



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Pre-Budget submission 2020

Inclusion Ireland

September 2020

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Ireland plain English guidelines**

Summary of recommendations

Ask	Recommendation	Who
Education 1. School supports 2. Early childhood care and education 3. Class sizes	<ul style="list-style-type: none"> Publish implementation plan for EPSEN Act. Extend AIM supports to children who attend ECCE Invest in teachers and infrastructure to address class size 	DES DES/ DCYA DES
Health/ wellbeing 1. Access to services 2. Disability services	<ul style="list-style-type: none"> Invest €500m in infrastructure and €100m in primary care Fund 100 additional therapy posts Shift existing disability budget to UNCRPD compliant services - 15% in Budget 2020 	DOH DOH DPER
Social inclusion 1. Cost of disability 2. Employment 3. Housing 4. Transport	<ul style="list-style-type: none"> Introduce cost of disability payment Ring-fence funding for Ability Programme projects and fund job coaches Invest in Reasonable Accommodation Fund Publish costed plan to end institutionalisation Allocate €300m to assess unmet need and ring-fence funding for supports Invest in accessible housing and allocate €28.38m to Housing Adaptation Grants Invest to ensure full accessibility of transport Resource the Passenger Assistance Scheme and Local Link rural transport programme 	DEASP DEASP DOH DHPLG DTTS
Participation 1. ADM (Capacity) Act 2. HSE plan	<ul style="list-style-type: none"> Invest €9.1m to establish Decision Support Service Fund the HSE to deliver the plan for effective participation in decision-making 	DJE DOH
Equality 1. Advocacy 2. Public sector Duty	<ul style="list-style-type: none"> Establish a National Advocacy Authority to develop an advocacy strategy Build PSD into all departmental strategies Consult people with disabilities on disability budget proofing 	DEASP DJE All DPER

About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.

Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.

About this Submission

Inclusion Ireland held consultations in Dublin, Cork, Tullamore & Sligo as well as an on-line survey with respondents from all 4 provinces of Ireland. People with a disability, family members and people who work in disability all took time to complete the survey. Their voices are included throughout this submission.

Introduction

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in March 2018 and is due to undertake its first reporting cycle in 2020, two years after ratification.

Ireland has the opportunity to take action in Budget 2020 to promote rights and equality for people with disabilities and ensure maximum compliance with the UNCRPD. The CRPD Committee has in the past been highly critical of countries with higher levels of poverty among people with disabilities, poor infrastructure to support legal capacity and institutionalised models of service provision.

Inclusion Ireland's pre-budget submission focuses on five key areas and identifies the relevant UNCRPD articles. Our key asks are:

1. Invest in Education
2. Promote health and wellbeing

3. Make social inclusion possible
4. Enable participation
5. Ensure equality

1. Invest in Education

Article 24 of the UNCRPD reaffirms the right of people with disabilities to an inclusive education on an equal basis with others and to the supports required to achieve this.

Educational opportunities are a crucial part of development for all children. However, children and young people with disabilities experience many barriers to education. Supports are required to ensure that young people with disabilities receive an inclusive education and are supported to reach their full potential.

School Supports

The Education for Persons with Special Educational Needs (EPSEN) Act was passed into law in July 2004. While some parts of the Act have come into force, 15 years after enactment, some key pieces have still not been commenced. These include those which give statutory rights to children with disabilities to an educational assessment, an individual education plan and the right to an independent appeals process.

Both the Irish Human Rights and Equality Commission (IHREC)¹ and the Ombudsman for Children have expressed concern at the lack of progress on EPSEN with the Children's Ombudsman stating "worryingly we do not have a specific timeline or commitment of when this will happen. That is simply not good enough."²

Implementation of the EPSEN Act would help to ensure equal and appropriate access to a host of school supports based upon assessed needs, including the new School Inclusion Model.

Without full commencement of the Act, measures progressed on a non-statutory footing run the risk of being removed at any time by a change in policy and children will have no right to redress.³

¹ IHREC (2015) Ireland and the ICESCR

² CRA Conference <https://www.oco.ie/news/dr-niall-muldoon-ombudsman-childrens-speech-childrens-rights-alliance-department-children-youth-affairs-first-child-summit/>

³ CRA 2019 report card

Supports in early childhood care and education

The Access and Inclusion Model (AIM), the programme to support young children with a disability to access the Early Childhood Care and Education (ECCE) scheme, has worked well. Children are supported to access the ECCE through generic supports, or for a child who has complex needs, through individualised supports such as a support worker.

However, these supports are only available to a child attending the limited ECCE scheme i.e. 15 hours per week and for a total of 38 weeks per year over two years. For the rest of their early year's engagement, the child will have no supports in place unless privately funded.

"EPSEN should be fully enacted. IEP's should be in place and meaningful with measureable goals including academic goals."

"If we are going down the road of full inclusion, a training needs analysis needs to be done and appropriate training identified and delivered. The EPSEN Act also needs to be fully enacted as it is up to the goodwill of teachers whether a child has an IEP or not."

"More schools need to be built as a lot of children with autism and disabilities need education and no schools are taking them."

"Integration only works with enough resources in place."

"I was in mainstream and then in special school. If I had more support in mainstream school with my learning and more staff it would have been much better".

"Increased funding is required to ensure all children access a full time education. Many children are attending shorter days due to schools' inability to support the child".

"You have to fight for every support. It's exhausting".

Class sizes

At present, 109,670 or almost 1 in 5 of all primary children attend a supersized class of more than 30 pupils.⁴ This number has decreased slightly in recent years and this good work must be sustained.

⁴ DES Statistical report 2018-2019. <https://www.education.ie/en/Publications/Statistics/Statistical-Reports/2018-2019-statistical-bulletin.pdf>

Large class sizes are a significant obstacle to effective teaching and learning⁵ and make it difficult for pupils with special educational needs both educationally and socially. The ratio must be reduced to ensure equality and a quality education system that serves all children.

Recommendations:

1. Publish a realistic and costed implementation plan for the EPSEN Act.
2. Extend the AIM supports available to children who attend ECCE to the rest of their day.
3. Invest in teachers and physical infrastructure to ensure no child is educated in a class of more than 30 student

Departments responsible:

Department of Education and Skills; Department of Children and Youth Affairs.

2. Promote health and wellbeing

Articles 25 and 26 of the UNCRPD are clear on the right to health, habilitation and rehabilitation. States must ensure that people with disabilities can enjoy the highest standard of health, and must provide the required health services as close as possible to the persons own community, including in rural areas.

Access to health and social care services

The Sláintecare report set out a vision for reform of health and social care services over a 10-year period, including legislating for a right to health and social care services at no or low cost and an expansion of community-based services to ensure adequate supply. However, implementation of the report's recommendations has been slow.

A recently published report indicated that there is huge regional inequity in the availability of community health and social care services such as GP's, public health nurses, counsellors, psychologists and therapists.⁶

⁵ NDA 2004

⁶ ESRI 2019. <https://www.esri.ie/publications/geographic-profile-of-healthcare-needs-and-non-acute-healthcare-supply-in-ireland>

Significant increases in the supply of these services are needed across the country.

Therapy services are a key support to both children and adults with disabilities and research indicates the importance of early intervention in the provision of therapy services.

A Transforming Lives working group report indicated that HSE therapy services were operating with a short-fall of 300-400 therapy staff as of 2016.⁷ Budget 2019 announced 100 additional therapy posts for 2019 to help alleviate the waiting lists for assessments of need. While these posts are most welcome, they are a fraction of the actual need and further increases are needed in Budget 2020 and subsequent budgets.

According to the HSE's most recent performance report, a child living in the Dublin area has virtually no chance of having their assessment of needs under the Disability Act 2005 completed within the legal 6-month timeframe set out in the Act. Nationally, only 6% of assessments were completed on time. CHO's 6 and 9 completed no assessment on time and CHO 7 only completed 1.2% on time.⁸

Nationally, the number of people waiting longer than 12 months for access to Occupational Therapy (OT) increased to 8530. Similar to other services, access to OT can also depend on where you live in the country. For example, in Cavan/Monaghan there are people waiting more than 2 years for OT access.⁹

"I had to wait 17 hours in a wheelchair to see a doctor in the hospital"

"There is a very long wait in walk-in clinics to see a doctor – sometimes more than three hours. That's a long time when you're not well".

"I was waiting over a year for an injection in my knee – it's very sore and I can't get around as quick".

"I would love to see someone come out to home to bring J out at weekends, there are only 4 outreach hours per month at present for some".

"Access as needed to speech and language therapy services for adults"

"Knowledge of intellectual disability in community and public health services" [is needed]

⁷ Transforming Lives, Report on future needs of disability services, Working Group 1, 2018.

⁸ Health Services Performance profile, January to March 2019 Quarterly report, HSE.

⁹ ibid

Better disability services

Alongside the implementation of the key reforms outlined in the Sláintecare report, Budget 2020 provides an opportunity to reform the existing spend on disability services.

Public expenditure on social care services to persons with disabilities is around €1.8 billion per year. Much of this spend is tied up in the provision services that are not UNCRPD compliant.

A Value for Money (VFM) review of the disability spend stated “...those using disability services do not participate in society in any meaningful way ... have little opportunity to self-determine or to live full and independent lives.¹⁰” In the seven years since the VFM report was published, there has been little progress in shifting this service model.

A more proactive approach by the Departments of Health and Public Expenditure and Reform would help to ensure that current spending on disability services is both UNCRPD compliant and in line with policy commitments as set out in the National Disability Inclusion Strategy.

As well as ensuring that all new monies allocated to disability services are spent on personalised, community based services, Government must put in place a multi-annual plan to transition the current HSE disability budget, which is governed by service arrangements, to personal and community-based models of supports.

Recommendations:

1. Invest the €500m allocation for infrastructure as set out in the Sláintecare plan
2. Invest €100m to improve access to primary care services
3. Fund 100 additional therapist posts
4. Require the HSE to ring-fence 15% of the disability budget for personal, community-based services to comply with the UNCRPD as a step towards making sure all services in receipt of public funding funded are compliant.

Departments responsible:

Department of Health; Department of Public Expenditure and Reform

¹⁰ Department of Health (2012). Value for Money and Policy Review of Disability Services in Ireland. Dublin: The Stationary Office.

3. Make social inclusion possible

Cost of disability

Article 28 of the UNCRPD is clear on the need to eradicate poverty for persons with disabilities. In Ireland, people with disabilities are more than three times as likely to experience consistent poverty as the general population.¹¹ Persons with a disability experience much higher rates of deprivation which means they go without some of the basic necessities for living. While improvements have been made in reducing overall poverty levels over past number of years, poverty among people with disabilities has not been effectively addressed.

People with intellectual disabilities are less likely to attend further education or be in employment. They also face additional costs such as specialist disability aids, home adaptations, higher energy costs or an increased need for taxis due to inadequate public transport and these costs have been estimated at an average of €207-€276 per week.¹²

The ESRI has said that “policies that reduce poverty among the general population do not adequately address deprivation experienced by vulnerable groups” and targeted interventions are needed in households where there is a disabled person.¹³

Specific measures to address the cost of disability are necessary in order to reduce poverty among persons with disabilities and these measures must address the extra costs that people face as well as increasing income.

Inclusion Ireland hopes that research recently commissioned by the Department of Employment Affairs and Social Protection will help to determine what the drivers of extra costs are for persons with disabilities in an Irish context and how the extra costs can be addressed.

However, a report published by Indecon/the NDA in 2004 found sufficient evidence for the introduction of a cost of disability payment. It is important that following the publication of the next report, that action is taken and that the recommendations from the report are implemented.

¹¹ CSO (2018). SILC

¹² Cullinan, J., Gannon, B. and Lyons, S. (2008) Estimating the Economic Cost of Disability in Ireland. ESRI

¹³ ESRI (2018). <https://www.esri.ie/news/irelands-deprivation-gap-is-large-and-increased-over-time>

Inclusion Ireland believes that a cost of disability payment should be available to all eligible persons with a disability, not just those in receipt of a social protection payment, in acknowledgment of the extra costs accrued by those who have a job.

An individually assessed, non-means tested payment, similar in nature to the Personal Independence Payment in the UK should be introduced to support mobility and daily living.

“It has cost me my career as I now cannot work”.

“People with disabilities experience disadvantage due to additional costs associated with many aspects of life: housing (accessibility, location, size), transport, supports (personal assistance, communication, sensory), dietary (cost of food/supplements), sensory (equipment and therapeutic interventions) and therapy provision inadequately provided by public system”.

“Additional costs for clothing/shoes that fit specifications of medical equipment”

“I have to buy adult wipes for changing my daughter...These cost €16 per week. I buy disposable incontinence sheets for under her wheelchair and our couch. They are €10 per week. Then there is the extra cost of our bins because of the weight of nappies”.

“A lot of things are expensive for people with disabilities, people need more money to cover costs ”

“The disability allowance is not enough to pay expenses”

Recommendations:

1. Introduce an individually assessed, non-means tested cost of disability payment to offset the additional costs associated with having a disability.

Departments responsible:

Department of Employment Affairs and Social Protection as well as other government departments who provide key services: Department of Health, Department of Housing, Department of Transport.

Employment

Article 27 of the UNCRPD affirms the right of persons with disabilities to work, on an equal basis with others. People with disabilities experience multiple barriers to accessing employment, including financial barriers, negative societal attitudes, environmental barriers, the education system and lack of opportunity.

Overall employment trends paint a positive picture with employment currently at one of the highest levels ever. However, people with intellectual disabilities have not benefitted from this upward trend with little change in the numbers of people with intellectual disabilities in employment between 2011 and 2016.¹⁴

Just 36% of people with disabilities of working age and 17% of people with an intellectual disability are in employment.¹⁵ Of the almost 29,000 people with intellectual disabilities who access HSE disability services, only 1% are in open employment.¹⁶

Finding employment is only one part of the process, workplace supports are crucial to sustaining employment over the medium and long term. The Comprehensive Employment Strategy for People with Disabilities (CES) notes that some people with disabilities may require a high level of support to obtain and retain employment. Recent research by Inclusion Ireland indicates that those with complex needs can obtain and keep a job, with the right supports.¹⁷ A job coach can be one such support.

The CES also sets out the value of individualised support from a job coach in supporting people with intellectual disabilities to find and keep jobs. A job coach, as described by the CES, works to prepare a person for employment, makes links with employers, and supports the person in the workplace in settling in and managing tasks.¹⁸

Job coaches are currently available through the Employability programme. However, from our advocacy work, Inclusion Ireland is aware of people with intellectual disabilities who have not been able to access Employability supports because they are not 'job ready'.

¹⁴ CSO (2017). Census 2011 and Census 2016

¹⁵ CSO (2017). Census 2016

¹⁶ NIDD

¹⁷ Magee, C., Murphy, T., Turley, M., Feely, M., García Iriarte, E., McConkey, R. and Inclusion Ireland (2019). 19 Stories of Social Inclusion – Ireland: Stories of belonging, contributing and connecting. <http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1673/19-stories-socialinclusion-ireland.pdf>

¹⁸ Government of Ireland (2015). Comprehensive Employment Strategy for People with Disabilities 2015-2024

The recently launched Ability Programme funds projects that are aimed at supporting young people with disabilities who are not currently job ready through the provision of a range of person-centred supports.

The projects should be evaluated to assess what has worked and what hasn't and those projects that have demonstrated positive outcomes for people with intellectual disabilities should be mainstreamed.

It is important that the pilot projects are not an end in themselves but translate into real jobs for persons with intellectual disabilities, with good support when transitioning into the open labour market.

"We can earn up to €120 without losing our book - we don't have nobody to help us to get jobs".

"We need help with filling out forms and more help to understand well, how to do the job – especially at the start"

"I want to get paid for work, I want an 'outside' job"

"We want 'outside' work in town. We want the government to provide us with someone who will help us to get jobs".

"Awareness among employers necessary"

"There is no on the job support for my son. He has very high support needs but would be well capable of a few hours of work per week. It's the support for this that is missing".

Recommendations:

1. Ring-fence the money used for the "Ability Programme" to ensure that those pilot projects that worked well are sustainable.
2. Fund the recruitment of job coaches for Intreo offices to provide 'on the job' support to enable those with high support needs to obtain and maintain employment
3. Invest in an advertising campaign for the 'Reasonable Accommodation Fund' to ensure that employers and people with disabilities are aware of the support available

Departments responsible:

Department of Employment Affairs and Social Protection

Housing

The UNCRPD (Art 19) reaffirms the right of all people with disabilities to live independently and be included in the community with the supports needed.

Presently, there are around 2300 people with disabilities still living in large institutional settings around the country¹⁹ and over 5000 more living in residential services²⁰, many of which offer limited choice or genuine community inclusion. There are also many thousands more adults with an intellectual disability living at home with ageing parents or siblings and limited supports, and a significant number of people inappropriately placed in nursing homes. As well as this, people with disabilities are twice as likely to experience homelessness as the general population.²¹

Deinstitutionalisation and community living

Despite the Government's commitment to close all institutional settings by 2018, the HSE and the Government have so far failed to meet the targets set out in the 'Time to Move On from Congregated Settings' report.

For deinstitutionalisation to be effective, and for community living to become a reality, a sufficient range of services must exist in the community to prevent institutional care.²² This requires joined up working across sectors such as housing and employment as well as health to ensure that mainstream services are accessible to people with disabilities and allow for inclusion and choice.

Housing supports

People with disabilities have highlighted the lack of available supports as one of the biggest barriers to accessing housing. It is difficult to access supports outside a crisis situation, and there is no clear pathway for a person to attain support services from the HSE in order to live independently in a local authority or rented home.

There are many people living in communities who do not receive support services from the HSE, and as a result are in no position to avail of

¹⁹ At end 2017, TTMO implementation group, Progress made under Time to Move on from Congregated Settings 2012-2017 infographic

²⁰ Health Research Board (2018). Report of the National Intellectual Disability Database 2017

²¹ CSO (2017). Census 2016

²² 2 European Expert Group on the Transition from Institutions to Community Based Care (2012). Common European guidelines on the transition from institutional to community based care.

housing from a local authority, Approved Housing Body (AHB), or in their rented home in order to live in supported independent living. Many people also report that there can be significant delays in response to people's applications for support. By the time people get responses to their applications their support needs may have changed.

"The Government need to give money to county councils to fix houses and make them more accessible and help us to live independently".

"Where I live, the steps are very bad into the house, 3 steps".

"(Support is needed) for independent living – support with cooking, self-care, cleaning".

"There is not enough information about what is available in the community".

"The housing grant is very limited for PAYE workers. Even with a family of 5, 2 of us with physical and sensory disabilities, we have to take out a second mortgage to put a wet room downstairs".

"Council won't provide accessible housing unless the HSE commits to necessary staffing, therefore the greater the level of need, the less chance of being housed".

"The system relies on relationships between individuals working in the health/social care sector and in county councils and approved housing bodies. Improvement is required to systems to ensure access to suitable housing is not reliant on relationships between individual staff".

Accessibility of houses

People with disabilities have reported that in their interactions with local authorities and disability service providers, there is a difficulty in acquiring accessible homes. This is worsened by a lack of data on accessible properties.

Through our advocacy work, Inclusion Ireland is aware of people being placed highly on the priority waiting list for a house, but being unable to get a home that meets their accessibility requirements. This is despite a commitment from the NDIS²³ on accessible housing and universal design

²³ National Disability Inclusion Strategy, 2017-2021

and the publication by the NDA of Universal Design Guidelines for Homes in Ireland.²⁴

Recommendations:

1. Publish a multi-year, fully costed plan to move the remaining residents out of institutions into homes in the community with the appropriate supports
2. Invest €300,000 to commission an assessment and costing of unmet housing and social care needs among people with disabilities living in non-CRPD compliant or unsustainable settings – including congregated settings, nursing homes, family homes or hospitals
3. Ring fence funding for support services to be made available for people with disabilities who have been allocated housing through local authority or Approved Housing Bodies (AHB's), or who may need supports to live in the private rental market
4. Invest in accessible social housing - Ensure that all new-build housing for which local authorities are responsible will be universally designed and accessible to all
5. Restore Housing Adaptation Grants funding to 2010 levels with an additional €28.38m.²⁵

Departments responsible:

Department of Housing, Planning and Local Government; Department of Health

Accessible transport

Article 9 of UNCRPD places an obligation on States Parties to ensure persons with disabilities can access transport in urban and rural areas on an equal basis with others. It requires states parties to take measures to identify and eliminate barriers to accessible transport. Accessible transport is a key requirement for people with disabilities in order to live independently and participate fully in all aspects of life.

Accessibility features

During Inclusion Ireland consultations on Budget 2020, issues frequently raised include: information such as timetables not being in accessible

²⁴ <http://universaldesign.ie/Built-Environment/Housing/>

²⁵ To restore the funding to 2010 levels per Minister Eoghan Murphy, 11th June 2019, response to PQs [23645/19] and [23646/19] <https://bit.ly/2Xn3X7u>

formats, inaccurate display or lack of audio systems, unstaffed bus and train stations and poor upkeep of existing accessibility features, such as ramps and lifts. These issues can be a significant barrier to people with intellectual disabilities travelling independently. The lack of accessible information is a recurring issue for people with intellectual disabilities but it does not appear to be a priority, with the emphasis on physical accessibility.

The Comprehensive Employment Strategy (Action 2.12), aims to develop the passenger assistance scheme where an assistant supports people to use public transport and plan journeys on Dublin Bus, Luas and DART. The scheme aims to give disabled people the confidence to use public transport and supported over 1000 individuals in 2016. Further development and extension nationwide would support people with intellectual disabilities to use public transport.

One standard for all transport providers

Where public transport is poor, unavailable or inaccessible, people are reliant on private services. At Inclusion Ireland consultations, people spoke of private bus companies not accepting the free travel pass, or private services on public routes prioritising non-free travel customers. Such experiences raise concern regarding different standards of reasonable accommodation between public and private services and the ability of private operators to deliver an equal and accessible service.

UNCRPD Article 9 (b) places an obligation on the Government to 'ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities'. The Department of Transport, Tourism and Sport and the National Transport Authority (NTA) are also obliged by the Public Sector Duty to ensure that licensing processes are rigorous in how they police private operators so as to enable equal universal access.

Rural transport

The availability and accessibility of rural transport is a significant issue for people with intellectual disabilities as the absence of an accessible service leads to an increased isolation and a sense of being cut off from services and community supports.

The draft Sectoral Plan for Accessible Transport for 2018 commits relevant departments and agencies to 'ensure that accessibility is a core criterion in the development of local and rural integrated transport services'. A target set by the NTA is achieving a fully accessible fleet by

2020 for the Rural Transport Programme (Local Link services). While services are open to the general public, older people and people with disabilities have traditionally formed the core customer base of the Programme.

The NTA's first strategic plan for the Local Link Rural Transport Programme (2018-2022) outlines key actions relating to 'Access for All'. These include accessibility requirements to be specified in service contracts; analysis of accessibility levels across all contracted operators following a retendering of existing rural services; and ensuring feedback from disability representative groups and key stakeholders is used to inform a best practice approach to accessibility in the Rural Transport Programme.

"The government should put more money into making it easier to get around - timetables are too hard to read, writing is too small to see".

"It should be a legal requirement that public transport and train stations be fully accessible. There should be more accessible taxis and they should be required to accommodate larger power wheelchairs"

"There is a high step on some of the buses that makes it hard for people with wheelchairs or sticks to get on"

"There are only 2 runs in the day in our area, which is not suitable for everyone." [Local link service]

"There is no public transport close to us. It is €20 in a taxi to the closest town so my 20-year-old son is dependent on us for transport. That's fine by us but it severely limits his independence".

"Limited outside Dublin. Having to give 4 hours' notice to travel is dreadful".

Recommendations:

1. Invest resources to ensure the NTA target of full accessibility by 2020 can be achieved. Attention should be paid to accessible information as well as physical access.
2. Further develop and extend the Passenger Assistance scheme nationwide, extending it and rolling it out in rural areas in conjunction with the Local Link Rural Transport Programme.

3. Implement tendering arrangements to ensure public and private operators deliver an equal and accessible service, in compliance with UNCRPD obligations and the Public Sector Duty
4. Resource the Local Link Rural Transport Programme to ensure actions are fully implemented within the required timeframes and in consultation with people with disabilities

Departments responsible:

Department of Transport, Tourism and Sport

4. Enable participation

Assisted Decision-Making

The Assisted Decision-Making (Capacity) Act 2015 was enacted at the end of 2015. Full commencement is the next critical step to ensure that individuals with disabilities have the support to exercise decision-making and choice in their lives.

The National Disability Inclusion Strategy committed to establishing the Decision Support Service in 2017, to commence the Assisted Decision-Making (Capacity) Act, to develop the associated Codes of Practice, and to promote and provide training in early 2018. The establishment of the Decision Support Service (DSS) is crucial to compliance with the UNCRPD, in particular the right to legal capacity (Article 12).

Although the DSS was established in October 2017, progress has been slow and the service is not expected to be operational until late 2020. The urgent need for the DSS has been well established and it is a crucial element in complying with Article 12.

It is essential that the Director is given adequate resources in Budget 2020 to execute her functions, including promoting public awareness, providing information, supervising compliance by decision-making assistants, co-decision-makers, decision-making representatives and attorneys and carrying out investigations.

“When they make the decision support service they need to come explain it properly to us. We need videos and booklets”.

“It would be good if people from the service could actually come and talk to us about it”.

“Our staff and managers need to know what’s happening with UNCRPD and assisted decision making. If they don’t get training, they won’t take us seriously”.

“I’d love support in this if it was available”

Recommendation:

1. Invest the €9.1m needed for 2020 to cover both operational and project costs in order to establish the DSS at the earliest opportunity

Department responsible:

Department of Justice and Equality

Plan for effective participation in decision making

‘Transforming Lives’ is the programme to implement the changes informed by the recommendations of the Value for Money and Policy Review of Disability Services in Ireland (2012). Since 2015, Working Group 3 has been working on a Plan for Effective Participation in Decision Making for People with Disabilities and Families.

This plan was published by the HSE in 2018 and sets out what needs to happen in order for people with disabilities to be involved in a meaningful way in decisions that impact their lives directly.

The plan details actions that can be taken within the HSE and Department of Health and details supports and strategies to improve participation of people with disabilities and at local/regional (CHO) and national level.

Despite the importance of this plan to the lives of people with disabilities, no funding was allocated for its implementation in the HSE’s service plan for 2019.

"I am on interview panels for new staff and I feel equal, I help decide who gets the job, but I would like to be paid for that work".

"If you go to make complaints nothing is done and people are afraid to speak up. You could be telling them and telling them and still nothing happens"

"In some houses staff pick the dinner and you don't get to choose"

"We need more easy to read so that we know what's happening"

"There should be more focus groups of people with disabilities in our local area".

"we have no part in the decision making and feel that those who do don't fully understand what the needs and challenges are for looking after a complex care child"

Recommendation:

1. Fund the HSE to implement Ordinary Lives in Ordinary Places, including resources for dedicated staff, implementation group, training materials and roll out.

Department responsible:

Department of Health

5. Ensure equality

Advocacy

Advocacy, self-advocacy and representation is essential for the realisation of the rights of disabled people. The Committee of the UN Convention on the Rights of Persons with Disabilities has recognised that "the effective and meaningful participation of persons with disabilities, through their representative organisations, is ...at the heart of the Convention".²⁶

State support for advocacy is crucial to successful advocacy. The UNCRPD Committee also recommended States parties "prioritizing resources to organisations of persons with disabilities that focus primarily on advocacy for disability rights".

²⁶ General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*

In an Irish context, advocacy is required for ensuring the success of the Assisted Decision-Making Act 2015 as well as the proposed adult safeguarding legislation. Advocacy can be an essential tool in preventing abuse and getting the voices of marginalised people into decision-making structures.

Inclusion Ireland has consistently criticised the fragmented nature of advocacy provision and called for a cohesive strategy. There is no consistent source of core funding for advocacy with the Department of Employment Affairs and Social Protection, HSE, Department of Health and the Department of Rural and Community Development²⁷ all among the funders. In addition, there is no advocacy service for children with disabilities.

Inclusion Ireland is concerned that the spreading of advocacy across multiple Government Departments dilutes the value placed on it and possibly threatens the work. Core funding cuts have also been made to umbrella organisations funded through the HSE as a result of the Value Improvement Programme and recent reports that the Irish Deaf Society were refused funding because their work related “in the main to advocacy, training and development²⁸ all lend themselves to a risk to advocacy.

Inclusion Ireland is calling for the Department of Employment Affairs and Social Protection as the lead department in advocacy provision and the Department of Justice as the department responsible for working towards an equal and inclusive society²⁹ to work together to ensure an advocacy strategy is developed and implemented.

Recommendation:

1. Establish a National Advocacy Authority (NAA) which would lead on developing a national advocacy strategy, in consultation with people with disabilities

Departments responsible:

Department of Employment Affairs and Social Protection; Department of Justice and Equality

²⁷ Through the Scheme to Support National Organisations

²⁸ <https://www.irishtimes.com/news/social-affairs/irish-deaf-society-on-brink-of-closure-due-to-lack-of-funds-1.3822021>

²⁹ Department of Justice Strategy Statement 2016-2019

“Advocacy for families is virtually non-existent. This is essential for younger people with disabilities”

“We need Inclusion Ireland around to fight for the UNCRPD to be brought into law”

“Inclusion Ireland is the only organisation that represents people with intellectual disabilities in Ireland. We need it to stay”.

“There needs to be more advocates. In my area there was no advocate for months. Even now (and the person is good) they only take on the most needy cases”.

“Prior to my son being 18 there was no advocacy service for him at all.”

“Our child has no voice. As his parents, we have come to realise that we have no voice, in spite of all our shouting. Advocacy for our child is not a charity issue; it is a justice issue. Advocacy from Inclusion Ireland for our young, intellectually disabled, non-verbal autistic son is essential”.

“More money should be spent on Advocacy Councils in all services. They can help you if we need information or want to help make decisions in our services. Sometimes when we try to do things they tell us we don’t have the money. Money should not stop advocacy; it is really important to spend money on advocacy”.

Public Sector Duty

In their most recent strategy statements, many government departments note their obligations under Section 42 of the Irish Human Rights and Equality Commission Act, 2014. The development of new departmental strategies this year provides all government departments with an opportunity to further develop and progress their commitments under the Duty.

Inclusion Ireland would encourage the Department of Finance and each government department to ensure that all decisions made for Budget 2020 are in line with this duty by being proactive in promoting equality; ensuring human rights are realised and eliminating discrimination.

As a minimum commitment towards fulfilling their public sector duty, government departments and the bodies under their aegis should provide accessible information to the public on the services they provide.

Recommendations:

1. Progress and build on previous PSD commitments in new strategy statement being developed by all departments and report on progress in annual reports
2. Consult people with disabilities as to what measures should be included to assess the impact of budgetary decisions on people with disabilities, as part of the DPER's equality budgeting initiative

Departments responsible:

Department of Public Expenditure and Reform; Department of Justice and Equality. All other government departments and public bodies under their aegis.

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Rialtas na hÉireann
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