

A Manifesto for Community Inclusion

General Election for the 32nd Dáil



INCLUSION IRELAND



INTRODUCTION

The next Government – if committed to the human rights and equality of persons with a disability – will implement a number of key reforms in the provision of disability services and supports. A political party or political grouping that wishes to demonstrate its commitment to the human rights and equality of persons with a disability should include the following reforms in its manifesto for the upcoming election:

- Ratification of the UN Convention on the Rights of Persons with a Disability (UNCPRD).
- A legislative base for the protection and provision of Personal Assistance (PA) supports.
- A system of direct payments to persons with a disability.
- A commission on the cost of disability.
- A senior Minister to deliver the employment strategy for persons with a disability.

These five key reforms would bring Ireland into the 21st Century in underpinning the rights of persons with a disability.

2016 will mark the 20th anniversary of the publication of the Commission on the Status of People with Disabilities report 'A Strategy for Equality'. The strategy stated that Irish society excluded people with disabilities from almost "every aspect of economic, social, political and cultural life."

The depth of anger, the level of debate and the demand for change which was expressed during the consultation for this manifesto suggests that many people feel that successive Governments have failed to deliver the commitments contained in 'A Strategy for Equality'.

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In a truly equal society, the rights of persons with a disability would be upheld and respected – such as the right to make your own decisions about your life, to have a job, to live independently and to have appropriate self-directed supports to engage in the economic, cultural and social life of the community.

However, these rights are rarely acknowledged in modern Ireland where persons with disabilities are often regarded as second-class citizens.

Persons with disabilities have been disproportionately disadvantaged in recent times and this has been demonstrated in numerous ways – social welfare cuts; failure to enact long promised legislation; under investment or cuts to education supports; exclusion from mainstream employment strategies; lack of investment in vital health and social services; and a transport system that is wholly inadequate at meeting the needs of the disabled members of the community.

The human rights and equality of persons with a disability will be a key issue during the lifetime of the next Government and we are committed to making it so.

We insist that all current members of the Oireachtas – and all election candidates for the next General Election committed to the rights of persons with a disability – commit themselves to working to deliver the reforms in this document.

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1. ENSURING EQUAL RIGHTS

1.1 Ratification of the UNCRPD

Ireland was one of the first EU member states to sign the UN Convention on the Rights of Persons with Disabilities (UNCRPD) when it was opened for signature on March 30th, 2007.

However, persons with disabilities are still waiting for the Irish Government to finally ratify the Convention and make the UNCRPD a part of Irish law.

The UNCRPD is an International Agreement directed at changing attitudes and approaches to persons with disabilities.

The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.

Ireland has fallen behind our counterparts in the EU in relation to the UNCRPD with our nearest neighbours the UK ratifying the agreement as far back as 2009. Ireland remains one of only three EU states not to ratify the Convention.

Ireland is currently on a par with North Korea, Egypt and Ethiopia in not ratifying the UNCRPD.

Key ask

- Ratification of the Convention on the Rights of Persons with Disabilities (UNCRPD) within first 100 days of new Government.

Department with responsibility: The Department of Justice & Equality.

1.2 Assisted Decision-Making Supports

The new government must ensure that the Assisted Decision-Making (Capacity) Bill 2013 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 Department of Justice and 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

- Make a commitment to expedite the enactment and commencement of the Assisted Decision-Making Bill.
- As a matter of priority, commit to establishing a 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.
- Close the office of the Ward of Court as quickly as possible.

Department with responsibility: The Department of Justice & Equality.

1.3 People with Disabilities as Victims of 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

2. A LIFE IN THE COMMUNITY

2.1 Personal Assistance (PA) Services

Personal Assistance (PA) Services is a critical element of any social justice infrastructure. Since it was introduced to Ireland over 23 years ago it has supported people to live independently and to participate in the community as equal citizens.

However, PA Services continue to operate as a pilot project in Ireland without any legislative framework. Given the lack of budgetary and legal protection, the future of PA Services is continually jeopardised with mounting economic pressures. The return to care-driven PA Services – as opposed to the original aim which was to facilitate social inclusion – is diluting the service and is threatening the ability of people to live independently.

Similarly the role of the Personal Assistant (PA) is becoming confused with that of a homecare assistant or home help. The key skills required to become a PA must be recognised and appropriate minimum levels of remuneration put in place for the role.

Key asks:

- PA Services must be established on a statutory basis, in compliance with Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).
- Sustainable funding must be dedicated to PA Services.
- The current PA Services waiting list must be cleared.
- A Registered Employment Agreement must be available to all PAs with a minimum hourly rate of €13 enacted.

Department with Responsibility: The Department of Health.

2.2 Introduce 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.

2.3 Accessibility

(a) Transport

Access to public and private transport is essential so people can access education and employment and take a full part in economic, social, cultural and community life.

Private: Over 130,000 households with a disability did not have a motor car in 2011.¹ This is a significant barrier when participating in social activities and enjoying community amenities. In rural areas, access to public transport networks can be limited. Private transport is a significant extra cost for households with a disability and the decision in 2013 to close the Mobility Allowance and Motorised Transport Grant Scheme to new applicants has placed people at an even greater risk of social exclusion.

The new travel subsidy scheme has been promised, however it has yet to be delivered. Measures that would enable persons with disabilities to keep their entitlement to free travel when taking a job have not been introduced.

Public: In reality most people who are dependent on public transport for access to the community; however there are a number of factors that are proving barriers:

- Most buses within the Bus Éireann fleet are not accessible for wheelchair users.
- Dublin Bus vehicles facilitate only one wheelchair user at a time.

¹ Central Statistics Office, (2012), Census of Population 2011

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- Most inter-city trains provided by Iarnród Éireann only facilitate two wheelchair users at any time and many require 24 hours notice to use them.
- Train stations are not consistently staffed which leads to lack of access to both the station and the carriage.

As a result, many people depend on dedicated door-to-door services like Vantastic, ACTs, CILs, Rural Bus and Lucan Disability Action Group in addition to taxis. Not only is the cost of utilising these services prohibitive on a daily basis, many of them are already stretched beyond capacity and frequently unavailable.

Key asks:

- Develop a replacement scheme for the Mobility Allowance.
- Develop a support based on the Motorised Transport Grant to support access to employment.
- Automatically issue a companion pass when issuing a Free Travel Pass.
- Extend the Free Travel Pass to cover door-to-door services.
- The Rural Transport Initiative must be implemented.
- A universal accessible roll-on, roll-off public transport services is urgently required and a commitment from the National Transport Authority (NTA) that all new vehicles procured across all transport providers will be accessible.
- Provide support for private service providers to work together to utilise the existing accessible transport fleet across the country.
- Reinstate the Disabled Driver and Disabled Passenger Scheme.

Department with responsibility: The Department of Transport.

(b) Accessible Toilets

Access to fully accessible toilet facilities is essential to enable persons with disabilities to access their community and to take a full part in social, cultural and community life.

As many people already know, standard disabled toilets do not meet the needs of all people with a disability as some need extra facilities such as a hoist and a height-adjustable bench. The lack of such quality and accessible facilities across Ireland is a societal and equality issue and not just a disability issue.

A campaign in the United Kingdom called Changing Places has proved hugely successful since its inception in 2007 and there are now over 750 fully accessible facilities in public areas, tourist centres and sporting arenas around the UK including a number of facilities in Northern Ireland.

These fully accessible toilets are a huge improvement on standard accessible toilets as each installation provides a height-adjustable adult-sized changing bench, a tracking hoist system and adequate space.

Key asks:

- Install fully accessible toilet facilities in public areas, tourist centres and sporting arenas across the country.
- Build accessible toilet facilities in civic spaces in every major city in Ireland including Dublin, Cork, Limerick, Galway, Waterford, Drogheda and Dundalk.
- Change 'Part M' of the Building Regulations to include fully accessible toilet facilities as standard.

Departments with responsibility: The Department of Finance (Office of Public Works) and the Department of the Environment, Community & Local Government.

2.4 Deinstitutionalisation

Over 3,000 people remain accommodated in large congregated settings. The 2011 report on congregated settings 'A Time to Move On' painted a bleak picture of the daily reality of people living in these institutions.

Government policy aims to close these institutions before 2018. However, only 100 people a year are moving from congregated settings to a life in the community. This means that, at the current rate, it will be the year 2050 before the last person moves.

Services providers are expected to maintain a cohort of people in congregated settings, while at the same time supporting people to live a life in the community and all of this without any increase in funding.

The right supports should also be provided for persons with disabilities who have complex medical needs and are moving from congregated settings to live in the community. These medical supports should be maintained and improved in a community setting.

Key asks:

- Publish an implementation plan for the programme of deinstitutionalisation.
- Provide a ring-fenced budget to enable the programme to be implemented within an agreed timeframe.
- Allocate sufficient resources for supports to facilitate living independently.
- Effective and efficient implementation of Health Information & Quality Authority (Hiqa) standards for those persons remaining in institutional or congregated settings.

Department with responsibility: The Department of Health.

2.5 Housing

Persons with disabilities have a right to good quality housing, which is appropriate to their circumstances and located in the community. Due to the severe lack of accessible social housing, persons with disabilities are facing long delays for suitable accommodation, with some reported delays of up to six years.

Difficulties are encountered when people are forced into rented accommodation due to the lack of accessible housing and the high costs involved. Escalating rents are forcing many to live away from their community and support networks, this creates further isolation.

Persons with disabilities also face a range of other issues including the complicated process of applying for the Housing Adaptation Grant, extreme pressure of meeting mortgage repayments and maintaining the extra costs associated with having a disability.

Key asks:

- Urgently provide increased access to accessible social housing.
- Ensure social housing allocations match individual need in terms of accessibility, support networks and services.
- Simplify the process of applying for the Housing Adaptation Grant and increase allocations.
- Increase Rent Allowance rates.

Department with responsibility: Department of the Environment, Community & Local Government.

3. RIGHT TO AN ADEQUATE INCOME

3.1 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.”²

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.

² John Cullinan, et al., 2011, ‘Estimating the extra cost of living for people with disabilities’, *Health Economics*, 20: pp. 582–599

3.2 Social Welfare Payments in Line with Cost of Living

Individual incomes and that of family carers suffered substantial cutbacks during the years of austerity. The list of cuts during this period has been considerable and includes wide-ranging areas such as health / individual supports; education support; income supports; revenue and tax credits; housing; and health / disability services.

The Disability Allowance, Blind Pension, Invalidity Pension, Carers Allowance and Supplementary Welfare Allowance have suffered cuts and supplementary allowances such as Fuel Allowance Scheme, the Telephone Allowance and the Electricity & Gas Allowance have also taken a hit.

As a result, persons 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.

Key asks:

- Disability Allowance must be restored to pre-austerity levels.
- Carers Allowance and Blind Pension & Invalidity Pension must be restored to previous rates.
- Supplementary allowances including the Telephone Allowance and Electricity & Gas Allowance must be restored to previous rates.

Department with responsibility: The Department of Social Protection.

3.3 Employment Opportunities

Access to employment opportunities and supports are essential to participate in mainstream society and contribute to community and the economy. However, people with disabilities are twice as likely to live below the poverty line as the rest of the population because of their exclusion from the workforce.

The potential loss of secondary benefits, such as the medical card, can also hinder the transition from social welfare into employment. Taking up full-time employment can result in the loss of the medical card, free travel and more. In many cases these extra costs are not offset by income.

To ensure the smooth rolling out of the Comprehensive Employment Strategy (CES), the new government must ensure that the Departments of Social Protection and Jobs, Enterprise & Innovation take up responsibility for this area of work and a lead Minister from either department is designated responsibility for overseeing the new strategy.

Key asks:

- Identify a lead minister from the Department of Social Protection or Jobs, Enterprise & Innovation for key responsibility for the employment strategy.
- Allow those in receipt of a disability payment access to all employment activation programmes.
- Allow those who are in receipt of a disability payment to keep their secondary benefits when accepting employment.
- End the practice of commercial sheltered workshops.

Departments with responsibility: The Dept of Social Protection and the Dept of Jobs, Enterprise & Innovation.

4. EDUCATION

4.1 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.

4.2 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.³ 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).⁴
- Introduce a disability awareness-raising programme for teachers and pupils.

Department with responsibility: The Department of Education & Skills.

³ The Salamanca Statement and Framework for Action on Special Education Needs, UNESCO, 1994.

⁴ Department of Education and Skills, Primary level education statistics, table 2.5 2013-2014.

4.3 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.⁵

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 27,272⁶.

Key ask:

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

Departments with responsibility: Department of Education & Skills.

⁵ Accessing Mainstream Training: Barriers for People with Intellectual Disabilities, WALK, 2015.

⁶ National Intellectual Disability Database Annual Report tables and figures 2013, Health Research Board.

5. SERVICES TO CHILDREN

5.1 Therapy Services

Only children born after June 2002 can access an assessment of their health needs under the Disability Act 2005.⁷

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.⁸

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.⁹

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.

⁷ Disability Act 2005 (Commencement) Order 2007.

⁸ Children's Disability Services in Ireland, National Disability Strategy, 2014.

⁹ HSE reply to Parliamentary Question of Deputy Colm Keaveney of 4.02.2014.

6. ADVOCACY

6.1 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).

7. CONTACT DETAILS FOR THE ORGANISATIONS

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