



**Budget 2009:
Inclusion Ireland
Submission to Government**

October 2008

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.

Forward

The stark decline in the economy and the ever increasing costs of hospital care and of demand led schemes such as medical cards has put extreme pressure on the HSE Budget. The HSE is obligated to remain within its Budget. Disability Services come under the HSE and at the beginning of this year alarm bells were ringing within the HSE. One way of saving money is to delay spending on agreed new services until the last possible minute, keeping the unspent money to offset the inevitable overruns of the budget at the end of the year. It made no difference that the money was earmarked for disability services because within the HSE there is no distinction between acute hospital services and community care. In 2007 €31 million was saved by delaying disability service developments

In 2008 the €50 million earmarked for funding new developments under the multi-annual investment plan 2007-2009 was delayed, and only after a sustained campaign by families was the money released. Parents of school-leavers were told that there would be no place for their child leaving school and no day places for those young people finishing rehabilitative training programmes.

“What is to happen to our sons and daughters as they are unable to lead independent lives? Are they to be sent home and forgotten about? If this is allowed to happen they will not only suffer the trauma of being excluded from the network of support they have known for three years, they will also lose contact with their friends - they will be isolated. As parents we are also traumatised because this is a prospect too awful to consider.”

(Parent of a 21 year old person with an intellectual disability)

Through delaying this development programme the HSE saved €17 million of the promised €50 million, having already saved €31million in 2007. This type of carry on naturally leads families of people with disabilities to question what will happen next year? Will they be faced with the same scenario? The Minister for Health has stated that cuts to the value of €144 million are being sought from the HSE this year despite the fact that the HSE is running nearly €300 million over Budget.

The HSE says that all new developments for 2008 will be delivered but there are growing concerns about the lack of an arrangement or plan to fund any new developments after 2009 when the multi-annual investment programme is seen to be completed. In these deeply challenging economic times it is hard to see anything replacing this investment programme. Indeed, it will be difficult to continue to provide the same level of current services with rising inflation and all other costs increasing and at the same time cuts to services being sought

Significant investment has gone into disability services in the last five years with the Government's Disability Strategy. Inclusion Ireland calls upon the Government in this Budget to confirm their commitment to their own strategy by not cutting funding of this most vulnerable of group in Irish society.

Inclusion Ireland Priority Areas for 2009

The full inclusion of people with disabilities in Irish life must continue to be a priority for Government in 2009. The ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2009 would be an important indication of the Government's commitment to people with disabilities and their families in Ireland.

- **Priority Issue 1: No Cuts in Services**

No further cuts by stealth in intellectual disability services in 2009 and the continuation of the multi-annual investment programme in 2009 which is an allocation of €50 million towards new services as described in priority issues 2 and 3.

- **Priority Issue 2: Ending Waiting Lists for Services**

This year, 2,157 people require a residential support service and 2,049 require a respite service (Annual Report of the National Intellectual Disability Database 2007). These figures have increased each year for the last five years. An increase in respite services for children and adults is urgently required. The recent report by the Health Research Board "*Trends in demand for services among children aged 0-5 with an intellectual disability 2003-2005*" shows that the need for respite and home support for this group is extremely high with 84 new residential support places required. Funds must also be assigned to those who are already in a service, but whose needs have significantly changed due to age or those who are living in substandard overcrowded services.

- **Priority Issue 3: Increased Therapeutic Services for both children and adults**

There is a substantial demand for new services relating to therapeutic inputs, in particular speech and language therapy, occupational therapy and psychology. In some areas children under five can be waiting for up to 20 months. Children over five and adults who are not covered under the Disability Act 2005 must wait even longer for such services.

- **Priority Issue 4: Transfer Programme to the Community**

There is an urgent need to complete the programme to transfer people with an intellectual disability who are inappropriately placed in psychiatric hospitals and who are living in outdated congregated settings. This programme must be completed by 2016.

- **Priority Issue 5: Supporting 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 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. In times of economic cutbacks, new ways of providing and funding services must be embraced.

- **Priority Issue 6: Income**

A further relaxation of the means test for Carer's Allowance with a view to its abolition by 2010.

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 2007 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. 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. Close to home in Northern Ireland and the UK there are examples of individualised funding initiatives which enable people with disabilities and their family members to be in control of the ways their services are provided and to help them achieve the right support when they need it.

2. Waiting Lists for Services

- The multi-annual programme of investment in new service development of €900 million over the period 2005-2009 forms part of the National Disability Strategy 2005. Unfortunately both in 2007 and 2008 money has been taken from this programme, through enforced savings, to offset overruns in the HSE budget. Budget 2008 allocated €41million for new services in intellectual disability and autism to provide 255 new residential, 85 new respite and 535 new day places. Information on these targets is not forthcoming from the Department of Health 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, if someone 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. Inclusion Ireland calls for the publication of the Audit carried out and completed in 2008 on the National Intellectual Disability Database to ensure accuracy of data reported on waiting lists for services and numbers coming on or moving off such lists.
- ‘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.

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. 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. The total number of people living in HSE run institutions in 2008 was 772. This does not take account of the number of people in non-statutory services, living in old residential settings run by voluntary organisations.
- 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 not be slowed down due to economic circumstances. Budget 2009 must contain the resources to ensure this task is completed by 2016.

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. 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 last June has 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. At the current rate of development it is unlikely that the Independent Assessment of need will be rolled out for school going children by 2010.

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 appointment last year of a Chief Social Services Inspector was welcomed by Inclusion Ireland. Draft national standards for residential services have now been developed and a public consultation process initiated. Inclusion Ireland was part of the group which developed these draft standards. There must be no delay in the time frame to implement these standards in early 2009. 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 states “*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*”.

7. Sheltered Workshops and Adult Day Services

- The HSE has established a high level working group to review HSE funded Adult Day Services. This Group will be reporting shortly. Inclusion Ireland is represented on this group and calls upon Government to ensure the financial support to enable the modernisation of existing day services, to reflect the principle of Access, Quality, Accountability and Person Centeredness and to end once and for all the practise of people working in real work situations for less than the minimum wage.

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 only the HSE has the right to assess people's means, and voluntary service providers should not be assessing means on behalf of the State. The levying of charges in this manner forces service providing organisations to take a charge from service users rather than encouraging independent living

9. HSE Schemes

- The transfer of all HSE run payments and allowances to the Dept of Social and Family Affairs must be completed by the end of 2009.
- 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 income limit excludes all but a small percentage of people and is a cause of great hardship to families. A start in this year's budget would be to treble the income limit eligibility for parents of children under 18
- 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 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 is extremely disappointed by the decision of the Minister last July, to delay the introduction of Personal Advocates provided for in the Act. Inclusion Ireland seeks a commitment that the service will be introduced in 2009. The provision of personal advocacy services, by supporting the community and voluntary sector to provide advocacy services to people with disabilities through pilot programmes is welcome. However, it is not a substitute for a personal advocate with statutory powers to enter any place where day care, residential care or training is provided for a person with a disability, and to make sure inquiries in such place in relation to the person as he or she considers appropriate, or to seek information from a statutory or voluntary body, or to represent the person at meeting. The Act also makes it an offence to obstruct an advocate in the performance of his or her functions. This Act was welcomed unanimously by people with disabilities and their families/carers. The question must be asked why, (for a saving of the minuscule sum of €500,000, as stated by the Minister in a Dáil debate 9th July 2008) was this decision made? It is a retrograde step and is at odds with the Department's own policy of ensuring that people with disabilities receive their full entitlements.

2. Support to Carers

- Inclusion Ireland welcomes the work undertaken to date in formulating a National Strategy for Carers to be delivered by the end of 2008.

Carer's Allowance

- As in all previous submissions, Inclusion Ireland repeats its conviction that the current criteria effectively rules out payment of a full Carer's Allowance to the majority of family carers in this country. 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 has been welcomed by Inclusion Ireland, but the time for a radical change to this Allowance is long overdue.
- The 2007 report of the National Intellectual Disability Database shows that nearly 64% or 16,366 people with an intellectual disability live at home out of a population of 25,613. This is an increase of 105 people since the previous report.
- 7,733 of those living at home have a moderate, severe or profound intellectual disability a small increase (56) since the previous year. Of this group, over 23% were aged 35 or more. This care saves the State considerable money (the average cost of residential support in a community setting is 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). The implementation of an Independent Assessment of Need (Health and Education), under the Disability Act 2005 for children aged 0-5 years should include an assessment of the needs of the family carer to include their income needs, and the immediate access to the available allowances and benefits. The Department of Social and Family Affairs should liaise with the 32 HSE Assessment Officers in this regard.

- Inclusion Ireland calls for a commitment to be given to introduce a payment for all full-time Carers linking the levels to labour market equivalents as outlined by the Carer's Association and other carers groups.
- The current means test to be applied to the carer's 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 €338 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 people full time.
- 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.
- Abolish the Habitual Residency clause for people returning to Ireland to provide family care.
- Provide all fulltime carers with medical cards.

Respite Care Grant

- The Respite Care Grant was increased last year to €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 and is very popular with carers. Inclusion Ireland seeks a commitment that this grant will be paid at the rate of €3,000 by 2009.
- Last year Inclusion Ireland called 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 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.

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 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%.

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 and looks forward to its completion. In the meantime, the level of this payment must be increased to a realistic level of at least €400 (monthly) based on the support needs of the child. This should be linked to the Independent Assessment of Need under the Disability Act.

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 Disability Allowance (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 should be introduced, to bring the minimum weekly payment to €217.80 to all people with a disability. The Living Alone Allowance to DA recipients should 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. This in turn must be related to an independent assessment of the person's needs.
- 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 is still to publish its report

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 carers 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 should be prepared for all agents, both service providers and families. These guidelines must state that the money be clearly earmarked as the individual’s property, only to be used for their benefit.
- 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. 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, as well as to the 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 the 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

The National Council for Special Education (NCSE) set up by the Education for Special Educational Needs Act 2004 was charged with drawing up a plan for its implementation. 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 real response from the Department. There are real fears that the roll out of the Act will be halted because of financial constraints. This must not be the scenario.

1. 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 EPSEN 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 2009 in line with the resource requirements identified by NCSE.
- It is estimated that there is a potential need for 17,600, new individual education plans per year. Placing huge demand on teachers and schools to meet the requirements of the Act.
- The assessment process both for health and 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.

2. Resources to meet Needs identified in Assessments

- Funding as outlined in the EPSEN Implementation Report for 2009 must 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

1. 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 in 2009 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 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 (443) are on the scheme.
- FÁS 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 FÁS 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 D of HC/HSE, and the Department of Social and Family Affairs 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 no later than 2009. 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

- 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 but are on the back burner. 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.
- 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 Government 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 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 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

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).

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
- FESTINA LENTE 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



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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