



**Budget 2011:  
Inclusion Ireland  
Submission to Government  
October 2010**

promoting rights, independence, dignity and equality

## **INCLUSION IRELAND**

**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 has 150 affiliated organisations providing services and supports to the 26,000 people with an intellectual disability in Ireland.**

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## FORWARD

The increasingly stark economic forecast for 2010 has become even starker for 2011. Ireland today is riddled with shattered dreams, with poverty levels set to increase in coming years, particularly for those dependant on social welfare. The Economic and Social Research Institute, Research Series 17 *Monitoring Poverty Trends in Ireland 2004-2007: Key Issues for Children People of Working Age and Older People* published on the 7<sup>th</sup> September singles out the long termed unemployed, lone parents and those unable to work due to disability or illness as the groups most at risk of becoming caught in a deepening poverty trap. It says Government policy is critical to 'poverty proof' the most vulnerable groups. Benefits have already been cut and we have been warned of further cuts to benefits ahead of December's budget.

Inclusion Ireland recognises the current economic situation is extraordinarily difficult, but this does not mean that crude cuts to social welfare or existing health and education services should be sanctioned without a proper review of the effectiveness and efficiency of those services and their capacity to provide the best outcomes for people with disabilities and their families.

For the last two years the Minister for Finance has framed his Budget in terms that Budget measures must protect the most vulnerable in our society such as: people with disabilities, children, older people, carers, those living on low incomes or at risk of poverty, and the homeless. This rhetoric differs from the reality, and devastating cuts have taken place this year in social welfare payments and health and education services. Decisions about Budget 2011 must consider and respect the priorities set out in the National Disability Strategy and any public expenditure cuts must not reduce services for people with disabilities. Political leadership, courage and vision are required to ensure that those with the greatest need get the greatest resources.

**There must be no further cuts in 2011!**

## **INCLUSION IRELAND PRIORITIES FOR 2011**

- **Priority Issue 1: No cuts in health and education frontline services to people with disabilities**
- **Priority Issue 2: No cuts in rates of social welfare payments or in supports to carers in 2011**
- **Priority Issue 3: The introduction of the personal advocacy service for people with disabilities, as outlined by the Citizens Information Act 2007, should be implemented as soon as possible**
- **Priority Issue 4: To complete the programme to transfer people with an intellectual disability inappropriately placed in psychiatric hospitals or who are living in outdated congregated settings by 2016**
- **Priority issue 4: The commencement of independent inspection of all residential services for adults with disabilities and the completion of national standards for children's services, including those for children with disabilities**
- **Priority Issue 5: The promotion of innovative measures for providing supported living respite services and day services, including a commitment to implement the recommendations of the HSE review of adult day services for people with disabilities. The publication of the review of disability services under the value for money and policy review**
- **Priority Issue 6: Commencement of modern capacity legislation to include guidelines for professionals working with and supporting people with an intellectual disability**

# SUBMISSION TO DEPARTMENT OF HEALTH & CHILDREN

## 1. Funding Cuts

- In July 2010 there were major protests over cuts to disability funding throughout the country. Families of people with intellectual disabilities were forced to take to the streets to highlight cuts to essential services such as respite care. In 2011 the HSE is expected to find a further €700,000 million in funding cuts over the €600,000 million found in 2010<sup>1</sup>. From past experience such cuts will inevitably find their way to frontline services unless there is rigorous vigilance. Inclusion Ireland calls on the Department of Health and Children (DOHC), to ensure that funding allocated to the HSE for disability services is ringfenced for such purposes, unlike 2010 when overspends in other areas of HSE budget, e.g. acute hospitals, led to further cuts in some disability service providers budgets. In 2010, savings were made by cuts to public service salaries, which included cuts to grant aided organisations. This cannot be repeated as per Croke Park agreement in 2011. 80% of the cost of disability services is staff costs. It is difficult to see where the saving will come from next year.
- The moratorium on recruitment of staff within the public services is having a disproportionate impact on frontline services for people with intellectual disability and mental health difficulties. There is an urgent need to review the moratorium for frontline staff. Improved work practices and efficiencies must also be looked at, to ease disruption to

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<sup>1</sup>In 2009 the HSE provided in the order of €1.6billion to fund disability services. It distributes 75% or €1.2b of this through non-profit organisations and a growing number of for profit groups who deliver over 80% of all disability services. There are 281 such bodies providing disability services in a variety of community and residential settings. Over 70% of the funding to these bodies goes to just 25 organisations.

service users.

## 2. Innovation and Reform

- A review of the efficiency and effectiveness of disability services is currently being undertaken by the DOHC, The Department of Finance and the HSE. The DOHC has stated that the review will see how well current services meet their objectives and that it will support future planning and development of disability services.
- A significant element of this “value for money review” is a policy review focusing on the creation of a cost-effective responsive and accountable system to support the full inclusion of people with disability. There is a consensus that the current model of delivering services to people with disabilities is no longer sustainable or desirable. The Report of the Expert Group on Resource Allocation and Financing in the Health Sector (July 2010) states:

*“international best practice in disability services (among the largest expenditure programmes within community and continuing care) is to move away explicitly from a medical model of care to a social model of support, with the emphasis on maximising self-determination, community participation (inclusion) and equal citizenship...This change in orientation and relationship in the area of disability services requires fundamental change in the understanding of the duty of care that is typically held, where the client is viewed as a dependent and passive recipient of services.”*
- The Review will address issues such as the allocation of resources on an individual basis, assessment of need, and procurement and commissioning of services.
- The Comptroller and Auditor General’s (C&AG) 2009 Annual Report (15<sup>th</sup> September) noted that there had been no substantial change in

the HSE's approach to funding non-profit organisations since the C&AG's value for money review of the sector in 2005, which highlighted a number of value for money and accountability problems within disability services. The Report states that "annual allocations continue to be made by reference to historic levels of funding" and "it would be desirable to move towards a situation where funding is informed by standard costing". Failure to do so means that funding is not linked to levels of identified need and as a result, is not always targeted at the areas of greatest need. The report highlights the importance of having comprehensive information from service providers and the difficulties of obtaining information on the numbers and grades of staff employed. The report found that costs for services for persons with similar degrees of disability varied from one provider to another.

- Inclusion Ireland calls for the publication of the Value for Money Review within the shortest time frame possible so that an informed debate and positive action can take place on the future direction of disability services in this country. The evidence from the reports outlined above show that there is an urgent need to introduce change and reform to the current model. There is a need for a more equitable model based on an assessment of individual need, which will enable the person to choose from a variety of the services and supports which best meet their assessed needs.
- A statutory right to an independent assessment of need is available since June for children from 0-5 years under the Disability Act. This was due to be extended for children aged up to 18 years by 2010, and for adults in 2011, but has now been deferred indefinitely. There are a considerable number of children who have not yet received their entitlement to an assessment under the Act. Overdue assessments stood at 844 at the end of 2009, compared to 627 in 2008.

### 3. People with Intellectual Disability in Psychiatric Hospitals & Congregated Settings

- Inclusion Ireland finds it totally unacceptable that over 25 years after Government policy clearly stated the need for separate facilities for people with an intellectual disability and people with a mental illness, nearly three hundred people with an intellectual disability remain in psychiatric hospitals. Four years ago, *A Vision for Change* also stated that this practice would end.
- The Department of Health and Children announced a €43million investment in the mental health strategy 'A Vision for Change' in Budget 2010. Disability and Mental Health Minister John Moloney said provision for continued funding of the programme will be made in the 2011 Estimates and subsequent years. This will be funded through the sale of former 'mental health assets', such as old institutions. Disturbingly, during the summer 2010 a series of grave reports on the mental health services in Ireland were published which catalogued a series of serious failings. The Annual Report of the Mental Health Commission showed "slippage" in a number of areas including staffing, therapeutic services and programmes, recreational activities, privacy and premises. The independent monitoring group in its annual review announced that there had been "little substantial progress" in the last year. In addition, spending on mental health services fell to 5.3% of the health budget in 2010 from 6.7% the previous year, and falls short of the 8.4% recommended by *A Vision for Change*. Budget 2011 must give urgent priority to mental health services.
- The Draft HSE Steering Group Report on Congregated Settings states that 4,000 people with disabilities still live in institutions, many in substandard conditions, costing on average €115,000 per annum. The Report has been delivered to the Department of Health and Children. The steering group was established in 2007 to address this issue of

Congregated Settings and to make recommendations to guide future policy. Inclusion Ireland calls for the report to be made public and that an implementation plan be drawn up to close congregated settings by 2017.

#### 4. Therapeutic Support Services

- The shortage in all areas of support services, in particular Speech and Language Therapy, Occupational Therapy and Physiotherapy continues. The Implementation of the Disability Act Part 2, providing for an independent assessment of need for children aged 0 to 5 years, in June 2007 has put significant demand on existing supports such as speech and language therapists and psychologists. Additional funding of €20 million to employ therapeutic support staff for children, to be divided between the Departments of Health and Children and Education was secured for 2009. It is unclear what new posts have been created with this funding and whether the staff moratorium applies to this group.

#### 5. National Quality Standards for Services

- The Health Information and Quality Authority (HIQA) published *National Quality Standards: Residential Services for People with Disabilities* in May 2009. Inclusion Ireland was part of the advisory group which developed these standards. The plan was that these standards would be rolled out by the end of 2009 following the commencement of the standards for older people in nursing homes in July 2009. The DOHC has stated that given the current pressures on public finances it is not possible to move to full statutory implementation of these standards, including those relating to registration and inspection. The DOHC and the HSE have suggested that the standards could be implemented on a non statutory (i.e. voluntary) basis, focusing initially on achieving improved standards of care within the existing physical infrastructure of care homes, and

current overall revenue and staffing levels. This is not acceptable to Inclusion Ireland. Last year, Minister John Moloney said that detailed proposals would be brought to Government early in the New Year in respect of the protection of adults with disabilities in residential services. Inclusion Ireland is unaware of what proposals have been brought and calls for the immediate implementation of these standards on a statutory basis.

- One of the key recommendations of the Ryan Report on Abuse is the need for independent and unannounced inspection of children's residential services. There is a noted absence of such inspection of services for children with disabilities. The action to be taken around inspection of services for children with disabilities outlined in the implementation plan launched by Minister Barry Andrews after the Ryan report states "the Health Act 2007 will be commenced to allow for the independent registration and inspection of all residential centres and respite services for children with a disability by December 2010". *Draft National Quality Standards for Residential and Foster Care Services for Children and Young People* have been developed by a HIQA Advisory Group of which Inclusion Ireland was a member. These standards must be implemented without delay as per the Minister's commitment.

## 6. Review of Adult Day Services

- The HSE established a high level working group to review HSE funded Adult Day Services in 2007. This group has completed its work and the report *New Directions* is being considered by the relevant HSE functions. Inclusion Ireland was represented on this group. Inclusion Ireland calls upon the HSE to address the priority issues and recommendations made in the report to ensure the reconfiguration and modernisation of existing day services to reflect the principles of Access, Quality, Accountability and Person Centeredness.

## 7. Long Stay Health Charges

- Inclusion Ireland continues to voice concern over the levying of inpatient charges to persons in 'long-stay care'. The statute published in July 2005, i.e. Health (Charges for In-Patient Services) Regulations 2005 S.I. No 276 of 2005, allows for the levying of charges on persons who are in receipt of in-patient services in premises where nursing care is provided on a 24 hours basis, (Class 1) and in premises where nursing care is not provided on a 24 hour basis (Class 2). In July 2006 the HSE published guidelines on how charges should be levied.
- Long stay charges were increased by €33.25 to €153.25 for those in receipt of 24 hour care and by €24.95 to €114.95 a week for those in receipt of part-time nursing care in 2008. This amounted to a 27.5% increase. People in Class 1 are left with €44.70 and Class 2 with €70.25. Any further increases in charges or a reduction in the rate of Disability Allowance currently at €196 per week could have repercussions for this. Leaving people with such limited disposable income after charges does not promote inclusion in society. Inclusion Ireland has been made aware of service users being asked to contribute towards the cost of services in a number of ways in order to make up shortfalls in funding.
- The HSE has delegated full responsibility for levying charges to agencies that provide services on behalf of the HSE. This responsibility includes carrying out assessments to determine the amount an individual should be charged. It is the view of Inclusion Ireland that only the HSE has the right to assess people's means and voluntary service providers should not be asked to assess means on behalf of the State.

## 8. Medical Card

- Children with an intellectual disability should be entitled to a medical card in their own right. Many have additional health needs and suffer poorer health than their peers as well as having more chronic illnesses. The current income limit excludes all but a small percentage of people and is a cause of great hardship to families.
- Following Budget 2010, there is now a Medical Card prescription charge of 50 cent per prescription up to a maximum charge of €10.00 per month per family. A person with a medical card will now pay 50 cent for each item they are prescribed. The efficiency and effectiveness of such a charge has not been proven and discriminates against people with disabilities as well as families with young children and older people.

# SUBMISSION TO DEPARTMENT OF SOCIAL PROTECTION

## 1. Support to Carers

- Inclusion Ireland rejects cuts to Carers Allowance announced as part of Budget 2010 in December. The Carers Allowance for those under 66 is €212. There can be no further reductions to the Carers Allowance in this budget. Current levels of payment must be maintained. There should be no reduction to the income thresholds for these allowances.
- The Budget should include measures to extend the hours carers can work outside the home to 19.5 hours, which will also allow carers to take advantage of FÁS Training and other Schemes.
- The Habitual Residency clause should be abolished for people returning to Ireland to provide family care.
- All full time carers should be provided with medical cards.
- The Respite Care Grant was maintained last year at €1,700 per annum per person being cared for and it is now payable for each eligible person being cared for. The Respite Care Grant gives people a great deal of flexibility and autonomy. Inclusion Ireland seeks a commitment that this grant will be paid at the same rate in 2010. The increasing crisis in finding centre based respite care for people with disabilities must lead to new innovative and cost effective approaches in providing respite care. The amount of hours full-time carers, who are eligible for this grant can work, should be extended to 19.5 hours per week as with Carer's Allowance. Members of Inclusion Ireland, not in receipt of Carer's Allowance or the Domiciliary Care Allowance who receive the Respite Care Allowance have expressed concern about the detailed

forms they must fill out annually, particularly if they are caring for people who have a permanent diagnosis of disability. Inclusion Ireland is aware of a number of people who have lost their eligibility for this allowance.

- The Carer's Benefit rate should be maintained and extended to 3 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 3 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.
- The Domiciliary Care Allowance was transferred from the Department of Health & Children in April 2009. Since then there have been concerns about the high levels of refusal relating to children with autism and mild intellectual disability. The rejection rate from January to May 2010 was over 50%. There is a need to review the application form to ensure that full information on a child's behaviour and the level of supervision that this might require is obtained, and not just information on the physical diagnosis. Greater attention should be given to behaviour in the training of medical assessors. Children with disturbed or challenging behaviour require a high level of support and supervision.

- Inclusion Ireland welcomed the publication in May 2010 of a study on young carers. The findings of the study, particularly those related to additional supports for young carers such as help in the home and information on services available to them must be implemented.
- Inclusion Ireland welcomes the decision to change the wording of the Carers question on Census 2011 to allow for an open-ended response. Inclusion Ireland will work with the Carers Association on a pre-census campaign later this year to ensure all people with caring responsibilities complete the question.

## **2. Payments to People with Disabilities**

- The Disability Allowance now stands at €196 a week following cuts as part of Budget 2010. The failure to pay a Christmas Bonus in 2009 also had a major impact on people with disabilities. These cutbacks were compounded by other cuts to child benefit, the prescription levy and cuts in dental treatment. There can be no further cuts to the Disability Allowance in 2011 Budget.
- A new control review policy was introduced for the Disability Allowance Scheme in January 2009. The move to a risk based model led to a number of people having their allowance stopped. Inclusion Ireland has been made aware of such cases and the problems with the length of time it has taken to appeal these decisions. The Department of Social Protection aims to deal with 90% of applications for Disability Allowance within 12 weeks. However, as at April 2010 only 60% of applications are being dealt with within 12 weeks.
- As at 30<sup>th</sup> April 2010, 3,499 appeals were pending by applicants for the Disability Allowance. In 2009 the average waiting time for an appeal to be processed was 26.2 weeks. This means that time taken between

applying for the Disability Allowance and waiting for an appeal to be processed could be over ten months.

- Inclusion Ireland calls for action on the National Action Plan for Social Inclusion 2007- 2016, which aims 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. This is even more important given the current economic climate. The numbers in receipt of Disability Allowance has more than doubled over the past ten years. Inclusion Ireland calls on the Department to analyse these figures. The current economic climate makes it more difficult for this group to enter the workforce. The Department is preparing for the introduction of a partial capacity scheme, which will allow people with disabilities to claim benefit while working part time. Full details on how this scheme will operate have yet to be clarified, and discussions with representative groups and people with disabilities must take place before any such scheme is introduced.
- The initiative undertaken by the Department in relation to young people on DA in the Midlands needs to be replicated in other parts of the country, but more remains to be done to gather reliable data to inform engagement strategies, which must include the introduction of a Cost of Disability Payment to acknowledge that many people with disabilities will have additional costs in trying to access employment.
- The Review of the Disability Allowance has not been published, despite promises to do so in early 2010.
- The impact of income from Discretionary Trust Funds and Pension schemes on the payment of Disability Allowance must be examined. Many parents set up Discretionary Trust Fund Schemes or Pension Schemes on behalf of their child with a disability. Families are

concerned that the income derived from these may lead to a reduction or loss of Disability Allowance and other benefits associated with it, particularly the medical card and travel pass. This has been raised by Inclusion Ireland for many years and is an area that needs to be clarified. An income disregard similar to that for people in rehabilitative employment should be investigated. The increase in the capital disregard for Disability Allowance to €50,000 has assisted this issue.

- Inclusion Ireland members have raised the position of people in receipt of Disability Allowance (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 Disability Allowance, the possibility of having different levels of payment of DA or supplements to DA (such as the living alone allowance), paid to people who live at home with their families or independently, or who are 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 Disability Allowance 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. Our members 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.

### 3. 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', who is assessed as lacking the capacity to manage their own financial affairs. Current criteria for assessing capacity to manage Disability Allowance involves a Medical Practitioner certifying on a DA agency form that a person does not have capacity to manage his/her financial affairs. The system of appointing an agent at the time of application for DA needs to be further developed to include clear confirmation that an individual is not able to manage his or her own income. The Department of Social Protection and the HSE should work together to develop a toolkit to give guidance with regard to assessing a person's capacity to manage their Disability Allowance.
- These guidelines must state that the money be clearly earmarked as the individual's property to be used for their benefit. Every effort should be made to ensure that each individual has his/her own bank account. The Disability Allowance application form for becoming an agent actually states that the account must be in the individual's name if a service provider is applying to become the agent. However, some banks are refusing to open accounts for people with intellectual disabilities in their own names.
- Appointed agents are generally either family members or a disability service provider. There are approximately 3,500 appointed service provider agents, who usually act for more than one individual. At present there is no regulation of this practice. The only option for those

unhappy with the agency agreement is to make a complaint to the Department of Social Protection, who will then investigate the complaint. However, such a system discriminates against people with disabilities. If you do not know who manages your money, you cannot be in a position to lodge a complaint.

- Inclusion Ireland recommends that the Department of Social Protection sets up a unit to monitor agency accounts similar to the Patients Private Property Account unit in the HSE whose role is to monitor /regulate Patient Private Property Accounts for those in HSE care facilities. Alternatively, all service provider agents should be required to lodge DA money into PPP accounts which would mean that HSE regulations and guidelines governing PPP accounts could be followed. The Department should liaise with the HSE on this matter. New regulations and guidelines governing PPP Accounts were due to be ready last year but are still not available.
- Some disability service providers require that the 'agency' is transferred to them before a person moves into a residential placement. This practice should not be a prerequisite for a person receiving a residential service and should cease.
- 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.

#### 4. Advocacy

- The introduction of the personal advocacy service for people with disabilities, as outlined by the Citizens Information Act 2007, should be implemented as soon as possible. This statutory advocacy service for people with disabilities was deferred in June 2008. The pilot schemes supported by the Citizen's Information Board will end on December 2010. Following an evaluation of these schemes commissioned by the Citizens Information Board a restructured advocacy service was recommended. The Board of CIB agreed to the recommendations for new services, and the proposals are now with the Department of Social Protection. It is essential that this service is given the go ahead without delay to enable a smooth transition between the pilot programme and the roll out of the new programme. At present the situation is clouded in uncertainty and confusion.
- The new service will be available in each geographical area in the country and will be targeted at those who are most vulnerable. It is essential that this service goes ahead and makes provision for advocates to have statutory powers as per the 2007 Act.

# SUBMISSION TO THE DEPARTMENT OF EDUCATION & SCIENCE

## 1. EPSEN

- The implementation of the Education for Persons with Special Educational Needs Act 2004 (EPSEN) was put on hold in 2008, and there has been no Government statement about when it will now be implemented. This is a very important piece of legislation that gives children with disabilities the right to attend mainstream schools with appropriate supports. The National Council for Special Education (NCSE) set up by EPSEN, was charged with drawing up a plan for implementing EPSEN. This plan was sent to the Department of Education in 2006 and set out the resources needed, and a timetable for all sections of the Act to be completed by 2010. To date there has been no response from the Department of Education.
- EPSEN allows for Individual Education Plans. Individual Education Plans allow for appropriate, focused education supports to be put in place. Children with disabilities may regress significantly if intervention is not made from an early stage. It is essential during this period that cooperation and planning for the eventual implementation of EPSEN continues.
- Inclusion Ireland calls on the Government to provide an independent appeals system for parents who are unhappy with cuts to education resources for their children with disabilities. Currently, if a parent is unhappy with the decision to have their child's Special Needs Assistant (SNA) cut or have their hours reduced, the only appeals process is through NCSE. The NCSE employs the Special Education Needs Organisers, who will have made the decision to reduce the SNA hours. This is simply an internal appeals procedure and it is not good enough. The EPSEN Act provides for the establishment of the Special

Education Appeals Board. Despite allocations of €68,695 in 2009 and €70,000 for 2010, the term of office of Board Members ended in April 2010 without hearing any appeals. The part of EPSEN relating to the Special Education Appeals Board must be drawn down immediately.

## **2. Special Needs Assistants**

- The NCSE Review of Special Needs Assistants (SNA) allocation to schools stated that 353 fewer SNAs will be sanctioned following the review. Inclusion Ireland received many queries from members following a reduction of hours or cut to SNAs in schools around the country. It must be noted that the 353 posts are whole-time equivalents and as such, many more than 353 children are affected. In the first quarter of 2010 SNAs were cut in the middle of school term, which was a very unsettling and disturbing experience for children. This should not happen again. The best interests of the child must be at the heart of all decisions around allocation of Special Needs Assistants. Criteria for Special Needs Assistants must also be examined to ensure SNAs provide children with the best possible assistance in their educational development.

## **3. Training**

- Further Special Education Needs (SEN) training for teachers in mainstream schools is essential to ensure they are equipped to provide appropriate support and education to the ever increasing number of children with special educational needs accessing mainstream schools. It is essential that schools be resourced to provide substitute tuition to facilitate teacher training in this area. The Department needs to invest the necessary resources to introduce a comprehensive programme of teacher and other professional training to ensure schools are equipped to appropriately meet the needs of all children with SEN. This is particularly essential in light of the decision in 2009 to cut back on special classes.

#### 4. Nursing Support in Special Schools

- Many special schools have reported concerns about the lack of appropriate nursing support within schools where children have significant medical needs. There is frustration around the lack of a dedicated funding stream where schools can apply for the necessary resources. Inclusion Ireland calls for a joint approach between the Department of Education and Science and the Department of Health and Children and the HSE to develop a policy and funding stream to address this gap.

## SUBMISSION TO DEPARTMENT OF ENTERPRISE, TRADE & EMPLOYMENT

- Inclusion Ireland is represented on the Consultative Forum for the development of a comprehensive Employment Strategy for People with Disabilities. This development of a Comprehensive Strategy is welcome as there have been various initiatives over the past decade to promote employment opportunities for people with disabilities but unemployment is still a significant problem for this group. It is imperative that the Strategy will provide innovative solutions to the many barriers currently in the system. However, despite promises, the Strategy has not yet been published, even in draft form. This is a key commitment in the Department of Enterprise, Trade and Employment's Sectoral plan. It is imperative the Strategy is published as soon as possible.
- Provision is due to be made in the forthcoming Social Welfare Bill for the Department of Social Protection to take on the employment aspects of FÁS. However, this has not been confirmed by Minister O'Cuív who said that the issue of who will lead on the strategy has yet to be finalised. As it stands, we expect that the lead for the employment strategy will be taken over by the Department of Social Protection sometime at the end of this year or early next year. FÁS has been providing mainstream training and employment services to those with a disability since the year 2000. Appropriate funding must be available to ensure there is greater awareness amongst people with disabilities and employers of the programmes of support available to them. Information campaigns specifically targeting people with an intellectual disability are necessary to ensure they are aware of their right to be in employment and aware of the supports available to them.

- The Wage Subsidy Scheme should be expanded. This Scheme has the potential to address some of the difficulties that have arisen in sheltered work centres where people are working but not enjoying employment rights. The Scheme, if promoted to individuals and potential employers, should be a popular one for those who are able to work more than 20 hours a week. However only a small number are on the scheme.
- There needs to be more joint working initiatives between the Department of Enterprise Trade and Employment, the Department of Health and Children and the HSE, and the Department of Social Protection to develop innovative supports and programmes for people to move from health and personal social services supports to employment, or access both when necessary. All people with disabilities regardless of whether they will enter employment, should have meaningful options for a daily occupation.
- The 2009 McCarthy Report stated that Community Employment workers in receipt of One Parent Family Allowance and Disability Allowance should have their allowances stopped. The proposals were not implemented in the 2009 budget, but in May 2010 Department of Finance sources said such proposals would not be ruled out. CE workers have said they are being told by FAS that at the end of their current contract, they will have to choose either their welfare entitlement or the CE payment. Many community projects rely on CE workers. Also, for many CE workers not being able to keep a partial allowance would act as a disincentive to go on a CE scheme. The Department must make clear its intentions for this scheme. Inclusion Ireland believes the current position must remain and those on CE schemes should be in a position to keep a partial allowance.

# SUBMISSION TO DEPARTMENT OF ENVIRONMENT, HERITAGE & LOCAL GOVERNMENT

## 1. National Housing Strategy for people with Disabilities

- Inclusion Ireland welcomes the work of the National Housing Strategy for People with Disabilities and hopes the final strategy will be published shortly. In recent decades successive Governments have failed to adequately address the housing needs of people with disabilities. As a result many people with a disability are trapped in unsuitable homes or inappropriate residential services. Many are forced to move into residential care settings due to the absence of adaptations to their own homes or adequate support within their own homes. People with an intellectual disability are further disadvantaged as their housing needs have traditionally been met by health funded services. People with an intellectual disability have a right to appropriate housing in their own communities.
- The Protocols being developed as part of the Housing Strategy are vitally important. These Protocols will govern arrangements between Local Authorities and the HSE so that a continuum of housing and health related supports can be provided seamlessly to people with an intellectual disability, ensuring their needs are met in their own communities.

## 2. Disabled Persons Housing Grant

- Amounts granted under the Housing Adaptation Grant must not be reduced in light of the current economic situation, and the continued benefit of the Grant should be highlighted in the Sectoral Plan Review. In this time of downturn in the building industry, there is a great opportunities for work in this area.

### **3. Access for All**

- Inclusion Ireland welcomes the commitments under the Department's Sectoral Plan and the Programme for Government to ensure access for all within public and private buildings and spaces.
- It is very disappointing that despite a review of Part M being initiated in December 2005, new guidelines will only be available at the end of 2010. This in turn puts back the date by which public buildings must be compatible with Part M, which was stated in the Disability Act to be not later than 31 December 2015, or not later than 10 years after the commencement of the amendment of Part M. It will now be 2020 at the earliest before compliance can be enforced. It is hoped that the new revised Part M guidelines will take account of more sophisticated wheelchairs, which was a major problem with the original Part M.
- The building regulations must be strictly enforced to ensure appropriate accessibility within new buildings, as well as buildings which undergo major refurbishment. The increased fines and simplified prosecution process, which was brought in with the Building Control Act 2007, will be worth little if enforcement and inspection is inadequate.

### **4. Mobility Allowance and Disabled Drivers & Passengers (Tax Concessions) Scheme**

- Inclusion Ireland has long campaigned for a relaxation of the stringent medical criteria laid down in the regulations governing the Mobility Allowance, and other schemes concerning drivers and passengers with a disability. The 2007 Programme for Government includes a commitment to review such eligibility criteria. In early 2009, the Equality Tribunal found the HSE unlawfully discriminated against people with an intellectual disability and mental health problems when deciding eligibility criteria for the HSE's mobility allowance. The Tribunal recommended that the Department of Health examine all

allowance schemes to ensure the assessment processes comply with the Equal Status Acts and she ordered that the HSE reassess the complainant's application for the mobility allowance.

- Under the disabled driver and disabled passenger scheme, severely and permanently disabled persons are entitled as drivers or passengers to repayment of VRT and VAT paid on specially constructed or adapted vehicles. To qualify, a person's disability must relate to the use of one or both legs or arms. Inclusion Ireland is aware of the hardship this causes to parents who have a child whose intellectual disability makes it very difficult for them to avail of public transport. A number of these children may technically have the use of their legs but are unable to walk for any distance or stand for any length of time. The Disabled Drivers and Disabled Passengers (Tax Concessions) Scheme – Independent Review Group, reported to the Minister of Finance in 2002, but it was not until July 2004 that the report was made public. This group made ten recommendations that it said should be implemented without further delay. The most important recommendation called for consideration to be given to making legislative change to repeal the current stringent medical criteria based on lack of limbs with a more general mobility-focused medical assessment. This recommendation is fully endorsed by Inclusion Ireland. The Department of Finance has placed a reservation on this proposal. Inclusion Ireland has calls for this to be lifted without delay.

## **5. Disabled Persons Parking Card**

- Inclusion Ireland welcomes the plan to review this scheme. The review must consider extending the Disabled Persons Parking Card Scheme to the families of people with an intellectual disability whose children or adult dependents have mobility problems or whose behaviour is such that it is impossible for them to use public transport or walk for any distances. The criteria for eligibility for the scheme, along with its current administration, needs to be considered in the Review.

# SUBMISSION TO OFFICE OF REVENUE COMMISSIONERS

## 1. Tax Relief

- Tax relief for home carers is only applicable to married couples and does not cover widowers or lone parents. This Tax Relief must be reviewed.
- Tax relief should be given to carers for predetermined categories of expenses associated with their caring commitment (e.g. technical aids, medical care, care products, renovations to home, bought in support care).

# SUBMISSION TO DEPARTMENT OF JUSTICE, EQUALITY & LAW REFORM

## 1. Capacity Legislation

- Inclusion Ireland continues to push for modern capacity legislation. Despite repeated promises, a Mental Capacity Bill has yet to be brought forward to the Oireachtas. Inclusion Ireland has been campaigning for changes to the law in this respect for many years. People with an intellectual disability do not have clear rights to make decisions. The law on deciding who has decision making capacity is totally inadequate and arrangements for supported and substitute decision making are non-existent. Ireland must introduce new capacity legislation in order to ratify the UN Convention on the Rights of Persons with Disability, which Ireland has signed up to.
- The Scheme of the Mental Capacity Bill was published in September 2008. While Inclusion Ireland recognises the importance of this new Scheme, the Scheme does not take on the recommendations of the Law Reform Commission Report on Vulnerable Adults and the Law, and is in danger of replacing the current Wards of Court system with another court system. Under the new Scheme, the courts will continue to be used to determine if a person with an intellectual disability has capacity. The specific exclusion of certain areas in the Scheme does not sit well with Article 12 of the UN Convention – “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”. The current legislation on sexual relationships is wholly inadequate and paternalistic, and the exclusion of marriage, divorce, voting and membership of a jury goes against the article also. Inclusion Ireland favours proposals put forward by the Law Reform Commission, which allows for tribunals to decide on capacity. This system would better support the person’s rights. Inclusion Ireland has presented a submission to the Department of Justice on the Scheme.

## INCLUSION IRELAND MEMBER ORGANISATIONS

ABILITY WEST (FORMERLY GALWAY ASSOCIATION)  
AIDAN'S (ST) SERVICES  
AISLING CENTRE P & F  
AISLING HOUSE P&F'S  
ANNE SULLIVAN CENTRE  
ARAS ATTRACTA  
ARD AOIBHINN CENTRE - AN BREACAD NUA  
ARRA VIEW RESIDENTIAL & RESPITE SERVICES  
BALLINASLOE ADVOCATES  
BASC ENTERPRISES, BANDON  
BLUESTACK FOUNDATION  
BRÉIFNE SOCIAL HOUSING  
BROTHERS OF CHARITY - CLARE  
BROTHERS OF CHARITY - GALWAY REGION  
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CAMPHILL COMMUNITY GRANGEMOCKLER  
CAMPHILL COMMUNITY KILCULLEN  
CAMPHILL DUFFCARRIG  
CAMPHILL FAMILY AND FRIENDS ASSOCIATION  
CAREWORLD  
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CASTLEBLANEY CARE ASSOCIATION  
CATHERINE'S (ST) ASSOCIATION LTD  
CENTRAL REMEDIAL CLINIC  
CENTRE FOR DISABILITY STUDIES, UCD  
CHEEVERSTOWN FAMILIES & FRIENDS  
CHEEVERSTOWN HOUSE  
CHILDREN'S SUNSHINE HOME  
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CO ACTION WEST CORK  
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COPE FOUNDATION  
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CORK CABAS PARENTS ASSOC  
CRONAN'S (ST) ASSOCIATION LTD  
DARA RESIDENTIAL SERVICES

DAUGHTERS OF CHARITY SERVICES (ST VINCENTS DE PAUL)  
DELTA CENTRE  
DÓCHAS (HOPE FOR PEOPLE WITH AUTISM)  
DOMUS SERVICES  
DONEGAL ASSOC OF P&F  
DOWN SYNDROME ASSOC, IRELAND  
DOWN SYNDROME ASSOC, SLIGO  
DOWN SYNDROME ASSOCIATION, TIPPERARY  
DRUMLIN HOUSE  
DUNDALK P&F  
DUNMORE HOUSE P&F ASSOCIATION  
EAST CORK PARENTS AND FRIENDS ASSOCIATION  
ENNISCORTHY DISTRICT, ASSOC OF P&F  
FESTINA LENTE FOUNDATION  
GABRIEL'S (ST) SPECIAL SCHOOL PARENTS' ASSOCIATION  
GRÁ AUTISM PARENTS GROUP  
HELPING HANDS, TALLAGHT  
HILDA'S (ST) SERVICES, ATHLONE  
HOLY FAMILY SCHOOL, COOTEHILL  
IASCW (IRISH ASSOCIATION OF SOCIAL CARE WORKERS)  
IRISH COUNTRYWOMEN'S ASSOCIATION  
IRISH FRAGILE X SOCIETY  
IRISH NATIONAL TEACHERS ORGANISATION  
IRISH NURSES & MIDWIVES ORGANISATION  
IRISH TRADE UNION TRUST  
JOHN (ST) OF GOD DAY CENTRE PARENTS & FRIENDS SUPPORT GROUP  
JOHN (ST) OF GODS CARMONA SERVICES  
JOSEPH'S (ST) FOUNDATION  
JOSEPH'S (ST) HOSPITAL, CLONSILLA P&F ASSOCIATION  
JOSEPH'S (ST) INTELLECTUAL DISABILITY SERVICES, ST ITA'S  
KARE  
KERRY PARENTS & FRIENDS ASSOCIATION  
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MARY'S (ST) DRUMCAR, DUBLIN BRANCH  
MARY'S (ST) P&F ASSOCIATION, DELVIN  
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MOOREHAVEN CENTRE P & F  
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NATIONAL CENTRE FOR EPILEPSY  
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PAVING THE WAY  
PEACEHAVEN TRUST  
PEAMOUNT HOSPITAL INC  
PEAMOUNT HOSPITAL P&F ASSOCIATION - LIMELIGHT  
PETER'S (ST) ASSOC OF P&F CASTLEPOLLARD  
POPE JOHN PAUL II CENTRE P&F ASSOCIATION  
PORTARLINGTON P&F OF MOORE ABBEY  
PORTMARNOCK INTEGRATED ARCH CLUB  
PRAXIS HOUSING ASSOC  
PROSPER FINGAL  
RAPHAEL'S (ST) P&F ASSOCIATION  
REHABCARE  
RETT SYNDROME ASSOCIATION OF IRELAND  
ROSCOMMON ASSOCIATION  
SCOIL CHIARAIN  
SIPTU  
SISTERS OF LA SAGESSE - CREGG HOUSE  
SOS KILKENNY LTD  
SOUTH TIPPERARY AUTISM SUPPORT GROUP  
SPECIAL NEEDS ACTIVE PARENTS (SNAP)  
SPECIAL OLYMPICS IRELAND  
ST JOHN OF GOD HOSPITAL SERVICES, IRELAND  
ST JOHN OF GOD NORTH EAST SERVICES (HILLTOP)  
STEWARTS HOSPITAL SERVICES LTD  
STEWART'S SCHOOL PARENTS ASSOCIATION  
SUNBEAM HOUSE SERVICES  
THE RED DOOR PARENTS SUPPORT GROUP  
THURLES P&F ASSOC OF PERSONS WITH SPECIAL NEEDS  
TIPPERARY ASSOCIATION FOR SPECIAL NEEDS  
WATERFORD ASSOCIATION  
WESTERN CARE ASSOCIATION  
WEXFORD CO COMMUNITY WORKSHOP (NEW ROSS) LTD  
WINDMILL THERAPEUTIC TRAINING UNIT LTD



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**promoting rights, independence, dignity and equality**



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**Inclusion Ireland is the largest national organisation representing and promoting the interests of all 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.**

**promoting rights, independence, dignity and equality**