



INCLUSION IRELAND

## **Submission from Inclusion Ireland on the *Report of Disability Policy Review***

### **1. Introduction**

**1.1** Inclusion Ireland is the largest national organisation representing and promoting the interest of people with an intellectual disability, their families and service providers in Ireland -160 affiliated organisations representing 25,000 people with an intellectual disability. This year Inclusion Ireland is celebrating 50 years of pioneering work, 1961-2011. The founders rejected the practice of institutionalising people with intellectual disabilities and instead set out to create the supports, services and the legislation necessary to make sure people could live in their own communities, and have their rights respected and upheld, including the right to make decisions.

**1.2** Inclusion Ireland welcomes the opportunity to comment on the Department of Health's document entitled *Report of Disability Policy Review*. This policy review provides a radical and new vision of how Government can provide services and supports for children and adults with disabilities and their families over the coming decades. Despite extensive financial resources into disability services in the last decade, and a National Disability Strategy, people with a disability have found themselves bearing harsh cuts in services and paying for their own care in services over which they have little control. Dr. Pauline Conroy put it succinctly that:

*Going to the theatre, enrolling your child in a secondary school, entering a polling station – such are major battlegrounds of rights and resources. The right to live independently with people of your choosing or none, in a place of your choosing with the essential adjustments for everyday living – these are modest enough proposals in a modern democracy (TASC Think piece, *Disability Difference and Democracy: Some Rights and Wrongs*, May 2010).*

**1.3** The CEO of Inclusion Ireland Deirdre Carroll was a member, in a personal capacity, of the Expert Reference Group established to review current policy in relation to disability services.

## **2. Current Disability Service provision**

**2.1** Inclusion Ireland has highlighted for many years the inadequacies of the current system of disability provision in Ireland. Prior to the economic down turn there appeared to be little interest or appetite for change. The report shows that specialist disability services in 2010 cost €1.47 billion after cuts in 2009, but this remains a significant 10.5% of the total health budget. The majority of disability services are delivered through the non statutory/voluntary services and figures are given (par. 2.2). Further information is given on staff numbers and categories, painting a picture of a highly professional, expensive medical system, where the individual has little say in how money is spent or has a choice of service provider.

**2.2** The Comptroller and Auditor General Report of 2005 into *Provision of Disability Services by Non Profit organisations*, was the first time that the deficiencies of this system were officially brought to the attention of government and put out in the public domain. It is worth noting that four years after this ground breaking report, the C&AG noted in 2009 that “*there has been no substantial change in the HSE approach to funding non profit organisations since these matter were examined in 2005*”, and that it “*would be desirable to move towards a situation where funding is informed by standard costing*”. This leads to questions about the respective responsibilities of the Department of Health, which is responsible for policy, and the HSE which is responsible for the purchasing of services from the not for profit sector, and the need to ensure that policy is implemented.

**2.3** The delivery of disability services (2.3) does not mention the for profit service/private providers, who have come into the disability domain in the last ten years. This number has been growing steadily. A number of these services have specialised in specific areas such as the care of children and adults with autism, and with behaviour or mental health difficulties. It is not clear if these services counted in the financial figures used in the report. Are they included as part of the non for profit service provider figures, or as part of the HSE funded services? Inclusion Ireland estimates that this sector is funded by the HSE to the tune of €20 million or more. The HSE will seek a service on behalf of a number of people with disabilities who they may have had difficulties in placing in non for profit services. This is a distorted version of the private market where the consumer pays directly for the service based on choice and market value.

## **3. Policy Overview**

**3.1** The Commission on the Status of People with Disabilities 1996 Report, *A Strategy for Equality*, was a landmark event and marked the arrival of a disability social

movement in Ireland. During the late nineties, up to 2004, there was also a flurry of legislation which provided for several new state institutions and new legislation to provide for equal treatment in a wide range of fields, including disability. In 2004, the National Disability Strategy was launched. Government policy now focussed on mainstreaming and social inclusion. Unlike other strategies such as the National Children's Strategy, there is no written strategy for the NDS, but it is made up of five elements, which are outlined in the report. The report also outlines the monitoring arrangements put in place for the strategy, but it should be noted that as of early April 2011, these arrangements are now being reviewed by the new Minister for Disability. The report outlines T2016 and other relevant policy legislation and developments in Ireland, as well as the international developments, most importantly, the UN Convention on the Rights of People with Disabilities, which the Irish government has signed, but not ratified.

**3.2** It should be noted that there are other UN Conventions which have had a direct impact on disability policy in the past, such as the UN Convention on Economic and Social Rights. Following a periodic review of the Irish Government by the UN Committee in Geneva in 2002, the Department of Health established a policy initiative in relation to people living in institutions, and adopted a programme to transfer people with an intellectual disability or autism from psychiatric hospitals and other inappropriate settings such as de-designated units and other large HSE residential centres. However, nearly ten years later, the 2011 *Report on Congregated Settings* found that over the period 1999-2008, reported admissions to congregated settings (692), had exceeded the number transferred to the community.

#### **4. The extent to which existing policies are consistent with the delivery of policy objectives in Towards 2016**

**4.1** As the report acknowledges, the issue is not about the inconsistencies between Government policies and those outlined in T2016 objectives 2-5, which pull together all the policy objectives concerning people with disabilities in the last 10 years. The key issue has been the degree to which policy objectives have been implemented.

**Objective 1:** Every person with a disability would, consistent with their needs and abilities have access to appropriate health, education, employment and training, and personal social services.

**Objective 2:** Every person with a disability would have access to public spaces buildings, transport information advocacy and other public services and appropriate housing.

**Objective 3:** Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and society, and to maximise their potential.

**Objective 4:** Carers would be acknowledged and supported in their caring role.

**4.2** The report rightly points out the lack of information on access to health services, but jumps from that to making a claim that it is difficult to judge whether people have adequate access to health and personal social services. All the consultation processes since 1993 have pointed to the great dissatisfaction of people with disabilities regarding access to health and other services.

**4.3** The key failures in implementation include:

- Difficulties with the current Assessment of Need process under the Disability Act in meeting its time frames for children under six, and the delay in extending the process to children aged 6-18 years, and adults over 18;
- Cuts in special needs resources in schools and the number of children transferring back to special schools at post primary level;
- Cuts in respite care, day and residential service provision;
- Growing waiting lists and an ageing population of people with an intellectual disability;
- Continuing failure to introduce independent standards or inspection of either adult or children services;
- Continuing low rate of people with disabilities in employment;
- Lack of training options and day services supports;
- 4,000 people still living in congregated settings
- Delay in producing a National Carers Strategy;

## **5. Sustainability**

**5.1** Inclusion Ireland expressed the view prior to the economic downturn, that the current health based model of providing disability services is no longer sustainable in terms of cost, growing demand, or in providing people with disabilities or their families with the type of supports they need or want.

## **Part B: Proposed Policy Framework**

### **6. The Lifecycle Framework**

**6.1** Inclusion Ireland supports the lifecycle approach, and agrees that if mainstreaming were fully realised, there would be no need for a separate policy for people with disabilities.

### **7. Mainstreaming**

**7.1** Mainstreaming has been discussed in the policy domain since 2002 when the Disability Legislative Consultative Group produced a paper entitled *Equality for All*, which was published in 2003. This document set out principles for the proposed new Disability Act. The Act, when enacted in 2005, had a strong commitment to mainstreaming. However, current mainstream health and personal social services do not meet the needs of people with disabilities. This is clearly witnessed by reports of children with special needs moving back from mainstream primary schools to special second levels schools, lack of access to dental services, mental health services and the high level of segregated services in existence.

### **8 Policy Vision Framework**

**8.1** Inclusion Ireland supports the policy vision and framework and the two overarching goals. Goal 1 outlines the vision of the full inclusion and self-determination for people with disabilities and Goal 2, the creation of a cost effective responsive and accountable system which will support the full inclusion and self determination of people with disabilities. It is Goal 2, which is key to ensuring that the policy vision is enacted, and is not left like so many policy initiatives in the past, on the shelf.

#### **Goal 1 - Full Inclusion and Self Determination**

### **9. Individualised Supports**

**9.1** The concept of individualised supports has been around for nearly two decades and is a model that operates in both the UK and Northern Ireland as well as in the USA and Canada. It is timely therefore that it is looked at within an Irish context. There are various ways of implementing individualised supports such as direct payments to an individual or his/her family, a payment to an independent broker who will administer the payment for a percentage fee and assist the person with accessing services, or at its simplest, the clear attachment of a sum of money for each individual in a transparent manner.

All of these methods are based on an assessment of need, however this assessment of need should not be the highly professionalised multi- disciplinary assessment of need that has occurred with children under 6 under the Disability Act.

## **10 Enablers**

**10.1** The need for enablers to support the vision of inclusion is essential. Some of these enablers as listed in the report, such as accessible environment transport, are self-evident, while others such as advocacy are new but equally important. The new National Advocacy Service has a role to play here – it has been established since the report was completed. However the advocates in this service still have no statutory standing. Advocacy can be provided in a variety of ways, as outlined in the report, and it does not necessarily mean that people will require an independent advocate such as those provided by the NAS or by groups such as Inclusion Ireland.

**10.2** One of the key enablers is the natural supports found in the family and in communities. It is a fact that the more people a person with a disability has in their life the better their quality of life is, and the safer they are.

**10.3** The report highlights the available supports for children with disabilities. Inclusion Ireland fully endorses the view in the report that children with disabilities are first and foremost children. The main health related issues for children relate to access to therapy services, in-home family supports, respite services and access to mainstream, and where appropriate, special schooling. Inclusion Ireland agrees with the views expressed about the rigidity of current respite services and the need for reform. In other jurisdictions it is not the norm for children to be cared for in residential centres. The ongoing failure to introduce the new HIQA standards (2009) for all children in out of home settings is noted in the report, and must be addressed without delay.

## **11 Joint Working Areas to Support Inclusion**

**11.1** Inclusion Ireland supports the general recommendations made in relation to housing supports, employment, health and education.

**11.2** The current position of those living in residential services must also be reviewed. It should be noted that the report does not mention the fact that this group of people are without the protection of independent inspection or standards and how this protection can be extended to the new vision of people living in the community, in housing co-operatives, foster care, shared parenting etc.

**11.3** The section on friendship and relationships makes no reference to the deficiencies in the current law, Criminal Law Sexual Offences Act 1993, and its impact on rights based disability policy and for people living in the community. The Law Reform Commission Consultation Paper on Sexual Offences and Capacity to Consent 2011 should be reviewed in this context and the law changed.

## **Goal 2: High quality, cost effective, responsive and accountable system**

### **12. A new system of supports**

**12.1** In order to put into practise the recommendations to achieve full inclusion and self-determination as set out under Goal 1, there has to be a strong governance framework which has been lacking to date.

**12.2** Inclusion Ireland agrees that the system of individualised supports and mainstream services proposed, requires a different approach to the assessment of need that is driven by the person and/or family (as appropriate). There are a variety of needs assessment tools, but there is a danger that time and effort will be spent on developing a complex professionalised system. Inclusion Ireland favours a model that will incorporate both self assessment by the person or by their family if appropriate, with professional input when required to establish health, therapy needs etc. It should be based on outcomes and reviewed annually with the funding. It should be a standardised tool.

**12.3** The resource allocation process is a complex issue and one which will prove challenging to implement. The current block grant system will have to change and this will take time and legislation. It will also require the support of service providers who are currently providing services. Some smaller providers are already allocating funding to individuals to allow them to choose their own support and develop their own plan, but the funding still goes directly to the provider. While this is very encouraging and will allow for useful learning in the Irish context, it cannot provide the model for going forward. A resource allocation model will need to be devised and new legislation and regulations to existing health care legislation brought in. Some models are already being looked at by the National Disability Authority.

**12.4** The main challenge will be to introduce whichever model is chosen. It is likely that smaller providers will be the first promoters of such models and will use it for their existing services users and for new entrants to services.

**12.5** The determination of rates will be based in certain bands linked to need. This

happens to some extent at present for day and new residential services, but is not linked to individual need but to some notion of dependency e.g. €79,000 for an average residential place as currently used.

**12.6** In the absence of legislation and in order to fast track a new system of individualised supports, Inclusion Ireland proposed that in each HSE region a number of pilot projects are undertaken with providers, individuals and families who opt for such a system. Different models of resource allocation could be tested out in such programmes.

**12.7** Larger service providers could be directed to set aside a percentage of the block grant each year, for example up to 5% first year, 7% next year etc, to provide for individualised supports. This could form part of the Service Level Agreement (SLA), which the HSE enters into with each provider.

**12.8** It must be noted that in a policy move to a new system of individualised supports and greater choice, that not all individuals or their families will want to avail of such individualised support. They may be satisfied with the current provision and wish to remain with their service provider. The minimum the new policy direction must provide for such a group is the knowledge of what sum of funding is attached to the person and what level of support or service is given for that sum. This should lead to greater transparency and efficiency and direction by consumers within existing services. Again, this could be part of the SLA.

**12.9** The concept of tendering for disability services is new to Ireland and links into individualised supports in so far as people will be able to access services knowing what they will get for their money. The growth in the private sector will add more choice to this process. The idea that there is a provider in an area who provides specified services, which meet certain standards and provide a level of service for a particular price for a three to five year period, is generally welcome. Some of these services will be provided for people already in their services, or for new people who choose to use their budget to purchase this service. If the provider loses the contract the next time around, the people in services should not be disrupted

**12.10** A comprehensive commissioning framework will be required and there will be a need to review current legislation. Also any service tendering for Government contracts will have to meet certain standards and be independently regulated. HIQA standards will be an essential component here in relation to the provision of any residential services.

## **13 Concluding remarks**

**13.1** This report, along with the HSE reports on the reform of day services *New Directions*, and on *Congregated Settings*, proposes a radical shift in Government policy regarding the provision of disability services. It is essential that people with disabilities and their families are given adequate information about this new policy direction, as well as how it will translate in action. What people require now is information on what it will mean for them. Such new direction will have its critics, and it is important that all the options are laid out for people.

**13.2** The Report of Disability Policy Review is a long and complex report, and in its current format is not readily accessible to people with disabilities, and the time frame given to respond was short. Inclusion Ireland proposes that two short summary documents be printed - one in plain English, and one in easy to read version. These documents should then be circulated to all people with disabilities and their families.

**13.3** A communications strategy should be devised that would cover a number of public meetings in HSE regions. Inclusion Ireland would be willing to support the Department of Health facilitating such meetings for people with an intellectual disability themselves, and for their family members.

**13.4** Health legislation will need to be reviewed as soon as possible to allow for changes in the current funding structures, and to bring in commissioning and procurement. It will also be essential to introduce new capacity legislation if individual budgets are to be introduced. People will have to have capacity to make decisions about their funding and to enter arrangements with providers.

**13.5** A detailed time frame will have to be laid out for the implementation of this new policy, but it should be no longer than 2021.