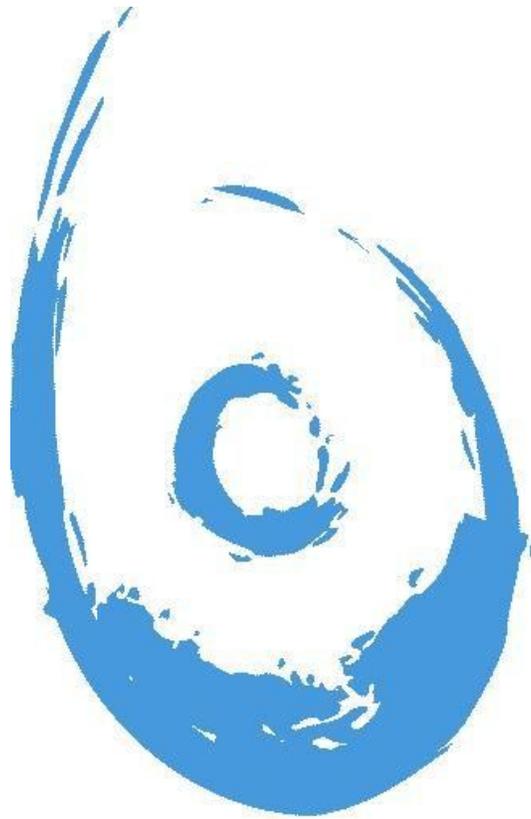


Inclusion Ireland



**Pre-Budget Submission to the
Department of Social Protection
- September 2011**

Inclusion Ireland is the largest national organisation representing and promoting the interests of people with an intellectual disability, their families and service providers in Ireland.

The Vision of Inclusion Ireland is one of people with an intellectual disability living and participating in their community with equal rights as citizens to live the life of their choice to their fullest potential.

The Mission of Inclusion Ireland is to be the independent champion of people with an intellectual disability and their families whose standing and expertise in intellectual disability is acknowledged and to ensure that people with an intellectual disability have their voices heard, are not isolated or segregated and lead more independent and healthier lives.

Founded in 1961 Inclusion Ireland is celebrating fifty years of work this year.

Introduction

The stark economic situation for 2010 became even starker in 2011 with the IMF, EU and ECB bailout. Ireland today is a harsh place for many individuals, particularly for those unable to work due to disability and their family carers. This group is most at risk of becoming caught in a deepening poverty trap. Benefits have already been cut twice since 2008, and while the Government has indicated there will be no cuts to rates in the next Budget, there are other ways cuts are made which impact on the income and living standards of people with disabilities and their families.

Inclusion Ireland is fully aware of the extraordinarily difficult economic situation the Government faces but this does not mean that crude cuts to social welfare, health and education services should be sanctioned without a proper review and audit of the effectiveness and efficiency of those services, and their capacity to provide the best outcomes for people. 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)

In 2012 the Government must find at least another €4 billion in savings. These savings will have to be made outside of statutory pay cuts following the Croke Park Agreement. This means that people with disabilities, of whom nearly 70% are not in the work place (either private or public), will once again be in the frontline for cuts, and bear more than their fair share of the burden facing the Irish people. One of the Goals of *Towards 2016* is to ensure that every person with a disability has access to an income.

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.** The cuts in the last two budgets have had significant consequences for people with disabilities. For example, people dependent on 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 would face a potential 30% reduction in their incomes.

Priority 3

- **Full implementation of regulations covering the appointment of agents for persons in receipt of Disability Allowance (DA).** The total number of Agency arrangements for DA is 34,796 (34% of all DA). 85%, 29,731, are Type 1 Agency arrangements - arrangements when the claimant cannot collect his/her DA. It allows the claimant to authorise another person to collect his/her DA. The DA in full must be given to the claimant. Type 2 Agency arrangements are when the claimant is deemed by a medical practitioner to be unable to manage his/her own financial affairs. There are 5,065 of these in place, many of which are for people living in an 'institution'. If no suitable person is available and willing to be appointed, a representative of the institution may be appointed. In such circumstances payment may be made directly to a central account and all legal inpatient charges are allowed to be deducted. Inclusion Ireland is concerned that some claimants are being asked to sign over their DA as a condition of receiving care, and that some Agency Type 1 arrangement may be 'de facto' Type 2 Agency arrangements.

1. Support to Carers

- Inclusion Ireland rejects reductions to the Carers Allowance in this budget. Current levels of payment must be maintained. The Carers Allowance is down, with cuts of €16.50 per week on the 2008 rate. Home care provides a more cost effective option to the State. Carers save the state over €2.5 billion and provide over 3.7 million hours of care in the home every week.
- The 2009 report of the National Intellectual Disability Database shows that over 64% 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).
- Social Welfare appeals in relation to Carers Allowance rose by 53% in 2010. Information on outcomes of appeals for Carers Allowance in 2010 (2,402) show that over half were allowed or the decisions of the Deciding Officer revised. The success rate for appeal is high, suggesting that carers need more information when completing an application. 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 be decided is 27 weeks, and 47 if an oral hearing is involved.
- Inclusion Ireland rejects any proposals to cut the half-rate Carers Allowance. The half-rate allowance was introduced in 2007, and offers excellent value in supporting people in their own homes.
- Extend 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.
- Provide all full time carers with medical cards.
- Consideration should be given to pay 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.

- Maintain the Respite Care Grant of €1,700 per annum, per person, being cared for. The Respite Care Grant gives people flexibility and autonomy and is popular with carers. Inclusion Ireland seeks a commitment that this grant will be paid at the same rate in 2012. 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 a very high cost choice.
- The Carer's Benefit rate should be maintained, and extended to three years. The period in which the 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.
- Inclusion Ireland supports the proposal from the Carers Association that the carers benefit model should be made similar to that of maternity benefit, where the amount of benefit is based on the percentage of the applicant's salary.
- Since the transfer of the Domiciliary Care Allowance to the Department of Social Protection, concern has been expressed at the high levels of refusal relating to children with autism and mild intellectual disability.
- Greater attention should be given to the causes of challenging behaviour in the training of medical assessors. Children with behavioural difficulties require a high level of support and supervision. Social Welfare Appeals in relation to Domiciliary Care rose by 122% in 2010. Information on the outcome of 1,246 of the appeals shows that a very high percentage, (64%), were allowed, or the decision of the Deciding Officer revised. It is unfair for families to have to go

through such a time consuming ordeal, waiting up to 50 weeks if an oral hearing is involved.

- Inclusion Ireland supports the proposals by both the Carers Association and the Disability Federation of Ireland on young carers.
- The Fuel Allowance and Household benefits schemes, which are available to those in receipt of disability or caring related payments, were greatly reduced this year (€65 million cut from the Budget). Energy costs are due to significantly rise this Autumn/Winter, which will increase the hardship for people with a disability and their carers.

2. Income Supports to People with Disabilities

(i) Disability Allowance

- Inclusion Ireland rejects cuts to the rates of Disability Allowance (DA). People on DA have seen their income fall by €847.60 a year since 2008.
- 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 from the Department.
- 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.

- Inclusion Ireland is aware of recommendations to change the entry age for DA from 16 to 18 years and to increase simultaneously the age to 18 for recipients of the Domiciliary Care Allowance (DCA). The weekly rate of DA is €188 or €9,776 annually. The DCA is € 309.50 per month or €3,714 per year. Even allowing for the annual respite care grant of €1,700 (which is available to persons in receipt of DCA), there is a large disparity between the two allowances.
- An acknowledgment of the extra cost of disability for people with disabilities and their families, and an agreed system to assess that cost based on degree of disability and associated costs may be of use in the event of the qualifying age for DA being raised to 18 years, as with other social welfare schemes. Options should be developed to enable such change to take place with the least possible impact on young people and the household in which they live.
- 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 over the 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 disability.
- The average Appeal for DA takes 31 weeks to process. This increases to 51 weeks if it involves an oral hearing. This is far too long and adequate secondment of staff should be made to significantly reduce waiting times.
- The impact of income from Discretionary Trust Funds and Pension schemes on the payment of DA: 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 DA 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.
- Given that the majority of people with a disability now receive the DA, the possibility of having different levels of payment of or supplements to DA (such as the living alone allowance) paid to people who live at home with their families or independently, or in residential/community based living arrangements funded by the HSE, should be reviewed to reflect the different needs of each category.
- 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 carer's in rural areas.
- The Value for Money Review of the Disability Allowance has been 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”. Many individuals with an intellectual disability receive their social welfare income through appointed agents, usually either family members or the service provider. The total number of Agency arrangements for DA is 34,796 (34% of all DA).

- There are two types of Agency arrangements :
 - Type 1 Agency arrangements - arrangements when the claimant cannot physically collect his/her DA. It allows the claimant to authorise another person to collect his/her DA. The full amount of DA must be given to the claimant by the agent. There are 29,731 Type 1 agency arrangements (85%);
 - Type 2 Agency arrangements are when the claimant is deemed by a medical practitioner to be unable to manage his/ her own financial affairs. There are 5,065 of these, agency arrangements in place for recipients of DA. Many of which are for people living in an ‘institution’;
- The majority of agents are parents, spouses or family members. However, the Regulations allow for the Minister to appoint a representative of an institution to act as an agent. This only happens when no parent, family member is willing to be appointed.
- Inclusion Ireland is concerned that some claimants are being asked to ‘sign over’ their DA as a condition of receiving care, and that some Agency Type 1 arrangements may be ‘de facto’ Type 2 Agency arrangements (i.e. people with impaired capacity have signed over the collection of their DA, which is then collected and managed by a service provider). There is no provision in the regulation for a claimant with impaired provision to sign over his her DA. The ‘signing over’ of social welfare payments should not be a condition of receiving care.
- 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 Regulations in respect of agency arrangements of this group of people.
- Inclusion Ireland welcomes revised regulations governing agency arrangements (SI 378 2009), which strengthens the area of accountability of patients’ money

as it provides for regulations that provide that records of all transactions on a patient's account must be kept and made available to relatives if requested.

- In situations where an individual is in the care of a service provider who acts as their agent, a pro-rata payment of DA should be paid to families for the time the individual spends with them e.g. if they stay at weekends, Christmas or summer etc. There is evidence that this practice is already in place with some service providers refunding the payment of DA to cover the time away from the residential care.
- Additional expenses incurred are also refunded by some service providers on production of receipts. Such arrangements ensure that the costs incurred by both sets of carers in meeting the needs of the claimant, are accommodated and reimbursed.
- There must be a comprehensive check on an individual's capacity to manage their own money. Some individuals are capable of managing their own money, but it continues to be managed by an agent because of arrangements made at the time of application for the payment. Inclusion Ireland welcomes the regulatory changes that have been introduced to address this issue (S.I. 378 of 2009), which requires that a person unable to manage financial affairs is *"certified by a registered medical practitioner in the prescribed form, to be a person who is unable for the time being to manage his/her own financial affairs"*, and which gives guidance as to how this can be assessed.
- Inclusion Ireland welcomes the recommendation by the Value for Money Review for comprehensive and user friendly guidelines to be developed and disseminated. Guidelines should be prepared for all agents and for service users. These guidelines must state that the money be clearly earmarked as the individual's property to be used for their benefit. There is also a danger that large sums can build up in a person's account over time and not used, only to be claimed by others after the person's death. Every effort should be made to ensure that each individual has his/her own bank account. Producing such a publication will ensure that all information pertaining to agency arrangements is available in one single user friendly document. It would clearly set out the procedures and administrative arrangements that are required when acting as

an agent. Additionally it could set out what is expected from all participants in the agency arrangement process.

- While new guidelines will provide clarification and national consistency, Inclusion Ireland recommends a review, with audit, of the agency system currently in operation.
- The Law Reform Commission has recommended that a person associated with a care facility should not be permitted to be appointed an agent under social welfare legislation. The Commission also recommended that agency agreements would be subject to the scrutiny of the Public Guardian system, which it proposed for all substitute decision makers.

(ii) Employment Supports

- Inclusion Ireland welcomes the integration of employment services and community employment services programme from FÁS and the Community Welfare Services, to the Department of Social Protection.
- The numbers in receipt of DA has more than doubled over the past ten years. It is now at a record high of 101,323. Inclusion Ireland calls for the 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.
- The recent Value for Money Review of the Disability Allowance has determined that a wide range of factors have been at play in relation to the increase in numbers on the DA and stresses the importance of early intervention on the part of labour activation services.
- 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 welcomes the activation initiatives undertaken by the Department in relation to young people on DA, but more remains to be done to gather reliable data to inform engagement strategies. The Disability Activation Project should be further developed and extended. The merger of some FÁS services with the Department may offer better opportunities for activation services.
- The recent Value for Money Review of the Disability Allowance has determined that a wide range of factors have been at play in relation to the increase in numbers on the DA and stresses the importance of early intervention on the part of labour activation services.
- The arrangements put in place which allow people to keep a proportion of their DA if they earn over €120 per week in rehabilitative work in the open market has proved to be a positive step. However, few of these claimants have moved onto the full open market. The reasons for this must be analysed, and ways of encouraging people into fulltime work developed.
- All Labour activation programmes must be available to people in receipt of DA. For example, The Job Bridge Labour Activation Programme is not open to any person in receipt of DA. This assumes that people on DA are unwilling or unable to work.
- Supported Employment Programmes can contribute to more people with disabilities engaging in meaningful employment. These programmes need to be attractive to prospective employers and participants. The rebranding of the FÁS Supported Employment Programme was a key recommendation of the WRC review.
- Inclusion Ireland calls on the Department to implement the key recommendations of the WRC review.
- 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 the DETE, with a view to reducing the potential for longer term welfare dependency.

3. Advocacy

- Inclusion Ireland welcomes the introduction of the new National Advocacy Service for people with a disability. In the short time it has been in place it has proved a valuable resource to people with disabilities and their families.
- 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.
- While this cooperation is forthcoming in the majority of cases from both voluntary and statutory providers of services, it is important for the future development of the National Advocacy Service that the relevant sections of the Citizens Information Act are enacted to give statutory powers to advocates working in the service.

Inclusion Ireland Member Organisations

ABILITY WEST FORMERLY GALWAY ASSOC
ST AIDAN'S DAY CARE CENTRE
AIRC
AISLING CENTRE P & F
ANNE SULLIVAN CENTRE
ARAS ATTRACTA
ARD AOIBHINN CENTRE
AUTINET COMMUNITY GROUP
BALLINASLOE ADVOCATES
BASC ENTERPRISES, BANDON
BRÉIFNE SOCIAL HOUSING
BROTHERS OF CHARITY SERVICES IRELAND
CAMPHILL COMMUNITY BALLYBAY
CAMPHILL COMMUNITY CARRICK-ON-SUIR
CAMPHILL COMMUNITY DUNSHANE
CAMPHILL COMMUNITY GRANGEMOCKLER
CAMPHILL COMMUNITY GREENACRES
CAMPHILL DUFFCARRIG
CARMONA SERVICES
CASTLEBLANEY CARE ASSOCIATION
CENTRAL REMEDIAL CLINIC
CENTRE FOR DISABILITY STUDIES, UCD
CHEEVERSTOWN HOUSE
CHILDREN'S SUNSHINE HOME
CLANN MOR RESIDENTIAL AND RESPITE LTD
CLARE FEDERATION
CO ACTION WEST CORK
COMMUNICATIONS WORKERS' UNION
COPE FOUNDATION
CORK ASSOC OF P&F
CRONAN'S ASSOCIATION LTD
DARA RESIDENTIAL SERVICES
DAUGHTERS OF CHARITY DUBLIN
DELTA CENTRE
DÓCHAS (HOPE FOR PEOPLE WITH AUTISM)

DOMUS SERVICES
DONEGAL ASSOC OF P&F
DOWN SYNDROME ASSOC, IRELAND
DOWN SYNDROME, TIPPERARY
DUNMORE HOUSE P&F ASSOCIATION
EAST CORK P&F
ENNISCORTHY DISTRICT, ASSOC OF P&F
FAMILY & FRIENDS OF GHEEL
GABRIEL'S (ST) SPECIAL SCHOOL PARENTS' ASSOCIATION
HELPING HANDS, TALLAGHT
ST HILDA'S, ATHLONE
HOLY FAMILY SCHOOL, COOTEHILL
IRISH FRAGILE X SOCIETY
IRISH NURSES & MIDWIVES ORGANISATION
ST JOHN OF GOD DAY CENTRE P&F GROUP
ST JOSEPH'S ID SERVICE, PORTRANE
ST JOSEPH'S PARENTS ASSOCIATION
KARE
KERRY PARENTS & FRIENDS ASSOCIATION
LÁMH
LAOIS DOWN SYNDROME IRELAND
L'ARCHE IRELAND LTD
LITTLE ANGELS ASSOCIATION, DONEGAL
LONGFORD ASSOCIATION FOR PEOPLE WITH AN INTELLECTUAL DISABILITY
LORREQUER HOUSE
MALTA SERVICES
ST MARY'S DRUMCAR, DUBLIN BRANCH
ST MARY'S P&F ASSOCIATION, DELVIN
ST MICHAEL'S HOUSE HQ
MIDWAY, MEATH
MONAGHAN BRANCH LTD
MOORE HAVEN CENTRE - TIPPERARY
MULLINGAR & DISTRICT P&F ASSOCIATION

NATIONAL FEDERATION OF ARCH CLUBS
NIID, TCD
NORTHWEST P&F ASSOCIATION
NURTURE HEALTHCARE SERVICES LTD
OFFALY ASSOCIATION
PAVING THE WAY
PEACEHAVEN TRUST
PEAMOUNT HOSPITAL INC
PEAMOUNT HOSPITAL P&F - LIMELIGHT
ST PETER'S ASSOC OF P&F CASTLEPOLLARD
POPE JOHN PAUL II CENTRE P&F ASSOC
PORTARLINGTON P&F OF MOORE ABBEY
PORTMARNOCK INTEGRATED ARCH CLUB
PRAXIS HOUSING ASSOCIATION
PROSPER FINGAL
ST RAPHAEL'S P&F ASSOCIATION
RED DOOR PARENTS SUPPORT GROUP
RETT SYNDROME ASSOCIATION IRELAND
ROSCOMMON ASSOCIATION
S.N.A.P PARENTS AND FRIENDS
SCOIL CHIARAIN
SISTERS OF CHARITY, JESUS AND MARY (MOORE
ABBAY)
SIPTU
SOS KILKENNY LTD
SOUTH TIPPERARY AUTISM SUPPORT GRP
SPECIAL OLYMPICS IRELAND
STEWART'S SCHOOL PARENTS ASSOCIATION
STEP
ST JOHN OF GOD NORTH EAST SERVICES
(HILLTOP)
SUNBEAM HOUSE SERVICES
THURLES P&F ASSOC
TIPPERARY ASSOCIATION
WALK WITH YOU
WATERFORD ASSOCIATION
WESTERN CARE ASSOCIATION
WINDMILL THERAPEUTIC TRAINING UNIT LTD

WISDOM SERVICES



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promoting rights, independence, dignity and equality