



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

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Budget 2008

**Inclusion Ireland Submission to Government**

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

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

Last December, against a background of a strongly performing economy, **Inclusion Ireland** welcomed a number of the new provisions by the Government in Budget 2007 in particular changes in the social welfare system which targeted poor households and people with disabilities and their carers. This year, with a less favourable economic forecast, it is imperative that the Government continues to make brave changes in order to meet the commitments outlined in the National Disability Strategy, The Social Partnership Agreement "Towards 2016" and more recently The National Action Plan for Social Inclusion.

**The full inclusion of people with disabilities in Irish life must continue to be a priority for the Government in 2008. The ratification in 2008 by the Irish Government of the United Nations Convention on the Rights of Persons with Disabilities would be an important indication of the Government's commitment to people with disabilities and their families in Ireland.**

## **Inclusion Ireland has 5 priority areas for 2008**

- **Priority Issue 1: Review of Funding Arrangements / Innovative Measures**

**Inclusion Ireland** calls on the Department of Health and Children to undertake a review of current funding arrangements for services for people with an intellectual disability and to promote innovative measures for providing supported living and respite services. The current system of distinct funding streams for residential, day and respite services is costly, inflexible and does not encourage independent lives.

**A sum of €10m for Care Packages, based on an independent needs assessment, to facilitate people with an intellectual disability to live in their own homes or to be supported in the community**

- **Priority Issue 2: To End Waiting Lists for Services**

This year **2,118** people require a residential support service and **1,954** require a respite service (Annual Report of the National Intellectual Disability Database 2006). An independent audit of the database has been called for by **Inclusion Ireland** in its previous Budget submissions. As the review is now completed a full report of the findings of the audit must be published by January 2008.

Money for new residential support services must be ring fenced. A separate allocation of funding must be assigned to those already availing of a service but whose needs have significantly changed or who are in substandard services. All funding for new places and improvements to old places must be clearly linked to each individual's assessment of need and identified by a pin number. An increase in respite services for children and adults is urgently required. One way to increase places is to allocate **€2m** in 2008 for pilot schemes in the four HSE regions to develop alternatives to centre based respite services.

**A sum of €75m revenue to include €10m for Care Packages, and €50m capital for this investment programme in 2008 with a commitment to a similar level of funding for the next three years**

- **Priority Issue 3: Transfer Programme to the Community**

To complete the programme to transfer people with an intellectual disability who are inappropriately placed in psychiatric hospitals & who are living in Congregated Settings  
**A sum of €15m revenue and an equivalent capital sum to be ring fenced in 2008**

- **Priority Issue 4: National Standards and Inspection**

The introduction of National Standards for Disability Services by the end of 2008.  
**€5m revenue to be ring fenced in 2008 for the implementation of the National Standards for Disability Services in Residential Settings**

- **Priority Issue 5: Income**

A further relaxation of the means test for Carer's Allowance with a view to its abolition by 2010. The introduction of a Cost of Disability Allowance and a Review of the Disability Allowance with a view to creating more work opportunities for people with disabilities.

**The cost of a non means tested Carers Allowance for all carers will be €150m per annum and a €40 per week Cost of Disability Allowance will be €160m per annum**

# Submission to the Department of Health & Children

## 1. Review of Funding Arrangements & the Promotion of Innovation

- **Inclusion Ireland** calls on the Department of Health and Children to undertake a review of current funding arrangements for services for people with an intellectual disability and to promote innovative measures for providing residential support and respite services to people with an intellectual disability. The system of separate and distinct funding streams for residential, day and respite services is costly, inflexible and does little to encourage people to lead full and independent lives.
- **Inclusion Ireland** calls for the introduction of care packages consisting of a mixture of grants, contracted services, therapeutic inputs, equipment and other such community services. There will be an independent assessment of need aimed at facilitating the person to either remain in their own home with their family, or to live in the community. A statutory right to an independent assessment of need is available since June for children from 0-5 years under the Disability Act and will be introduced for children aged up to 18 years by 2010 and for adults in 2011.
- Home care packages have been introduced successfully for older people. €30m was set aside in 2007 for an additional 2000 home care packages for the older person and €25m has been set aside for 2008. There is no reason why this model cannot be transferred to people with disabilities. The introduction of care packages will be cost effective and help reduce waiting lists. People are often put on waiting lists due to the absence of community based services. **Inclusion Ireland** is aware of cases where people have been offered full time residential places (average of €70,000 per annum) because there was no funding stream for supports to facilitate them to live independently in their own community.

## 2. Waiting Lists for Services

- The multi-annual programme of investment in new service development of **€900m over the period 2005-2009 was announced as part of the National Disability Strategy in 2005**. The progress report of the National Disability Strategy Stakeholders Monitoring group of July 2007 states that an extra €100m was provided in both 2006 and 2007 for all disability services and capital funding of €55m in both years. Budget 2007 allocated **€41m** for new services in intellectual disability and autism to provide **255 new residential places, 85 new respite place and 535 new day places**.

Information on these targets is not yet available from the Department of Health and Children or the HSE. **Inclusion Ireland** calls for this information to be published. At a minimum there must be information on the number of people who have received a new

service each year by type of service and whether they have been taken off waiting lists. Clear mechanisms must be put in place to monitor the numbers receiving new services and those who have received an upgraded service. For example - moved from a five day residential service to a seven day service, etc. Unless such figures are published routinely there is no way of monitoring progress on targets reached under the investment programme.

**Towards 2016** states that central to the implementation of the National Disability Strategy will be a process of financial accountability and that clear guidelines will be developed to ensure that the investment in the Strategy delivers value for money and real tangible benefits to people with disabilities.

**A sum of €75m revenue (which includes €10m for care packages and €2m for innovative respite services) to be allocated in 2008 along with €55m capital under the continuing investment programme**

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

- **Inclusion Ireland** welcomes the progress that has been made in reducing the number of people with an intellectual disability resident in psychiatric hospitals. The figure is now at 348. This however, does not include people in former psychiatric hospitals (de-designated units) or others in substandard services in need of upgrading. The highest numbers in any one psychiatric hospital are accommodated in St Joseph's Services at St Ita's Hospital, Portrane. The Annual Report of the Mental Health Commission 2006 states "*There are 185 patients with intellectual disability remaining in St Ita's Hospital, some in conditions that are not acceptable*". The report calls for their transfer to appropriate services to enable them to get the skilled and specialised support not generally available in psychiatric hospitals. The practice of relocating people to private nursing homes is not acceptable.

- A high level steering group has been established by the HSE to address the issues of Congregated Settings. **Inclusion Ireland** is a member of this group. The report of this group must be completed by the end of 2008.

**The programme of relocating service users to improved and alternative care facilities must be continued throughout the country. A sum of €15m revenue and equivalent capital sum should be ring fenced in 2008 for this project. Budget 2008 must contain the resources to complete this task**

### **4. Mental Health Services**

- "*A Vision for Change*", the Report of the Expert Group on Mental Health Policy (2006) recommends a programme of capital and non capital investment in mental health services. It also makes specific recommendations on the mental health needs

of people with an intellectual disability. To date little has occurred to implement these recommendations. There is an almost complete absence of in-patient facilities available for people with an intellectual disability with a mental disorder who require in-patient treatment and there are no multi-disciplinary mental health teams. The Mental Health Inspectorate in its annual report for 2006 concludes “..that there is no will to provide an adequate mental health service to this group of people”

**Inclusion Ireland calls for the planned implementation of the Report ‘A Vision for Change’ by the end of 2010**

## **5. 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 last June will put significant demand on existing supports such as speech and language therapist and psychologists. The Government must continue to support the expansion of these services if it is to meet its obligation under the Disability Act 2005 and the Education for Persons with Special Educational Needs Act 2004. A HSE National Steering Group has been established for the implementation of the Disability Act and **Inclusion Ireland** is a member of this Group.

## **6. Standards for Services**

- The establishment on a statutory basis of the Social Services Inspectorate (SSI) through the legislation (Health Act 2006) as part of the Health Information and Quality Authority (**HIQA**) and the recent appointment of a Chief Social Services Inspector is welcomed by **Inclusion Ireland**. The development and implementation of standards for residential services must be a priority for **HIQA**. A national standards group has been set up by HIQA and Inclusion Ireland has been invited to nominate a representative to the group. A significant amount of work has been completed by the National Disability Authority and the Department of Health & Children on draft standards which can be built upon and used by the standards group. The delay in the time frame for implementing standards for older people in nursing homes is worrying and should not delay the development of Disability Standards. The current absence of standards makes it impossible to judge the quality of services. Conclusions from the Report of the Comptroller and Auditor General (Dec 2005) on the provision of Disability Services by Non-profit Organisations state ‘*Standards of care will focus attention on service outcomes and consistency in quality and performance on a national basis. The most effective approach to standards enforcement is to build them into agreements with non-profit organisations and provide for independent monitoring*’

**Inclusion Ireland calls for the implementation of National Standards in Disability Services for people living in residential settings by the end of 2008. €5m**

**revenue should be ring fenced in 2008 to establish structures for the implementation of the National Standards for Disability Services**

## **7. Sheltered Workshops**

- The recent media publicity on workshops where people with disability work highlights the failure to implement the Code of Practice for Sheltered Occupational Services prepared by a Working Group established under the Programme for Prosperity and Fairness for the Department of Health and Children in July 2003. It is no longer acceptable that people with disabilities should work for less than the minimum wage. The HSE has established a high level working group on which **Inclusion Ireland** is represented.

**The Department of Health & Children must support the HSE led Working Group to enable it to complete its task by September 2008 and then speedily begin to make the necessary policy and practice changes to address the current inadequacies.**

## **8. Long Stay Health Charges**

**Inclusion Ireland** continues to have concerns on 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, and in premises where nursing care is not provided on a 24 hour basis. In July 2006 the HSE published guidelines on how charges should be levied.

- 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 it is only the HSE that has the right to assess people's means in relation to charges and voluntary service providers should not be assessing means on behalf of the State.
- The levying of charges in this manner does not take cognisance of a supported living model but forces service providing organisations to take a charge from service users rather than encouraging independent living
- The legality of charging people with a disability living in HSE funded community group homes where there is *no* nursing care provided has been clarified under the guidelines and voluntary agencies who provide residential services, without nursing care, on behalf of the HSE may solicit a "private contribution" for maintenance from residents. There is no legislation or guidelines to cover this practice and to protect the

income of the person.

- Income from in-patient charges should be taken into account by the DoHC & HSE in the determination of costs bands for residential services to avoid double funding.

## **9 HSE Schemes**

The transfer of all HSE run payments and allowances to the Dept of Social and Family Affairs will ensure more equitable and standardised application criteria and process. This transfer should be completed by the end of 2008.

### **Medical Card**

- Children with an intellectual disability should be entitled to a medical card in their own right regardless of the means of the family. Some children receive a long term illness card but it is on a discretionary basis and is reviewed annually. The income limits for medical cards must be increased. The current weekly income limit excludes all but a small percentage of people and is a cause of great hardship to families with children who incur additional medical expenses because of their disability. A start in this years budget would be to treble the income limit eligibility for parents of children under 18 years of age

### **HSE Travel Allowance**

- This allowance is paid to intellectual disability service providers to assist with the travel cost of people attending their day services. The allowance varies across HSE areas in the amount paid per week from €12 to €15. It has not been increased in some HSE areas for 17 years. This allowance is particularly useful to those in rural areas.

## **Submission to Department of Social & Family Affairs**

### **1. Advocacy**

- The Citizens Information Act 2007 makes provision for the delivery of advocacy services for people with disabilities by the Citizens Information Board. **Inclusion Ireland**, as one of the few services in Ireland providing an independent personal advocacy service to people with an intellectual disability is very aware of the demand for this service and seeks a commitment that **€3m** is set aside in 2008 for personal advocacy services.

### **2. Support to Carers**

- **Inclusion Ireland** calls for the National Strategy for Carers to be delivered by the end of 2008. The present piecemeal system of means tested allowances, benefits and once off grants does not support the totality of carers needs.

#### **Carer's Allowance**

- As in all previous submissions **Inclusion Ireland** repeats its conviction that the criteria effectively rule out payment of a full Carer's Allowance to the majority of family carers in this country, an estimated **150,000** persons. Less than one in six carers qualify for the Allowance. The incremental increases in numbers receiving the Allowance each year and the introduction of a half-rate Carer's Allowance to carers who are getting or are entitled to another social welfare payment have been welcomed by **Inclusion Ireland** but the time for a radical change to this Allowance is now overdue.
- The 2006 report of the **National Intellectual Disability Database** shows that nearly **64% or 16,245** people with an intellectual disability live at home out of a population of **25,518**.
- **7,675** of those living at home have a moderate, severe or profound intellectual disability. This care saves the State considerable money (the average cost of residential support in a community setting is now in the region of €70,000 per annum and can be up to €300,000 and in some cases more for people with complex and high support needs).

**Inclusion Ireland calls for a commitment to be given to introduce a non means tested payment for all full-time Carers Allowance within the next three years.**

- The current means test to be applied to the carers income only pending the introduction of a new payment

- The continued relaxation of the means test so that anyone earning less than **€400 (single) and €800 (couple)** per week will receive the Allowance.
- The rate of the Allowance should be increased to bring the rate to **€250 per week**
- **The additional payment of 50% for those who care for more than one person should be increased to 100%.** There are cases where a carer may be caring for more than two person's full time. Unfortunately, there are few economies of scale in these instances
- Extend the hours carers can work outside the home to 20 hours which will also allow carers to take advantage of FAS Training Schemes

### **Respite Care Grant**

- **The Respite Care Grant** was increased last year to €1,500 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 and is very popular with carers. **Inclusion Ireland** seeks a commitment that this grant will be paid at the rate of **€3,000** per person cared for by 2009.
- **Inclusion Ireland calls** for the introduction of a pilot scheme in conjunction with the **HSE** under the aegis of the Family Support Agency where an enhanced Respite Care Grant could be used by carers in the direct purchase of respite services to allow for flexibility, choice and a family centred approach to provision.
- The amount of hours full-time carers, who are eligible for this grant can work should be extended to **20 hours per week** as with Carer's Allowance

### **Carer's Benefit**

- **The Carer's Benefit** has been welcomed by **Inclusion Ireland** but the **rate should be increased by at least 20% 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 would have an unbroken contribution record for a number of years.
- **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 relatively low take up of this benefit implies this is not an attractive option and the Department should investigate the reasons for this. **As with the Carers Allowance additional payment of 50% for a second person cared for to be increased to 100%**

- **A cost of care payment regardless of income of €100 per week towards the additional cost of caring for a person at home.** The payment would be based on the care needs and caring commitment of the carer based on a comprehensive needs assessment for family carers.

### **Domiciliary Care Allowance**

- **Inclusion Ireland** welcomes the work being undertaken by the Department on the transfer of Domiciliary Care Allowance and other allowances from the Department of Health & Children to the Department of Social and Family Affairs and looks forward to its completion. In the meantime the level of this payment must be increased to a **realistic level of at least €350 based on the support needs of the child.**

### **Young Carers**

- **Inclusion Ireland** supports the proposals by both the Carers Association and the Disability Federation of Ireland on young carers and urges the undertaking of research as promised in “Towards 2016” to study the extent and impact on children of this practice

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

### **Disability Allowance**

- **Inclusion Ireland** welcomes the extension of the **DA** to all people resident in institutions. This ended one of the great injustices in the social welfare system.
- An increase in the level of payment of **Disability Allowance by €20 to bring the minimum weekly payment to €205.80** to all people with a disability. The Living Alone Allowance to **DA** recipients to be increased to at least **€20 per week.**

### **DA and Employment**

- **Inclusion Ireland** welcomes the commitment in 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 numbers in receipt of **DA** has more than doubled over the past ten years and while welcoming the fact that those entitled to **DA** receive it, **Inclusion Ireland** calls on the Department to analyse these figures with a view to encouraging more people with disabilities to enter the work force.
- **Inclusion Ireland** welcomes the initiative undertaken by the Department in relation to young people on **DA** in the Midlands 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 arrangements put in place which allow people to keep a proportion of their **DA** (on a sliding scale) if they earn over €120 per week in rehabilitative work in the open market is a positive step.
- The interdepartmental group on the Cost of Disability should publish a report no later than June 2008 with a view to introducing a **Cost of Disability Allowance by 2009**

### **DA and Trust Funds**

- 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 child with a disability. Families are concerned that the income derived from these may lead to a reduction or loss of **DA** and other benefits associated with the **DA**, particularly the medical card and travel pass. This has been raised by **Inclusion Ireland** 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 last year in the capital disregard for **DA** to €50,000 has assisted this issue

### **Disability and Spouses or Partners**

- **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**

### **DA and Travel Pass**

- 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 carer's in rural areas.

### **DA & Charges levied on people with disabilities in long stay services**

The introduction of regulations under new legislation, which allows the HSE to impose charges on people in long stay residential services, came into effect in July 2005. Over 30% of people with an intellectual disability live in residential facilities of some kind (residential centres, community group homes etc). For the majority of these individuals their only income is their DA. Where there is nursing staff in a residential service, people can now be legally charged up to either €120 or €90 per week, depending on whether they receive full or part-time nursing care.

- **It is the view of Inclusion Ireland that these charges are excessive and leave little money for people to live with dignity in their communities. An increase in the DA will help offset some of the impact of these charges.**

- The legality of charging people with a disability living in HSE funded community group homes where there is no nursing care provided has now been clarified and voluntary agencies who provide residential services, without nursing care, on behalf of the HSE may solicit a “private contribution” for maintenance from residents, the majority of whose only source of income is the **DA**. There is no legislation or guidelines to cover this practice, to protect the income of the person and guard against financial abuse.

## **DA and 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. There is no system of monitoring or supervision of how agents deal with this money. If the person is not living in a residential service, the money clearly must be used for basic requirements such as food, clothing and shelter. If the person is in a residential service, the basics are provided and if there are long stay charges levied then the remainder is for personal use and must be used for the person’s benefit. At present it is not always clear how this money is being used. **Guidelines must be prepared for all agents, both services providers and families.** These guidelines must state that the money be clearly earmarked as the individual’s property only to be used for the benefit of the individual.

- Families should inform service providers if they act as an agent for their family member when the person moves into a residential setting. Some services request that the “agency” is transferred to them. This should be a private matter between the family and the service provider. If the family do not wish to relinquish the agency other arrangements should be put in place to allow for the payment of charges or the agreed contribution.

- Equally if Service Providers are acting as agent for receipt of a person’s DA, they should where appropriate inform family members and / or an advocate.

Guidelines should include a requirement to be transparent and open about how service users' income is being used.

- Services who are agents for persons in part-time care who receive a full **DA** should make a pro rata payment to ensure that the person has an adequate income when they return home at weekends and for holidays.
- **Inclusion Ireland** is aware of individuals who may be able to manage their own money but still have their income managed by an agent due to an arrangement from the time of application for the payment. The system of **appointing an agent at time of application for DA needs to be further developed to include confirmation that an individual is not able to manage his or her own income.**
- Some service providers who were automatically appointed an agent for service users in institutional settings who became entitled to DA from January 2007 have not yet informed service users or their families of this income. **There should be an obligation on service providers who are appointed as agents to disclose all information about the income to the individual and / or his or her family or advocate (where appropriate) as well as other authorities such as HSE.** Consultation should take place with the service users, their families/advocates (where appropriate) on the use of the income.
- **Inclusion Ireland recommends a review of the agency system currently in operation.** An important first step would be the consideration of a joint agency between service providers & family members or others where the person is deemed to lack capacity.
- 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 agreement would be subject to the scrutiny of the Public Guardian system which it proposed for all substitute decision makers. **Inclusion Ireland** supports this recommendation
- **Inclusion Ireland recommends an independent body be established to be responsible for monitoring the use of service user's income**

### **Different categories of DA**

- Given that the majority of people with a disability now receive the **DA**, 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.

#### **4. Family Support Agency**

- **Inclusion Ireland** recommends that a specific budget line be assigned to the **Family Support Agency** for a pilot project to support families headed by people with disabilities. One such project could focus on a small but growing group of women with an intellectual disability who become mothers and the specific supports they require to parent successfully. Most of these women come to the attention of the HSE when a crisis occurs and the usual outcome is that their child / children are taken into care. A project undertaken in conjunction with voluntary agencies, the HSE and other relevant groups such as **Inclusion Ireland** which could evaluate the specific interventions that need to be undertaken. This project would have enormous long term benefits of reducing the number of women with an intellectual disability requiring crisis intervention when they become mothers.

**A sum of €250,000 should be set aside for this pilot project in 2008**

## **Submission to the Department of Education & Science**

### **1. Education for Persons with Special Educational Needs Act 2004**

The NCSE presented its Implementation Report to the Department of Education and Science on 1<sup>st</sup> October 2007 now over a year ago. The Report is a detailed blue print for the Dept to implement this crucial piece of legislation so that children with Special Educational Needs can benefit from equal opportunities in our education system.

- **Inclusion Ireland calls on the Minister for Education & Science to initiate the implementation of the Act without further delay and to put in motion the Plan as outlined by the NCSE including the necessary resources as identified in the Report.**
- Many of the Implementation dates have already past and there is no excuse for further delay. By 2008 nearly four years will have passed since the Act was published. The Implementation Plan is now already one year behind schedule due to the Department's delay. The changing structures within SEN provision is causing frustration amongst children, parents, schools, teachers etc working within in

### **2. Assessment of Need**

- The HSE has commenced the Assessment of Need process legislated for in Part 2 of the Disability Act 2005 from June 2007. It is imperative that the assessment process is directly linked to the implementation of the EPSSEN Act 2004 and must not exclude children outside this age group who may urgently require an assessment to access a school place. Children with SEN may regress significantly if intervention is not made from an early stage

**The funding required in ensuring assessments are carried out appropriately and timely must be ring fenced within the Budget for Education in 2008 in line with the resource requirements identified by NCSE. This must include funding to carry out assessments of need on students who may not be in the 0 - 5 category but who urgently require an appropriate educational service.**

- The assessment process both for health & educational needs must be standardised across the country with personnel carrying out assessments being adequately trained and qualified to carry them out. Those doing assessments must be seen to be independent of the resources or services available.

#### **Resources to meet Needs identified in Assessments**

- Funding as outlined in the EPSSEN Implementation Report for 2008 to be ring fenced to meet the educational needs identified from assessments, including resources to implement the IEP process, for additional learning support teachers, resource teachers etc, special needs assistants, counselling and welfare services,

equipment, facilities and educational materials.

### **3. Resources to Follow the Student**

- The implementation of a structured transition programme where the special needs entitlements of students transfer when they progress from primary to second level school. Resources provided should follow the student and not the school.

### **4. Training**

- Further 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 DES 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**

### **5. 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 DES and DH&C and HSE to develop a policy and funding stream to address this gap.

## **Submission to Dept of Enterprise, Trade & Employment**

### **Comprehensive Employment Strategy for People with Disabilities**

**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. **The Strategy should be ready for implementation by the end of 2008 with the Dept committed to providing the necessary policy changes and resources.**

- The Strategy must provide solutions that will create opportunities for people with an intellectual disability to access flexible and responsive supports to enable them to gain, retain and progress in employment.
- The Review of the Wage Subsidy Scheme should be published by the end of January 2008. 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 (443) are on the scheme.
- FAS has been providing mainstream training and employment services to those with a disability since the year 2000. In line with the Employment Strategy, appropriate funding must be available to FAS 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 Indecon study on the efficiency and effectiveness of vocational and rehabilitative training services for people with disabilities provided by specialist training providers has identified some crucial barriers that may be preventing people from moving from training to employment. These recommendations should be implemented without delay and incorporated into the Employment Strategy.
- There needs to be more joint working initiatives between DETE and DofHC / HSE 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.

# **Submission to Dept of the Environment, Heritage & Local Government**

## **1. National Housing Strategy for people with Disabilities**

**Inclusion Ireland** welcomes the work now begun on the National Housing Strategy for People with disabilities and looks forward to contributing to it. 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 National Housing Strategy for People with Disabilities must be developed by end 2008. It should include Protocols to 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.**
- The National Housing Strategy for People with Disabilities must include the review of information recorded on the National Intellectual Disability Database on requirements for residential services and the review of Local Authority housing waiting lists. These waiting lists along with the information that will be gathered from assessments under the statutory Assessment of Need process should give an overall picture of the need for housing and living supports amongst the population of people
- **Inclusion Ireland** welcomes the developments of a Protocol for collaboration between the HSE and Local Authorities under the statutory Assessment of Need process. These structures must be operational when the assessment of need is rolled out for those over 5 and in particular for adults. Structures need to include how the HSE will collaborate with social housing associations to provide supported living services to people with an intellectual disability.

## **2. Disabled Persons Housing Grant**

**Inclusion Ireland** welcomes the publication of the review of the DPHG.

- In line with commitments in the Programme for Government the new proposals for the DPHG must be implemented without delay to improve equity and ensure the Grant will enable more disabled people to live independently in their own homes, in their own communities and not in residential services that prove more costly to the

State. The revised Housing Adaptation Grant schemes were due to come into effect in 2007.

### **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 & private buildings and spaces.
- The building regulations must be strictly enforced to ensure appropriate accessibility within new buildings, as well as buildings which undergo major refurbishment.
- Local Authorities must be appropriately funded and made aware of the necessity to make footpaths, parks, information and services accessible to all people with disabilities

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

The Programme for Govt includes a commitment to review the eligibility criteria for the disabled driver and disabled passenger scheme and other adaptation schemes.

- **Inclusion Ireland** calls for a relaxation of the stringent medical criteria laid down in the regulations governing this scheme. Under these regulations severely and permanently disabled persons are entitled as drivers or passengers to repayment of Vehicle Registration Tax and Value Added Tax paid on specially constructed or adapted vehicles. To qualify, a person's disability must conform to the medical criteria, which govern "severely and permanently disabled" as defined in the regulations. This definition is extremely narrow and relates to 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 high cost of buying a car suitable for these children prevent many families from undertaking such a purchase and confine the child to his or her home. The means tested mobility allowance available from Health Boards does not provide a reasonable alternative.
- 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 10 recommendations that 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 as it has with 4 of the other 9 recommendations. This should be lifted

without delay.

## **2. 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, by two voluntary organisations that act as gatekeepers need to be considered in the Review.

## **Submission to Office of Revenue Commissioners**

### **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)

## Inclusion Ireland Member Organisations

- ABILITY WEST FORMERLY GALWAY ASSOC
- ST AIDAN'S DAY CARE CENTRE
- AISLING CENTRE P & F
- ANNE SULLIVAN CENTRE
- ST ANNE'S SEAN ROSS ABBEY
- ARAS ATTRACTA
- ARD - NA - SEARHA PARENTS GROUP
- ARD AOIBHINN CENTRE
- ARRA VIEW SERVICES LTD
- AUTINET COMMUNITY GROUP
- BALLINASLOE ADVOCATES
- BASC ENTERPRISES, BANDON
- BRÉIFNE SOCIAL HOUSING
- BROTHERS OF CHARITY - CLARE
- BROTHERS OF CHARITY - CLARINBRIDGE
- BROTHERS OF CHARITY - GALWAY REGION
- BROTHERS OF CHARITY – LIMERICK
- BROTHERS OF CHARITY - ROSCOMMON
- BROTHERS OF CHARITY - SOUTH EASTERN
- BROTHERS OF CHARITY - SOUTHERN
- CAMPHILL COMMUNITY BALLYBAY
- CAMPHILL COMMUNITY CARRICK-ON-SUIR
- CAMPHILL COMMUNITY DUNSHANE
- CAMPHILL COMMUNITY GRANGEMOCKLER
- CAMPHILL COMMUNITY GREENACRES
- CAMPHILL COMMUNITY KILCULLEN
- CAMPHILL DUFFCARRIG
- CAREWATCH
- CARING & SHARING ASSOC (CASA)
- CARRICKMACROSS ASSOC OF P&F
- CARRIGLEA CAIRDE SERVICES
- CASTLEBAR COMMUNITY DROP IN
- CASTLEBLANEY CARE ASSOCIATION
- ST CATHERINE'S ASSOCIATION LTD
- CENTRAL REMEDIAL CLINIC
- CENTRE FOR DISABILITY STUDIES, UCD
- CHEEVERSTOWN FAMILIES & FRIENDS
- CHEEVERSTOWN HOUSE
- CHILDREN'S SUNSHINE HOME
- CLANN MOR RESIDENTIAL AND RESPITE LTD
- CLARE FEDERATION
- CLOGHER HOUSE FRIENDS
- CLONES BRANCH
- CO ACTION WEST CORK
- COISTE CUCHULINN
- COMMUNICATIONS WORKERS' UNION
- COPE FOUNDATION
- CORK ASSOC OF P&F
- CORK CEBAS PARENTS ASSOC
- CRONAN'S ASSOCIATION LTD
- DARA RESIDENTIAL SERVICES
- DAUGHTERS OF CHARITY SERVICES
- 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, TIPPERARY
- DRUMLIN HOUSE
- DUNDALK P&F
- DUNMORE HOUSE - CARMONA SERVICES
- DUNMORE HOUSE P&F ASSOCIATION
- EARLY LANGUAGE INTERVENTION
- EAST CORK P&F
- EMBRACE
- ENNISCORTHY DISTRICT, ASSOC OF P&F
- FAMILY & FRIENDS OF GHEEL
- FAMILY NETWORK STEWARTS 2000
- FESTINALENTE FOUNDATION
- FINGAL ASSOCIATION
- FUNDRUMS
- GRÁ AUTISM PARENTS GROUP
- HELPING HANDS, TALLAGHT
- ST HILDA'S, ATHLONE
- HILLTOP SERVICES
- HOLY ANGELS, GLENMAROON
- HOLY FAMILY SCHOOL, COOTEHILL
- HOSPITALLER ORDER OF ST JOHN OF GOD
- INISHOWEN LEARNING DISABILITY NETWORK
- IRISH COUNTRYWOMEN'S ASSOCIATION
- IRISH FRAGILE X SOCIETY
- IRISH NATIONAL TEACHERS ORGANISATION
- IRISH NURSES ORGANISATION
- IRISH TRADE UNION TRUST
- ST JOHN OF GOD DAY CENTRE P&F GROUP
- ST JOHN OF GOD HOSPITALLER SERVICE
- ST JOSEPH'S FOUNDATION, CHARLEVILLE
- ST JOSEPH'S HOSPITAL, CLONSILLA P&F
- ST JOSEPH'S ID SERVICE, PORTRANE
- ST JOSEPH'S PARENTS ASSOCIATION
- KARE
- KERRY PARENTS & FRIENDS ASSOCIATION
- KILKENNY ASSOCIATION, KASMHA
- KILKENNY COLLECTIVE FOR ARTS
- LÁMH
- LAOIS FRIENDS
- L'ARCHE IRELAND LTD
- LIMERICK P&F ASSOCIATION
- LITTLE ANGELS ASSOCIATION, DONEGAL
- LONGFORD ASSOCIATION
- LORREQUER HOUSE

- ST MARY'S DRUMCAR
- ST MARY'S DRUMCAR, DUBLIN BRANCH
- ST MARY'S P&F ASSOCIATION, DELVIN
- ST MARY'S SCHOOL DRUMCAR PARENTS
- MENNI DAY SERVICES - ST JOHN OF GOD
- MENNI SERVICES FAMILIES & FRIENDS
- ST MICHAEL'S HOUSE HQ
- MIDWAY, MEATH
- MONAGHAN BRANCH LTD
- MOORE ABBEY, MONASTEREVIN
- MOORE HAVEN CENTRE - TIPPERARY
- MOOREHAVEN CENTRE P & F
- MULLINGAR & DISTRICT P&F ASSOCIATION
- NATIONAL FEDERATION OF ARCH CLUBS
- NIID, TCD
- NORTHWEST P&F ASSOCIATION
- NURSE MANAGERS ASSOCIATION
- NURSE TEACHERS GROUP
- OFFALY ASSOCIATION
- ONEZONE SUPPORT GROUP
- ORDER OF MALTA REGIONAL SERVICES
- OUR LADY OF GOOD COUNSEL SCH - P&F
- PARENTING WITH A DIFFERENCE
- PARENTS FOR INTEGRATION
- ST PATRICK'S CENTRE, KILKENNY LTD
- ST PAUL'S SPECIAL SCH PARENTS ASSOC
- 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
- PROSPER FINGAL
- PSYCHOLOGICAL SOCIETY OF IRELAND
- ST RAPHAEL'S P&F ASSOCIATION
- REHABCARE
- RETT SYNDROME ASSOCIATION IRELAND
- ROSCOMMON ASSOCIATION
- S.N.A.P PARENTS AND FRIENDS
- S.O.F.T (SUPPORT ORG FOR TRISOMY)
- SCOIL CHIARAIN
- SHADOWBOX THEATRE COMPANY
- SIPTU
- SISTERS OF CHARITY - ST MARGARET'S
- SISTERS OF LA SAGESSE - CREGG HOUSE
- SOCIAL WORKERS IN LEARNING DISABILITIES
- SOS KILKENNY LTD
- SOUTH TIPPERARY AUTISM SUPPORT GRP
- SPECIAL OLYMPICS IRELAND
- STEWART'S HOSPITAL
- STEWART'S SCHOOL PARENTS ASSOCIATION
- SUNBEAM HOUSE SERVICES
- THURLES P&F ASSOC
- TIPPERARY ASSOCIATION
- WALKINSTOWN ASSOCIATION
- WATERFORD ASSOCIATION
- WESTERN CARE ASSOCIATION
- WEXFORD CO COMM WRKSHP (NEW ROSS)
- WINDMILL THERAPEUTIC TRAINING UNIT LTD
- YOUTH INTERGRATION



## **INCLUSION IRELAND**

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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.

Founded in 1961 **Inclusion Ireland** has nearly 170 affiliated organisations providing services and supports to the 26,000 people with an intellectual disability in Ireland.

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