income payments; reductions in child benefit; withdrawal of the Christmas bonus payment in 2009, reduction in fuel allowance payments; introduction of the €100 household charge in 2012; cuts to household benefits package; reduction in of Back to School Clothing and Footwear Allowance in 2012 (by €50); reduction in respite care grant in 2012; reduction in full allowance. These cuts have been exacerbated by increases in the cost of living since 2009.

The impact of European governments' austerity plans on the rights of people with disabilities was the subject of a 2012 report by the European Foundation Centre. It found that 'austerity measures that directly and indirectly affected social security benefits had a significant impact on the standard of living of persons with disabilities'.

Employment rates of people with health problems or disability in Ireland, at 33%, are among the lowest in the OECD. In turn, more than 37% live in poverty (compared to an OECD average of 22%). This is 2.5 times the figure of the general population of Ireland (OECD, 2010). Only around 5% of people with an intellectual disability are in employment.

Priorities for the Department of Social Protection

Priority 1

- **No cuts, whether direct or indirect, to the payment rates for the Disability Allowance, Carers Allowance, Respite Care Grant or Domiciliary Care Allowance:** Recent budget cuts have had significant consequences for people with disabilities. For example, people receiving Disability Allowance are down €847.60 a year since 2008, and the effect of the 20% cut to the Respite Care Grant in Budget 2013 has added to financial stress on many families.

Priority 2

- **Introduce a cost of disability payment:** A cost of disability payment has been recommended in numerous reports for many years. Introducing this payment must be seriously addressed by the Department.

Priority 3

- **Advocacy:** People with a disability require a broad range of advocacy services and supports. The Department, in partnership with the Department of Health and disability organisations, should develop a national advocacy strategy for people with a disability.

1. Income supports to people with disabilities

The 2011 Programme for Government committed to “ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them”. Inclusion Ireland welcomes that there were no cuts to DA in 2012, and but people on DA have seen their income fall by €847.60 a year since 2008, and there cannot be any further cuts to DA this year.

Clarification is needed on what will be implemented following the publication of the Second Report of the Advisory Group on Tax and Social Welfare. Among the remit of this Group was to look at Budget 2012 proposals for reducing DA to those aged under 25, to bring DA in line with Jobseekers Allowance. The Group says it has particular concerns about the additional barriers faced by people with disabilities in seeking education, training and employment, which are applicable “regardless of age”. Inclusion Ireland welcomes this acknowledgement, which clearly shows that original proposals Government put forward to reduce payments from €188 per week to €100 for people aged 18 to 21 and to €144 per week for people aged 22 to 24, shows a total lack of understanding of the support needs of people with a disability and disregards the additional costs associated with disability.

Many parents set up Discretionary Trust Fund Schemes or Pension Schemes on behalf of their son or daughter. Families are concerned that the income derived from these may lead to a reduction or loss of Disability Allowance and other benefits associated with DA (medical card and travel pass). Inclusion Ireland has raised this before. An income disregard similar to that for people in rehabilitative employment should be investigated. The increase in the capital disregard for DA to €50,000 has assisted.

Inclusion Ireland members have raised the position of people in receipt of DA who get married or cohabit. If a person in receipt of DA marries a person who is working they risk losing their DA and associated benefits. The DA should be paid to the person in his/her own right.

The Value for Money Review of the Disability Allowance was welcomed by Inclusion Ireland. This is a very comprehensive document with many useful recommendations, which should be followed up.

1.1 Cost of Disability payment

Inclusion Ireland believes there is need for reform of Disability Allowance, which must include a cost of disability analysis. A cost of disability payment to meet the extra costs

associated with a disability has been recommended in numerous reports and studies. In 1996, a cost of disability payment was first recommended by the Commission on the Status of People with Disabilities. The National Rehabilitation Board (NRB) subsequently published several papers on the cost of disability. In 2002, the Government established a working group to examine the feasibility of a cost of disability payment. The National Disability Authority published a report on the Cost of Disability in 2004.

More recently, a study into the cost of disability found that addressing the extra economic costs of disability to be 'a logical step towards alleviating elements of social exclusion for people with disability'. The study used the standard of living standard of living approach to estimating the cost of disability. It found that this approach 'allows us to quantify, for the first time, the additional long-run economic costs of living associated with disability' and the study concludes that 'the extra economic cost of disability in Ireland is large and varies by severity of disability, with important implications for measures of poverty.'¹

The Report of the Advisory Group on Tax and Social Welfare (2012) noted that the need for a cost of disability payment was cited in many previous reports, including the 1996 Report of the Commission on the Status of People with Disabilities and Towards 2016. The Group's Report stated it had a very specific remit that did not include an examination of the use of cost of disability payment, and that this limited their own deliberations:

The scope of the Group's deliberations on the Budget 2012 proposals is limited by the specific nature of these proposals. It is difficult, for example, to explore changes to income maintenance/supports for people with disabilities without also engaging in issues about the costs of participation, equitable treatment of all those of working age or potentially arbitrary age cut-offs where the needs of those on either side of the cut-off do not change but their income support payments could change considerably (para. 4.1)

The Group also noted that many of the submissions they received stated that moving DA for those aged under 25 into line with JA showed "a clear lack of understanding of the position of those with a disability and their families", and "fails to take into account the extra costs associated with having a disability including: transport, medical and extra day to day living expenses". Many submissions called for a cost of disability payment and Inclusion Ireland believes this is key to modernisation of the social welfare system. Inclusion Ireland strongly believes the introduction of a Cost of Disability Payment is

¹ Cullinan J, Gannon, B Lyons, S., 2011, 'Estimating the extra cost of living for people with disabilities', *Health Economics*, 20: 582–599

essential and is something that has been called for by Inclusion Ireland and other organisations for many years.

2. Employment Supports

Inclusion Ireland calls for action on the National Action Plan for Social Inclusion 2007-2016, to increase the numbers of people with disabilities in employment in the open labour market supported by enhanced vocational training, employment programmes and further development of supports.

Inclusion Ireland calls for the development and publication of a clear strategy to increase awareness of the employment supports available to people with a disability.

Inclusion Ireland welcomed the decision to open the JobBridge scheme to those on Disability Allowance. All Labour activation programmes must be available to people in receipt of DA.

Inclusion Ireland calls on the Department to collaborate with the HSE (as it implements the recommendations of the Adult Day Services Review), the Department of Education and Skills, and the Department of Jobs, Enterprise and Innovation, with a view to reducing the potential for longer term welfare dependency.

3. Advocacy support

Inclusion Ireland welcomes the introduction of a National Advocacy Service for people with disabilities in 2011. The National Advocacy Service provides a representative advocacy to people with disabilities. However, the Personal Advocacy Service, as provided for under the Citizens Information Act 2007, has yet to be introduced.

People with disabilities require a broad range of advocacy services and supports. This was a key recommendation of the Commission on the Status of People with Disabilities in 1996 and has been recommended in a number of reports since. Currently, funding for advocacy for people with a disability, including self-advocacy, representative advocacy and peer advocacy, is provided by different Government departments. There is a need for a consistent, joined-up approach. A broad range of advocacy services and supports should be available to people with a disability. The Department, in partnership with the Department of Health and disability organisations, should develop a national advocacy strategy for people with a disability.

The Personal Advocacy Service, as provided for under the Citizens Information Act 2007, must be introduced without further delay.

4. Supporting Carers

Inclusion Ireland welcomed the July 2012 publication of the National Carer's Strategy and the recognition contained therein of the contribution of carers to Irish society. It is limited in that it does not set out a series of measureable and timebound actions to which the Government is committed, nor does it commit to additional services or supports to carers in the short to medium term. It does pledge to strengthen awareness about the role of carers and to develop supports and services to protect the physical, mental and emotional wellbeing of carers. A plan of how this will be done has yet to be drawn up. This must be prioritised.

Inclusion Ireland particularly welcomed the commitment in the Carer's Strategy to recognise the needs of carers through income supports (objective 1.3). Government must follow through on this pledge by maintaining current levels of payment in Budget 2014. Carers save the state over €2.5 billion and provide over 3.7 million hours of care in the home every week. The 2011 report of the National Intellectual Disability Database shows that 65% of people with an intellectual disability live at home. This care saves the State considerable money (the average cost of residential support in a community setting is in the region of €80,000 per annum, and can be up to €300,000 in some cases). While Inclusion Ireland welcomed the decision not to cut the Carers Allowance in Budget 2013, the Carers Allowance has already seen cuts of €16.50 per week on the 2008 rate, and further cuts would have a serious impact.

4.1 Other Allowances to Carers

The effects continue to be felt of the Budget 2013 decision to cut the Respite Care Grant by 20%. That cut came on top of nationwide cuts to respite provision by the HSE, which have been steadily eroded. The Respite Care Grant enables carers to purchase additional supports as part of a package of care and support for all family members. It is one of the few provisions that provide families with choice and flexibility and thus represents the type of funding model which this Government has stated it wishes to develop. There can be no further cuts to social welfare allowances.

Inclusion Ireland rejects any proposals to cut the half-rate Carers Allowance. The half-rate allowance was introduced in 2007, and offers excellent value for supporting people in their own homes. For groups such as single parents, it is an essential payment.

4.2 Domiciliary Care Allowance

Clarification is needed on what will be implemented following the publication of the Report of the Domiciliary Care Allowance (DCA) Review Group, and the Second Report of the Advisory Group on Tax and Social Welfare. Both recommend that DCA should

continue to be payable up to age 18, with the starting age for Disability Allowance (DA) to be increased to age 18. Inclusion Ireland remains concerned at the cost difference arising from this, which amounts to €523.07 a month for those affected. This issue directly ties into the need for a cost of disability payment, which Inclusion Ireland has been campaigning for, for many years and which is discussed in more detail on page 9 of this submission.

Inclusion Ireland welcomes the recommendation from the DCA Review Group that withdrawal of DCA on review should not lead to the immediate withdrawal of Carers Allowance, as Inclusion Ireland is aware of cases where families were asked to 'payback' Carers Allowance received after DCA payments stopped. This is obviously grossly unfair and puts unnecessary financial pressure on families, who had not realised the link between the two payments.

The DCA Review also correctly acknowledges that appropriate services should be available for children in receipt of DCA, and the Report highlights concerns at the cost incurred by parents in accessing reports and assembling information to enable them to make a claim for DCA. It also acknowledges the amount of time spent on assessment work and form filling by professionals, and the resultant impact on therapy provision. The Report says "the Departments of Social Protection, Health and Education and Skills with the involvement of the NDA will continue to co-operate on this issue after the current review is completed". It is important that the Department clarifies how it will deal with this issue and what work is to be undertaken now that the Review Group has finished meeting. There must be consultation with families on any work in this regard.

The Advisory Group on Tax and Social Welfare recommends examining "the scope for inking DCA claimants into early intervention and prevention services, to improve long-term outcomes". The Group recommends that, as part of the 'additional care and attention' dimension of DCA, consideration be given to the needs of the affected child to avail of therapies and services now and into the future, and that efforts are made to link into these services where possible. It also states that "early investment in intervention and rehabilitative care will help to ensure that their abilities to fully participate in society both as children and as adults are maximised". The Department needs to clarify if it will make recommendations to the Department of Health in respect of these proposals from the Advisory Group.

4.3 Carers – other issues

The Carer's Benefit rate should be maintained, and extended to three years. The period in which relevant contributions are required to have been paid should take account of people who left work a number of years ago in order to take up caring duties, and

therefore would not have paid the required contributions in the relevant tax year, or in the 12 months immediately before the start of Carer's Benefit, but who have an unbroken contribution record for a number of years. Allowing people to stay on this benefit for three years may help reduce the unemployment rate and make it a more attractive option. There is a low uptake of this benefit.

There should be an extension of the hours carers can work outside the home to 19.5 hours. This will also allow carers to take advantage of training and other employment schemes.

The Habitual Residency clause should be abolished for people returning to Ireland to provide family care.

Consideration should be given to paying Carers Allowance pro-rata. Currently, a person being cared for must be at home four nights and days for a pro-rata payment to be made. If a person is at home and cared for three nights and days, no payment is made.

5. Accessible information

All social welfare information, including forms, must be accessible and clear and easy to navigate. Information and application forms for social welfare payments should be provided in Plain English. Application forms should also be made available in 'easy to understand' formats. The Department of Social Protection has an obligation under the Disability Act 2005 to make its services accessible to people with disabilities.

As of March 2013, the average waiting period for a decision for disability allowance was 17 weeks, with an estimated 60% of those waiting for a decision 12 weeks or more.² Many initial applications contain inaccurate information. This delays processing of applications. These delays could be alleviated by the Department providing a more accessible, easy to understand application process.

² Citizens Information Board, Social Policy Quarterly Report, October – December 2012)

6. Agency Agreements

Inclusion Ireland is concerned with the application of agency arrangements for people with an intellectual disability. Social welfare regulations allow for the appointment of an agent to collect and manage the social welfare payments of persons who lack the capacity to manage their financial affairs. Under the regulations governing appointment of agents, a claimant's lack of capacity must be certified by a medical practitioner. These are the only circumstances when a claimant's social welfare payment can be collected and managed on their behalf.

Inclusion Ireland is concerned that these arrangements are not always in place for a significant number of claimants with an intellectual disability who cannot manage their social welfare payments. In other words, third parties are collecting and managing the social welfare payments of people with an intellectual disability without the legal authority to do so.

The social welfare regulations make clear that service providers can only be appointed in exceptional circumstances. However, Inclusion Ireland has received many reports of pressure being placed on people with an intellectual disability and their family members to 'sign over' collection and management of disability allowance payments to service providers. Quite often this is a condition of receiving a residential or day service.

The Department should undertake a review of all agency arrangements to ensure compliance with social welfare regulations.

7. Disability Proofing

Disability proofing of all substantive proposals requiring Government approval is mandatory. The Cabinet Handbook requires that all "substantive Memoranda" should indicate the impact on people with disabilities. Government should consider a disability impact assessment to identify and assess the impact of any proposed changes to services, policies and practices in relation to their consequences for equality for persons with a disability. The Government should undertake a disability impact assessment of all Budget 2014 proposals to identify and assess the impact of any changes to services; income supports and policies affecting people with a disability.



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Unit C2, The Steelworks, Foley Street, Dublin 1, Ireland.

Tel: +353 1 855 9891 Fax: +353 1 855 9904 info@inclusionireland.ie www.inclusionireland.ie

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