



INCLUSION IRELAND

National Association for People with an Intellectual Disability

A Disability Manifesto for Equality and Human Rights

Intellectual disability issues for the 32nd Dáil

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1. Advocacy Supports

Advocacy comes in many different forms such as self-advocacy, citizen advocacy and representative advocacy. Advocacy can be described as self-determination and personal autonomy and can be a key safeguard for adults in care.

Much of the advocacy provided and supported is located in the community and voluntary sector. However, the lack of a coordinated approach to advocacy, coupled with significant cuts to voluntary groups, has left the sector under-resourced and fragmented.

A broad spectrum of advocacy is urgently required which includes the introduction of an advocacy service with statutory powers.

The Citizens Information Act 2007 provides for statutory powers for disability advocates to enter residential services and make enquires about vulnerable adults. However, the Citizens Information Act has yet to be fully commenced.

A National Advocacy Authority should also be established and this body would have responsibility for coordination and oversight for all advocacy services to persons in receipt of public services.

Key asks:

- Full commencement of the Citizens Information Act 2007.
- Establishment of a National Advocacy Authority.

Departments with responsibility: The Dept of Social Protection, the Dept of Health and the Health Services Executive (HSE).

2. Therapy Services

Only children born after June 2002 can access an assessment of their health needs under the Disability Act 2005.¹

Inclusion Ireland published 'The Case of Speech and Language Therapy' in September 2014 and this report noted the lack of a functioning therapy service, with access dependent upon where a child lives in Ireland.

The National Disability Authority (NDA) has also noted the severe lack of therapists treating and assessing children with a disability.²

Although the provision of extra therapist posts in the last two budgets was welcome, without additional therapists, thousands of children will continue to wait for more than 12 months for vital therapies that assist them in developing to their fullest potential.³

Key asks:

- Recruit an additional 150-200 speech and language therapists over the lifetime of the new Government.
- Fill vacant posts due to maternity leave, illness or leave of absence (this accounts for 10% of posts).
- Commence the Disability Act 2005 to include all persons with a disability.

Department with responsibility: The Department of Health.

¹ Disability Act 2005 (Commencement) Order 2007.

² Children's Disability Services in Ireland, National Disability Strategy, 2014.

³ HSE reply to Parliamentary Question of Deputy Colm Keaveney of 4.02.2014.

3. Access to Early Childhood Education

At present all children can avail of one year of free early child care education (ECCE). Each child may access 15 hours of early years education per week for 38 weeks (September to June).^[1]

Up to now the only accommodation for children with a disability was to avail of this scheme on a part-time basis over a two-year period.^[2] Budget 2016 provided funding for supports for children with a disability to attend the ECCE. This is cautiously welcome by Inclusion Ireland.

However, we wait to see the criteria for access to such support before fully endorsing these proposals.

Key ask:

- Children who require an assistant to access the ECCE should have this support.

Department with responsibility: The Department of Children & Youth Affairs.

^[1] The free preschool year, guide to parents, Department of children and Youth Affairs.

^[2] Department of Children and Youth Affairs, Free Preschool year in early childhood care and education, Guide for Parents.

4. Inclusive Education Supports

Most persons with a disability fare much better when educated with their peers in mainstream school. Inclusive schools create inclusive communities, combat discriminatory attitudes and provide an effective education for the majority of children.⁴ However, many children with a disability require additional supports to be educated with their peers. These supports come in the form of special needs assistants (SNAs), resource teaching hours, school transport and assistive technology.

The Education of Persons with Special Education Needs (EPSEN) Act 2004 when commenced will allow children to get education supports based upon a statutory assessment. Legislation has passed through the Oireachtas; however this legislation has yet to be enacted.

One barrier to effective mainstream education is the amount of Irish children being educated in classes of more than 30. In addition to access, a disability awareness-raising programme must be implemented at both primary and secondary level for teachers and pupils. Negative attitudes towards disability can significantly hinder a child's progress through the education system.

Key asks:

- Publish a plan to implement the EPSEN Act 2004.
- Reduce the amount of classes with more than 30 children (currently more than 124,000).⁵
- Introduce a disability awareness-raising programme for teachers and pupils.

Department with responsibility: The Department of Education & Skills.

⁴ The Salamanca Statement and Framework for Action on Special Education Needs, UNESCO, 1994.

⁵ Department of Education and Skills, Primary level education statistics, table 2.5 2013-2014.

5. Life-Long Education and Training

Young people who have an intellectual disability continue to have difficulty in gaining access to further education.

As explained in the Leinster-based service provider WALK education publication 'Accessing Mainstream Training: Barriers for People with Intellectual Disabilities', there are very few courses in further education that are accessible to people with an intellectual disability.⁶

This lack of opportunity is evidenced in the National Intellectual Disability Database (NIDD).

The NIDD notes that only 32 people report third-level education as their principal day service and only 276 list vocational training as their principal day service. This is from a cohort of 27,272⁷.

Key ask:

- Make courses available in further education and training accessible to persons with an intellectual disability.

Departments with responsibility: Department of Education & Skills.

⁶ Accessing Mainstream Training: Barriers for People with Intellectual Disabilities, WALK, 2015.

⁷ National Intellectual Disability Database Annual Report tables and figures 2013, Health Research Board.

6. Introduction of Direct Payments

Public expenditure on health and personal social services to persons with disabilities is around €1.4 billion per annum. These services are currently undergoing significant reform.

This reform programme is about moving towards a new model of person-centred, community-based supports. One of the key features of this model is personal or individualised budgets.

Direct payments are about giving persons with disabilities choice and control over the services and supports that they receive. They offer flexibility and empower people to make decisions about their lives.

The direct payments model covers all types of personal and social supports including community, day, residential respite and therapeutic services.

The new government must ensure that between 8%-15% of the current HSE disability budget which is governed by service-level agreements (SLAs) is ringfenced for individualised and community-based models of supports.

Key ask:

- Ring fence 8%-15% of the HSE disability budget governed by service-level arrangements (SLAs) to individualised and community-based models of supports. This percentage should be increased on an annual basis.

Department with Responsibility: The Department of Health.

7. Recognising the Cost of Disability

People with disabilities are much less likely to be in work compared to people without a disability. Only three out of 10 adults with a disability of working age have a job. A lack of suitable opportunities is forcing people with a disability to depend on social welfare payments.

These payments have been reduced in recent budgets and increases in the cost of living have further diminished household budgets. As a result, people with disabilities are twice as likely to live below the poverty line compared to the rest of the population and experience higher levels of consistent poverty compared to any other group in society at 13% compared to 2% of those at work.

Official poverty statistics do not consider the costs of having a disability. These costs are substantial and have been estimated to represent 35.4% of disposable household income. Addressing the extra economic costs of disability is “a logical step towards alleviating elements of social exclusion for people with disability.”⁸

Key asks:

- Increase social welfare payments to ensure they meet inflation and the cost of living increases.
- Establish a commission to identify economic costs of disability and make recommendations for changes to the social welfare and taxation systems.

Departments with Responsibility: Department of Social Protection, Department of Finance and the Revenue Commissioners.

⁸ John Cullinan, et al., 2011, ‘Estimating the extra cost of living for people with disabilities’, *Health Economics*, 20: pp. 582–599

8. Assisted Decision-Making Supports

The new government must ensure that the Assisted Decision-Making (Capacity) Act 2015 is commenced in full, establish the Decision Support Service (DSS) and appoint the Director of the DSS.

A wide-ranging national consultation with self-advocates and experts through experience should occur in drawing up the Codes of Practice as laid out in the legislation for all potential formal and informal decision makers.

The Departments of Health and Justice & Equality must commit to a scheme of funding that allows for education and training of all persons affected by the legislation, their families and members of the public.

A commitment is also sought that all current adult Wards of Court are reviewed and discharged within three years and appropriate supports are put in place depending on the will and preferences of the individual. An appropriate review of these Ward's funds should occur with appropriate measures taken to ensure any losses are compensated for.

Key asks

- Commit to commence the Assisted Decision-Making (Capacity) Act 2015 before the International Day of Persons with Disabilities on December 3rd, 2016.
- As a matter of priority, commit to establishing the Decision Support Service (DSS) and introduce a code of practice for informal decision making with the involvement of self-advocates.
- Review all current Wards of Court in line with the timescale set out by law.

Department with responsibility: The Departments of Health and Justice & Equality.

9. Disability Hate Crime

Ireland is well behind other EU member states in tackling crimes motivated by hatred or hostility and crimes against persons with disabilities are on the increase.

Ireland's current laws have been found to be completely inadequate when dealing with hate crimes and legislation that makes hate crime a criminal offence is required as well as enhanced sentencing for people found guilty of hate crime.

Persons with disabilities who are victims of crime are currently not treated as a specific victim group within the Irish criminal justice system.

Victims of hate crime experience significant barriers to accessing justice on an equal basis with others and the current policy measures are insufficient.

Ireland has a legal obligation to implement in full the EU Directive on Victims' Rights.

Key asks:

- Introduce hate crime legislation.
- Fully implement the EU Victims' Rights Directive.

Department with Responsibility: The Department of Justice & Equality

10. Respite Care

Respite care is an essential resource that offers important support to the whole family. However, the provision of respite care services is in a state of disarray with no ring-fenced budget designated to protect these much-needed services.

The quality, setting and frequency of respite care services vary greatly from area to area. In many cases parents are not being offered a service that caters to individual needs and are being offered a one-size-fits-all model. But each family has differing needs. Parents should have greater choice over the services and supports they receive and different models of respite care should be available.

The new Government must provide some clarity and coordination to frustrated family members who are struggling to secure adequate respite care and are being left at the whim of service providers.

A working group should be established with the objective of establishing a National Respite Strategy to address the ad hoc provision of respite care services.

Key asks:

- Establish a National Respite Strategy.
- Address ad hoc provision of respite care across Ireland.

Department with Responsibility: The Department of Health.