

## **National Disability Inclusion Strategy**

### ***A Submission by the Citizens Information Board***

#### **Introduction**

The Citizens Information Board (CIB) welcomes the opportunity to make a Submission on the new National Disability Inclusion Strategy which is being developed by the Department of Justice and Equality in conjunction with the National Disability Authority and the National Disability Strategy Implementation Group. The Board considers that the development of such a strategy and its related implementation is crucially important in order to give new and much needed impetus to social inclusion as it relates to people with different types of disability.

The Submission is divided into two main sections. Section One sets out some contextual factors which are considered centrally relevant in the development of the Strategy. Section Two identifies some priority areas for inclusion in the Strategy.

#### ***Role of the Citizens Information Board***

The principal functions of the Citizens Information Board (CIB) are to support the provision of and, where appropriate, provide directly to the public, independent information, advice and advocacy services in relation to social services. The CIB is also required to assist and support individuals, particularly those with disabilities, in identifying their needs and options and in accessing their entitlements to social services.<sup>1</sup> Other functions of the Board are to support, promote and develop: (i) greater accessibility, co-ordination and public awareness of social services; (ii) the dissemination of integrated information in relation to such services by statutory bodies and voluntary bodies and (iii) the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services.

The CIB funds and supports the nationwide network of Citizens Information Services (CISs) and the Citizens Information Phone Service (CIPS). It also provides and manages the Citizens Information Website ([www.citizensinformation.ie](http://www.citizensinformation.ie)). The National Advocacy Service for People with Disabilities (NAS) is funded and supported by the CIB as is the Sign Language Interpreting Service (SLIS).

The NAS provides an independent, confidential and free, representative advocacy service that works to ensure that when life decisions are made, due consideration is given to the will and preference of people with disabilities and that their rights are

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<sup>1</sup> In this regard, the Citizens Information Act 2007 provided for the introduction by the CIB of a range of advocacy services, including a Personal Advocacy Service aimed at people with a disability. The establishment by the Citizens Information Board of the Personal Advocacy Service was deferred by the Government in 2008 in the light of budgetary circumstances.

safeguarded.<sup>2</sup> The primary target group for NAS is more vulnerable people with disabilities. NAS has a particular remit to support people with disabilities who are isolated from their community, have communication differences, are inappropriately accommodated, live in residential services, attend day services and have limited informal or natural supports.

SLIS is the National Sign Language Interpreting Service for Ireland with the overall goal of ensuring that Deaf people can exercise their rights under equality and disability legislation and access their entitlements to public and social services on an equal basis with others.

## **2. Contextual Considerations**

### **2.1 Social Inclusion and People with Disabilities**

Social inclusion requires the recognition of all people as full members of society and respect for all of their rights. This involves the removal of barriers that might prevent the enjoyment of these rights by some, the creation of appropriate supportive and protective environments and “changing the attitudes and practices of individuals, organisations and associations so that they can fully and equally participate in and contribute to the life of their community and culture” (UNICEF 2007:1).<sup>3</sup>

Four dimensions of social inclusion can be identified<sup>4</sup>:

- Access to public goods and services
- Experiencing valued and expected social roles
- Being recognized as an individual and trusted to perform these social roles
- Belonging to a social network

A 2009 national inclusive research project conducted in Ireland and involving people with an intellectual disability as co-researchers found that people with an intellectual disability wanted to be the same as the rest of society in respect of core domains of living – paid employment, accommodation, communication, money management, partners in relationships – and generally to be respected citizens (National Institute for Intellectual Disability 2009).<sup>5</sup>

### **2.2 Right to Self-determination**

The focus in the UN Convention on the Rights of persons with Disabilities is clearly

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<sup>2</sup> NAS supported over a 1,000 clients in 2014 including people with an intellectual//learning disability (43%); people with physical/sensory disabilities (30%); people with mental health difficulties (21%); and people on the autistic spectrum (6%).

<sup>3</sup> UNICEF (2007), *Promoting the Rights of Children with Disabilities*, Innocenti Digest No. 13, UNICEF

<sup>4</sup> Cobigo, V., Ouellette-Kuntz, H., Lysaght, R. and Martin L. (2012), “Shifting our Conceptualization of Social Inclusion”, *Stigma Research and Action Vol. 2(2): 75–84 2012. DOI 10.5463/SRA.v1i1.10*

<sup>5</sup> National Institute for Intellectual Disability (2009), *All we want to say: Life in Ireland for people with intellectual disabilities*, Trinity College Dublin.

on empowerment and personal autonomy and the right of people to make decisions about all aspects of their lives including, for example, decisions about healthcare, finances, relationships and where and with whom to live, as outlined in Article 12.. The Convention supports and promotes the right of people with disabilities to enjoy full 'legal capacity on an equal basis with others' (Article 12(2)). The Convention also states that: 'persons with disabilities should have the opportunity to be actively involved in decision-making processes . . . including those directly concerning them' (Preamble, section 0). (Provision for supported decision-making is included in the Assisted Decision-making (Capacity) Bill 2013 currently going through the Oireachtas).

Article 13 refers to effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants.

Article 16 states that measures should be taken to protect people with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse.

Article 25 stipulates that health services should include health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons.

Article 30 refers to the right of persons with disabilities to take part on an equal basis with others in cultural life and to take all appropriate measures to ensure that persons with disabilities enjoy access to cultural materials and activities.

The Strategy should, therefore, include provisions for people with disabilities to enable them to:

- Maximise their capacity
- Live with dignity, independence, optimum function
- Direct their own lives
- Minimise the barriers to full participation in society created by either organisational systems or social perceptions.

### ***2.3 Right to Independent Living***

Article 19 of the UN Convention recognizes the equal right of all persons with disabilities to live in the community, with choices equal to others. It requires that people with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangements.

The Article contains two further stipulations relevant to the Disability Inclusion Strategy:

- Persons with disabilities should have access to a range of in-home, residential and other community support services, including personal assistance

necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

- Community services and facilities for the general population should be available on an equal basis to persons with disabilities and be responsive to their needs.

People with disabilities should, like the rest of the population, be empowered to determine their place of residence. No one should be obliged to live in a long-term residential service against their will, particularly if this is because of the absence of accessible and/or supported housing options or alternative independent living services in the community, as is sometimes the case. Having a real home, one comparable to that of most people, is a need that is fundamental to the well-being of people with a disability.<sup>6</sup>

For many people with disabilities, particularly those with an intellectual disability, exercising choice in relation to living arrangements will not happen without the sustained support of service providers and frequently, only with the support of an advocate and/or family members. Also, provision needs to be made for a developmental approach which allows for the fact that people's way of choosing and ability to choose may change over the life cycle.

### **2.5 Individualised Supports**

Individual needs-based assessment, widely recognised in legislation and policy statements<sup>7</sup> relating to people with disabilities, is an important determinant of social inclusion and should be carried out in such a manner as to facilitate individual choice and the provision of a range of support options to take account of individual circumstances. While an individualised supports approach has strong potential to further enhance the social inclusion of people with disabilities across the life-cycle, the option of designing an individual service for oneself through control of the funding allocated for one's support and care is largely underdeveloped in Ireland.

The individualised support model must be governed by the presumption of legal capacity which is being addressed in the current Assisted Decision-making (Capacity) Bill. Capacity should be assessed in a way which is fair and appropriate and which is free from prejudices based on external factors such as old age, mental illness or intellectual disability. In pursuing an individualised support model, it is crucial to acknowledge that there are some people (those with severe or profound disabilities) who will require long-term state guaranteed specialised services. Indeed, the Commission on the Status of People with Disabilities highlighted the particular

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<sup>6</sup> CIB acknowledges the framework for the delivery of housing for people with disabilities through mainstream housing policy set out in the 'National Housing Strategy for People with a Disability 2011-2016'. See also *The Right Living Space: Housing and Accommodation Needs of People with Disabilities*

[http://www.citizensinformationboard.ie/downloads/report\\_housing\\_needs\\_disability\\_2007.pdf](http://www.citizensinformationboard.ie/downloads/report_housing_needs_disability_2007.pdf)

<sup>7</sup> See [http://health.gov.ie/wp-content/uploads/2014/08/ERG\\_Disability\\_Policy\\_Review\\_Final.pdf](http://health.gov.ie/wp-content/uploads/2014/08/ERG_Disability_Policy_Review_Final.pdf)

vulnerability of this group of people stating that “...they will inevitably be dependent on significant state support throughout their lives, irrespective of the resources of their families. Thus, the state has a special responsibility to act as guarantor of their health services, safety, and quality of life.”<sup>8</sup>

## **2.5 Poverty and Deprivation among People with Disabilities**

Addressing the level of poverty and deprivation people with disabilities experience should be at the core of the National Disability Inclusion Strategy. According to EU\_SILC data<sup>9</sup>, in 2013, the overall ‘at risk of poverty’ rate was 15.2% (16.5% in 2012). Those most at risk of poverty in 2013 were individuals who were unemployed (36.7%) and those living in accommodation that was rented at below the market rate or rent free (35.2%). The ‘at risk of poverty’ rate for individuals living in households where there was no person at work was 34.5% and 18.1% for those not at work due to illness or disability (down from 30.1% in 2012).

Those living in accommodation that was rented at below the market rate or rent free (56.6%), those describing their principal economic status as unemployed (54.9%) and those who were not at work due to illness or disability (53.1%) had deprivation rates of over 50% in 2013. It is likely that a high proportion of people with disabilities are unemployed and living in subsidised accommodation

An analysis of consistent poverty rates by principal economic status shows that the consistent poverty rate was highest among individuals who were unemployed (23.9%). It was 10.8% for those who were not at work due to illness or disability (down from 17.6% in 2012).

Poverty and basic deprivation rates for people with disabilities continue to be at a higher level than for the population generally. The fact that data collection generally in Ireland<sup>10</sup> does not take account of the extra costs associated with living with a disabling condition or chronic illness may mean that ‘at risk of poverty’ and deprivation rates may actually underestimate the situation of people with disabilities. The Social Portrait of People with Disabilities (2011) noted that “the at-risk of poverty rate, which takes no account of differences in household expenditure associated with the disability, will tend to understate the true level of economic disadvantage of people with disabilities”<sup>11</sup>

## **2.6 Access to Social Care and Health Services**

Despite improvements in recent years, the pathway to health and personal social services, i.e., getting from the starting point of identifying a need for a service to actually getting the service can still be complex and challenging for people with disabilities and their families. Frequently there continues to be a mismatch between

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<sup>8</sup> *A Strategy for Equality, Report of the Commission on the Status of People with Disabilities*, Government Publications 1996, Section 23.2

<sup>9</sup> [http://www.cso.ie/en/releasesandpublications/er/silc/surveyonincomeandlivingconditions2013/#.VYfS7\\_blcg](http://www.cso.ie/en/releasesandpublications/er/silc/surveyonincomeandlivingconditions2013/#.VYfS7_blcg)

<sup>10</sup> Neither the EU-SILC or the SWITCH model (used by the ESRI to examine the impact of actual policy changes on real households) take account of the extra costs of living with a disability, poverty and basic deprivation rates for people with disabilities may be underestimated

<sup>11</sup> Cullinan, J., Gannon, B. and Lyons, S. (2011), “Estimating the extra cost of living for people with disabilities”. *Health Econ.*, 20: 582–599. doi: 10.1002/hec.1619.

general service provision and the ability of people with disabilities to access health and social care services appropriate to their needs.

Ongoing issues identified by Citizens Information Services (CISs) and NAS include, in particular:

- Absence of an integrated continuum of support and assisted living services
- Uneven service distribution and different practices in different parts of the country
- Shortage of community-based physiotherapists, occupational therapists and speech therapists
- Lengthy waiting periods for house adaptations
- Difficulties in accessing services because of lack of suitable transport<sup>12</sup>
- Lack of, or an insufficient level, of Personal Assistance hours for those wishing to move from residential services to allow them live independently, even in cases where suitable accommodation had been sourced
- Relatively slow progress on implementing the recommendations of the *Time to Move On* report<sup>13</sup>
- Lack of support from their current service provider and/or their family for people wishing to move to more independent living;

There continues to be a basic question as to whose responsibility it is to ensure that appropriate integrated support systems between housing, income and personal social services are in place for people with disabilities with complex needs who wish to live independently in the community.

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<sup>12</sup> *Getting There: Transport and Access to Social Services*, Citizens Information Board Social Policy Report 2010 [http://www.citizensinformationboard.ie/downloads/Getting\\_There\\_Report\\_2010.pdf](http://www.citizensinformationboard.ie/downloads/Getting_There_Report_2010.pdf)

<sup>13</sup>

<http://www.hse.ie/eng/services/list/4/disability/congregatedsettings/congregatedsettingsreportfinal.pdf>

## **Priority Themes to be Addressed in a New National Disability Inclusion Strategy**

Based on the above considerations, six priority themes for consideration in developing the National Disability Inclusion Strategy are identified.

### ***Priority 1: Effective Participation by People with Disabilities***

There is an essential difference between consultation and participation – those who are consulted offer their opinions which are taken into account more or less by those making the decisions, while those who participate share directly in the decision-making process and the outcomes. Participation is thus a dynamic and ongoing process (as distinct from one-off consultations) and real participation by target groups requires investment in time, energy and commitment by the agency concerned.

Good participation practice recognises and acknowledges different types of disability and related diversity and develops diverse and appropriate mechanisms to ensure that people with different types of disability are effectively included. There is a critical difference between people being involved in once-off consultation and giving stakeholders real power to affect outcomes.

### ***Priority 2: The Provision of Supports Commensurate with Need***

There is a need to locate the Disability Inclusion Strategy in the context of economic inequality and wider measures of personal and societal wellbeing as referenced in the three pillars of *active inclusion* developed by the European Commission in 2008<sup>14</sup>:

- Adequate income supports
- Inclusive labour markets, and
- Access to quality services

Provision should be made in the Strategy for the following:

- People with disabilities should have an adequate income and community supports to enable them to live independently in the community;
- Income supports should reflect at risk poverty and deprivation rates among people with disabilities and take into account the extra cost of living with a disability;
- All government departments and service delivery agencies should work in tandem to deliver optimum outcomes for people with disabilities based on an individualised support model.

### ***Priority 3: Maximising Capacity***

The concept of maximising capacity requires a fundamental dismantling of the label 'disability' and a focus on individuals as unique persons with hopes and dreams

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<sup>14</sup> <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32008H0867&from=EN>

rather than people who just engage with the service delivery system. It also requires further exploration of how the authentic voice of people with disabilities can be heard, including in research<sup>15</sup>.

- People with a disability should be supported to maximise their capacity and enabled to live with dignity, independence, optimum function, to direct their own lives and to minimise the barriers to full participation in society created by either organisational systems or social perceptions.
- The life cycle approach, strongly endorsed in *Towards 2016*, which refers to the provision of supports to meet the particular needs of people in different phases of their life - childhood, working age and older people, should be at the centre of the Disability Inclusion Strategy.

#### ***Priority 4: Integrating People with Disabilities into the Workforce***

People with disabilities should have equal opportunities to work. The Employment Strategy for People with Disabilities should thus emphasise the importance of people with disabilities having access to employment opportunities and the importance of mainstream employment support.

- Training agencies should develop supports geared towards the additional needs of people with disabilities - this is especially important in the case of people with an intellectual disability who are particularly disadvantaged under current structures;
- Since people with disabilities have the same right to take up employment and access relevant employment supports as the rest of the population, it is important that conditions attached to social welfare payments, secondary benefits, criteria for accessing activation/training programmes do not impact unfairly on people with disabilities;
- Work activation programmes and related support services should thus be provided to people with disabilities at the same level as other unemployed or underemployed people;
- Young people with disabilities should have equal access with others to all programmes that operate under the Youth Guarantee;
- The integration of social welfare income/employment support should be sufficiently flexible to cater for the needs of people who need to sign on and off benefits because of the episodic nature of their disability and the needs of those who can only work part-time;

#### ***Priority 5: Integrated Policy Development***

Access to services for people with disabilities must be delivered according to principles of equity and social inclusion so that people in need have equality of

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<sup>15</sup> Carpenter, J. and McConkey, R. (2012), 'Disabled Children's Voices: The Nature and Role of Future Empirical Enquiry', *Children & Society* Vol. 26(3):251–261



access to quality services regardless of age, domicile, geographical location, diagnosis or service boundaries. The OECD Report, *Sickness, Disability and Work* (2008)<sup>16</sup> recommended that that “silo-thinking must be replaced by strong coordination and integration of policies and services” in order to improve the position of people with disabilities.

Monitoring mechanisms put in place by the DSP (the Social Inclusion Monitor and the Social Impact Assessment of the Main Welfare and Direct Tax Measures) are crucially important. However, more emphasis is required on disability payments in terms of the cost of disability and the impact of other measures, e.g., transport and mobility supports.

Where there are cross-Departmental aspects involved in the Disability Inclusion Strategy it is important that one Department takes lead responsibility for ensuring good referral, information sharing and cross-Departmental or cross-agency coordination. The following aspects of service delivery should be made explicit in the Strategy:

- The respective responsibilities of different agencies in supporting young adults with disabilities through the transition to post-school options, including, protocols for individually-tailored referrals based on an assessment of potential and the identification of related support/training needs;
- The role of different agencies, e.g. Solas, in supporting people with disabilities;
- Clarity as to what the role of Intreo is in integrating people with disabilities into the work force

***Priority 6: Implementing the ‘Nothing for/about us, without us’ Maxim in Developing the Strategy***

The proactive involvement of people with disabilities in implementing the strategy is a fundamental and should be a strategic priority. How to achieve participation across the whole spectrum of people with disabilities should be a key consideration. Active participation should be fundamental to the consultation process.

There is reference in the consultation phases as outlined to seminars and meetings with organisations at national level as well as a series of regional public meetings to allow maximum participation by anyone interested in contributing to the development of the revised Strategy. This is clearly an important part of the strategy developmental process. However, in order for it to be truly meaningful for people with disabilities, it must include the proactive targeting and inclusion of people with different types of disability in the process. Protocols to implement this need to be put in place before the next phase of the consultation process commences.

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<sup>16</sup> [http://www.oecd.org/document/62/0,3343,en\\_2649\\_33933\\_41662270\\_1\\_1\\_1\\_37419,00.html](http://www.oecd.org/document/62/0,3343,en_2649_33933_41662270_1_1_1_37419,00.html)