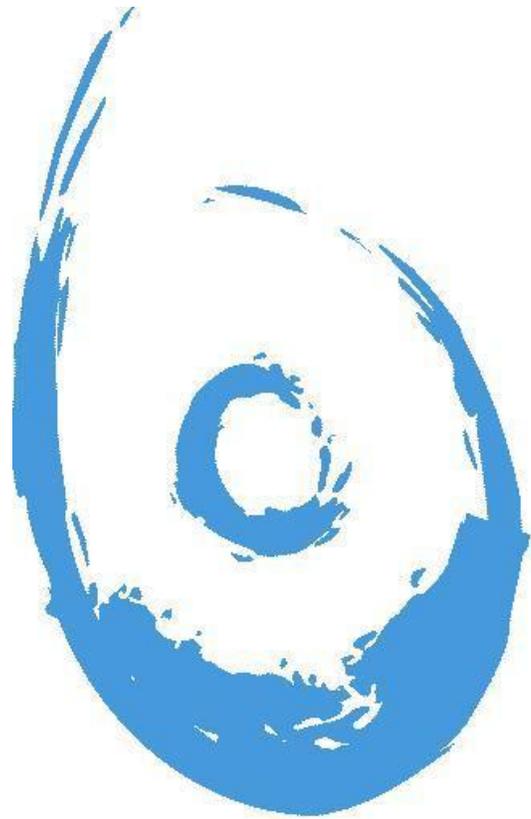


# **Inclusion Ireland**



**Pre-Budget Submission to the  
Department of Social Protection  
- September 2012**

## 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.

The National Disability Strategy (NDS) was launched by the Government in 2004 with the overall aim of supporting equal participation of people with disabilities in society. The Department of Justice and Equality had lead responsibility for coordination of the NDS. The NDS was comprised of five elements:

- The Disability Act 2005;
- Education for Persons with Special Educational Needs Act 2004;
- Citizen's Information Act 2007;
- Sectoral Plans of six Government Departments;
- A multi-annual investment programme for the period 2006-2009;

In November 2011, the Department of Justice identified four high-level goals for an Implementation Plan. These goals are:

- Maximise potential;
- Equal citizenship and equality before the law;
- Independence, choice and control;
- Participation – to live ordinary lives in ordinary places;

The implementation of a National Disability Strategy is the agreed focus of disability policy under *Towards 2016*. Inclusion Ireland endorses the vision for persons with disabilities as set out in *Towards 2016*:

'The parties to the agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families as part of the local community, free from discrimination'

A key goal of *Towards 2016* is:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;

People with disabilities and their families are at risk of becoming caught in a deepening poverty trap. Benefits have already been cut twice since 2008, and cuts have affected all areas in which they receive support from the State. This has directly impacted on a serious reduction in the income and living standards of people with disabilities and their families.

A debate is urgently required on Irish welfare policy. A key question is “how is the welfare spend of €29 billion (40% of all public spending) used?” A foundational issue in this debate is how to target those most in need - universalism or targeted programmes. According to the terms of the EU IMF agreement:

*“...welfare reductions are expected to obtain via a reform of the child and disability benefits and the introduction of a single means tested social-assistance payment for working age people” (IMF 2010:25)*

Government says they must ensure further significant savings via Budget 2013. These savings will have to be made outside of statutory pay cuts following the Croke Park Agreement. This means that people with disabilities will once again be in the frontline for cuts, and bear more than their fair share of the burden facing the Irish people.

Recognition of the inter-connectedness of Government Departments and the policies they propose is central to the pursuit of a coherent all-of-Government approach to disability policy. Substantive policies which impact directly on the high level goals set out in T2016, which were endorsed by the Disability Stakeholders Group, should be reviewed by that group and assessed in terms of the impact on implementation of national disability policy.

### **Advocacy**

Advocacy is about having your voice heard. The word advocacy comes from the Latin word *advocare* - meaning to call. There are many different types or models of advocacy. When a person speaks up for themselves it is called self advocacy. On occasions where people find themselves in situations when their voice cannot be heard, an advocate can be provided. This type of advocacy is called representative advocacy and is provided by a paid advocate (National Advisory Service). Advocacy can also be provided in a non-paid capacity. This is called volunteer or citizen advocacy. Peer advocacy is when a person with a shared experience supports another person to have their voice heard. This can be a person with an intellectual disability supporting another

person with an intellectual disability or a parent supporting another parent. Inclusion Ireland believes that the availability of a broad spectrum of advocacy supports is critical to enabling and driving the full implementation of the high level goals as set out in T2016. Inclusion Ireland calls for the Department of Social Protection to engage key stakeholders to plan towards the introduction of a broad spectrum of advocacy services.

Inclusion Ireland welcomed the introduction of the new National Advocacy Service (NAS) for people with a disability. However, the advocates working in this service do not have statutory powers to investigate cases or enter any places that provide services. They have no power to obtain information or attend meetings or consultations, and can only operate on the basis of voluntary cooperation of service providers. We are aware from the work of the NAS and their reports to the National Advisory Group, of which Inclusion Ireland is a member, that cooperation from service providers and some professional groups is not always forthcoming. Inclusion Ireland calls for the full implementation of the Citizens Information Act so that NAS advocates are statutorily empowered. Inclusion Ireland also calls for the reports of NAS advocates to be available to the public with appropriate protection of people's confidentiality.

## 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.

### Priority 2

- **Retain the half rate Carers Allowance.** This payment is received by approximately 21,000 Carers. To eliminate this allowance would mean that those in receipt of it face a potential 30% reduction in their incomes. This payment is particularly important for single parents.

### Priority 3

- **Provide better information and assistance to applicants in making social welfare applications, including the availability of easy to read and plain English information.** A total of 11,211 appeals have been determined by the Social Welfare Appeals Office in the period 1 January to 31 May 2012, of which 5,373 (47.9%) had a successful outcome for the appellant. This shows that many of those making an initial application may have provided insufficient information, or were unaware of what was needed. Unnecessary appeals are time consuming for both the Department and the applicant, and could be avoided by improving the application process. Making an appeal is also a complicated and difficult process for many applicants, and consideration should be given to making a liaison/support person available for those who need assistance.

## 1. Support to Carers

- Inclusion Ireland welcomes the July 2012 publication of the National Carer's Strategy and the recognition contained therein of the contribution of carers to Irish society. While 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 with clear implementation timelines must be drawn up as soon as possible.
- Inclusion Ireland welcomes 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 2013. Carers save the state over €2.5 billion and provide over 3.7 million hours of care in the home every week. The 2010 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 2012, the Carers Allowance has already seen cuts of €16.50 per week on the 2008 rate, and further cuts would have a serious impact.
- The average time for a decision to be made on a Carer's Allowance application rose from 13 weeks in 2011 to 28 weeks in the period January to April 2012. This is an extraordinarily high increase, and seven months is a very long period for an applicant to be waiting on a decision. This must be addressed.
- The success rate for appealing decisions is high, suggesting that carers need more information when completing the application form. They should not have to go through an appeal process unnecessarily. The process is also time consuming and costly in terms of staff resources. The average time for an appeal to conclude is also very high, and applicants can be waiting over 18 months from the time they make their initial application to receiving a final decision following an oral hearing.

- 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.
- 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.
- Abolish the Habitual Residency clause 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.
- Inclusion Ireland welcomes the establishment of the Domiciliary Care Allowance (DCA) Review Group and the inclusion of parent representatives on the group, including three representatives from an NGO working group, which Inclusion Ireland is involved in. DCA is classed under EU Regulation 883/2004 as a Family Benefit, and must be recognised as such by the Department of Social Protection.
- The application process for DCA is heavily based on the medical model of disability. Parents are asked to explain how their child is so 'severely disabled'. Medical practitioners are asked to detail the applicant child's medical history including hospitalisation and surgery. This is not consistent with government policy. Most people with a disability are very healthy, but do have additional care needs.
- The application and appeals processes for DCA are lengthy and bureaucratic, and are not transparent enough. If an application for DCA is refused, there needs to be a full report detailing what criteria was not met, the appeal process available and that the parent can avail of representation in appealing the decision. Inclusion Ireland has made a full submission to the DCA Review Group.
- The Respite Care Grant of €1,700 per annum, per person being cared for, must be maintained. The Respite Care Grant gives people flexibility and autonomy and is

essential for carers. Inclusion Ireland seeks a commitment that this grant will be paid at the same rate in 2013. The Respite Care Grant can be used by carers to directly purchase respite services and allows for flexibility, choice and a family centered approach to provision. The increasing crisis in funding centre-based respite care for people with disabilities makes this grant essential. The model of residential based respite care has proven to be very high cost.

- 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.
- The Fuel Allowance and Household benefits schemes, which are available to those in receipt of disability or caring related payments, were greatly reduced in July 2011 (€65 million cut from the Budget). In addition, Budget 2012 saw the heating season for Fuel Allowance reduced by 6 weeks, to 26 weeks. Energy costs have since risen, and are due to rise again this Autumn/Winter, which will decrease quality of life of people with a disability and their carers, and further entrap them in a cycle of poverty.

## **2. Income Supports to People with Disabilities**

- Any budget proposals must be disability proofed. 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. People with a disability and their families are very vulnerable to any changes in criteria for allowance or benefits, and any cuts to allowances. Four out of ten people with a disability experienced increased deprivation between 2009 and 2010, according to an EU survey published by the CSO. The survey showed people with disabilities experienced deprivation levels of 42%, which was by far the highest level compared with other people such as the unemployed, students or older people. 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 (as opposed to secondhand); or not able to eat meat or fish at least every second day. People with disabilities did not experience the boom period in the same way as people without a disability, as the proportion of workers with a disability remained relatively unchanged from 2003 to 2009, and stood at between 5 and 6% of the total workforce, as shown in an ESRI study published in 2011.

- 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”. There must be no further cuts to Disability Allowance (DA). People on DA have seen their income fall by €847.60 a year since 2008.
- Inclusion Ireland welcomed the Government’s decision to pause implementation of two proposals in Budget 2012 that would have had a severe impact on people with disabilities and their families if they had gone ahead, namely the reduction of DA for new claimants aged under 25 by up to 47%, and raising the qualifying age for Disability Allowance from 16 to 18. These issues have now been referred to the Committee on Taxation and Reform. There must be full consultation with people with disabilities and their families on any recommendations from the Committee. Pushing ahead with these measures would show a total lack of understanding of the support needs of people with a disability, and would disregard the additional costs associated with disability.
- Inclusion Ireland believes there is need for reform of Disability Allowance, which must include a cost of disability analysis. The introduction of a Cost of Disability Payment to acknowledge that many people with disabilities will have additional costs has been called for by Inclusion Ireland and other organisations for many years. The strong work disincentive for people with disabilities arising from the extra costs of accessing work such as extra transport costs, as well as the loss of secondary benefits, chiefly the medical card, is well known. Inclusion Ireland supports the OECD Review solution of making the entitlement to the medical card independent of benefit status for people with a disability.
- It is very worrying to note that the refusal rate for initial applications for Disability Allowance rose from 54% in 2010 to 61% in the first quarter of 2012. The average

time taken to award an application for disability allowance in 2011 was 17 weeks. This must be addressed.

- Changes introduced in July 2011 to the way in which Health (in patient) Charges are calculated mean that the charge for people on DA who live in institutional residential care (Class 1) has increased from €153.25 to €155. The personal allowance – the minimum a person can be left with after a charge is deducted, has decreased, from €44.70 to €33.00. Today a person with a disability living in institutional care in receipt of DA has a disposable income of €33 per week. In 2004 that same person would have received a weekly payment of €35.
- For those in receipt of part-time nursing care (Class 2), living mostly in community residences, the situation is only slightly better. The new maximum rate has been increased from €114.95 to €120 before deductions, and the personal allowance has decreased from €70.25 to €64.00. These charges are an immediate and hidden cut to the incomes of the approximately 9,000 people with disabilities who live in institutions or community residences.
- 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 Companion Travel Pass for people in receipt of DA should be extended to cover a companion on a round trip without the disabled person e.g. a parent who has to accompany his/her child to a residential home/school after weekends or holidays at

home, or who has to make a trip to collect the child. Of necessity, one trip is made without the person with the allowance.

- The lack of community transport or suitable transport in rural areas means that travel passes are of no benefit to many. Peoples have asked that arrangements be made to use their free travel pass with private taxi services, private buses and other forms of community transport. This should also apply to carers in rural areas.
- 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.

### **(ii) Agency Agreements**

- Some people with an intellectual disability do not have the capacity to manage their financial affairs. The social welfare legislation allows for the appointment of an agent “to receive and deal with any sum payable by way of benefit on behalf of the claimant or beneficiary”. The total number of Agency arrangements for DA is 34,796 (34% of all DA). Inclusion Ireland has expressed to the Department our major concerns over the current provision of agency arrangements, including the practice that some claimants are being asked to ‘sign over’ their DA as a condition of receiving care from disability services. Inclusion Ireland calls for a review of all agency arrangements for all persons in receipt of DA living in residential care, and to implement the revised regulations governing agency arrangements (SI 378 2009), which strengthens the accountability of peoples’ money.

### **(iii) 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 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.



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