



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Pre-Budget Submission 2021

Inclusion Ireland

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Ireland plain English guidelines**

INCLUSION IRELAND PRE-BUDGET 2021 SUMMARY

Ask	Recommendation	Who
Education	Invest in teachers and infrastructure to address class sizes	DES
	Produce a costed plan to fully commence the EPSEN Act 2004	DES
	Fully commence the Education (Admissions to Schools) Act	DES
Rights-based services	Invest €500m for infrastructure as set out in Sláintecare plan	DoH
	Invest €100m to improve access to primary care services	DoH / DCDEI
	Fund 100 additional therapist posts for each of next 3 years	DCDEI
	Ring-fence 15% of disability budget for community-based services	DCDEI
	Expand the Personalised Budget pilot project	DCDEI
	Fund the MHID Programme	DCDEI / DoH
Social inclusion	Increase funding for de-institutionalisation	DCDEI / DoH
	Invest in accessible social housing units	DHLGH
	Ring-fence funding for support services for people with disabilities to live in homes in the community	DHLGH / DCDEI
	Fund the mainstreaming of the "Ability Programme" and the recruitment of job coaches for Intreo offices	DSP
	Introduce a cost of disability payment	DSP
	Improve targets for reducing poverty	DSP
	Invest to ensure full accessibility across transport services	DCCT
	Extend the Passenger Assistance scheme nationwide	DCCT
	Resource the Local Link Rural Transport Programme	DCCT
Equality and participation	Invest to fully establish the Decision Support Service	DoJ
	Provide funding for the Plan for Effective Participation	DoH
	Establish a National Advocacy Authority and consult with disabled people on a national advocacy strategy	DoJ



Inclusion Ireland Easy to Read Pre-Budget 2021

In October, the government will announce the Budget for 2021.



The Budget is the government's plan about how it will spend money next year.



Inclusion Ireland believes the government should make budget decisions that will protect the rights of people with disabilities.

Inclusion Ireland is asking for the following to be included as part of the Budget:

1. Invest in Education



- Make class sizes smaller and train teachers so that they can include all people with disabilities in their classes.
- Start the law which says that a child must be offered a place in a local school if they cannot find a suitable place anywhere else.



- Start the EPSEN Act (2004) so that students can easily get assessments and supports

2. Invest in Health and Disability Support Services



Make it easier for people with an intellectual disability to use primary care services like doctors and therapy.

- Give €100 million to Primary Care and €500 million to the new plan for health. (Slaintecare)



There are very long waiting lists for therapy like speech and language and physiotherapy.

- Give money for 100 more therapists this year.



Many day services do not give people much choice about the support they get to live more independently in the community.

- Give more money from the disability budget to improve this support.
- let more people apply to the Personalised Budget pilot project



Covid-19 has had a very bad effect on some people's mental health.

- Make more funding available for the HSE National Mental Health Intellectual Disability (MHID) Programme.



3. Support Community Inclusion

- Give more money to support people to move from institutions to homes in the community
- Increase the number of accessible houses that people with disabilities can rent
- Increase the funding for people with disabilities to get services and support to live independently in houses in the community.
- Make it easier to get these support services.



- Fund job coaches for Intreo offices to help people with high support needs get a job and keep a job
- Introduce a cost of disability payment



- Invest money to make sure public transport is accessible
- This includes making sure that information is easy to get and easy to understand
- Give more money for the Travel Assistance Scheme and Local Link transport in rural areas



4. Participation and Rights

The Assisted Decision Making Act was passed in 2015.

- Invest the money needed to fully open the Decision Support Service.



The HSE has a plan to get people with disabilities much more involved in making decisions about plans and policies.

- Invest the money needed to make this plan work.



There are many gaps in the advocacy support available for people with a disability and for parents of children with a disability

- Consult with disabled people and others about a National Advocacy Strategy
- Make funding available for a National Advocacy Authority (NAA).



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.

Introduction

The current Covid-19 period has resulted in significant changes to the lives of people across the country, and none more so than people with disabilities. It is important that during this challenging time the Government, through the Budgetary process, makes commitments to promote the rights of people with disabilities.

This must include eliminating discrimination, providing equality of opportunity, supporting people in maximising their potential, removing barriers which impact on access to services, education, work or healthcare, and targeted improvements in welfare.

Inclusion Ireland believes that persons with disabilities should live self-determined lives and Budget 2021 provides an opportunity to create a more equal & just society and to further develop pathways into a life in the community for people with a disability.

This submission identifies 4 key action areas informed by the relevant UNCRPD Articles. These are:

1. Invest in inclusive education
2. Provide rights-based services
3. Support community inclusion
4. Enable equality and participation

1. Invest in inclusive education

Article 24 of the UNCRPD places obligations on the Irish government to ensure that people with disabilities are not excluded from education on the basis of disability and can access education on an equal basis with others.

In recent years, the Department of Education and Skills (DES) has significantly increased the spending on special education. However, many children with disabilities continue to be excluded from the education system and are not getting the supports required to access education at the same level as other children without disabilities.

More investment is required to provide these supports so that children and young people with disabilities receive an inclusive education and are supported to reach their full potential.

Class sizes

Large class sizes are one of the biggest challenges facing teachers in supporting children with disabilities and are a key barrier to the delivery of inclusive education¹. Over 2016/2017 the average class size in Ireland was 24.6 compared to the OECD average of 21.0².

In primary schools 109,670 or almost 1 in 5 of all primary school children attend a supersized class of more than 30 pupils³. Large classes of up to 30 pupils leaves little space for the kind of differentiated strategies necessary to support the diversity of learning needs, leaving teachers feeling stressed that they were not doing their best for either SEN students or the class as a whole. The ratio must be reduced to ensure equality and a quality education system that serves all children.

EPSEN and Education Act

When enacted in 2004, the Education of Persons with Special Education Needs (EPSEN) Act 2004 represented a fundamental shift in how the needs of children with special education needs would be met. The Act provides for educational assessments and independent appeals. Under the Act it was envisioned that a child would have access to a statutory

¹ ASTI finding in their survey <https://www.asti.ie/news/latest-news/lack-of-training-no-planning-time-largeclasses-key-challenges-to-inclusive-education>

² DES (2019) Education at a Glance 2019. OECD Indicators. A Country Profile for Ireland. Statistics Section. September 2019. For 2018 it has decreased slightly to 24.3.

³ DES Statistical report 2018-2019.

<https://www.education.ie/en/Publications/Statistics/StatisticalReports/2018-2019-statistical-bulletin.pdf>

assessment of supports and an individual education plan. Despite it being a central pillar of the National Disability Strategy, the EPSEN Act 2004 has never been fully commenced, 16 years later. This means that Irish children with a disability cannot access assessments with a right of appeal or individual education plans on a statutory basis

The Education (Admissions to Schools) Act 2018 allows for the NCSE or Tusla to place a child into a school where they cannot find a local school to attend. However, this part of the act has not yet been commenced. This legislation is urgently needed to address the unwillingness of some schools to enrol children with disabilities and the creation by some schools of barriers to enrolment in their policies.

What people said in our consultation about education

“Teachers need more training on disabilities so that they know how to teach kids with disabilities and the things they need to get by in school”.

“Everyone should be able to learn together and go to school together. When I was younger, I had to go to a special school and none of my friends were there”

“I had to apply to over 30 schools at the time and couldn't get a place... this is one of the biggest issues for kids with disabilities”

“My child was expelled from his first national school due to a complete lack of understanding and awareness from the principal. This then permeated to the rest of the staff.”

“Invest in teachers. Make special ed training mandatory for teachers.”

“We should get the same education that our family and friends got; it needs to be made more equal.”

Recommendations:

1. Invest in teachers and physical infrastructure to reduce maximum class sizes to less than 30 pupils and over time to less than 20 pupils per class. All teachers need to be adequately trained to work with a spectrum of children with disabilities.
2. Produce a costed implementation plan to fully commence the EPSEN Act 2004 and amend Section 2 to remove exemptions to inclusive education.
3. Fully commence the Education (Admissions to Schools) Act 2018 to allow for a child to be placed in a local school when they cannot find a suitable place.

Departments Responsible:

Department of Education

2. Provide rights-based services

Articles 25 and 26 of the UNCRPD are clear on the right to health, habitation 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 areas⁴.

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, and the funding required to establish the infrastructure is needed.

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 therapists⁵. 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.

The HSE National Service Plan 2020 outlined a number of priorities and actions to improve the provision of the Assessment of Need process under the Disability Act 2005. The plan promised a significant reduction of

⁴ Article 25, UNCRPD

⁵ ESRI 2019. <https://www.esri.ie/publications/geographic-profile-of-healthcare-needs-and-non-acute-healthcare-supply-in-ireland>

existing long waiting times with the introduction of 100 new therapy posts in 2019⁶. As of November 2019, only 63 of these positions have been filled⁷. Further to this, the new standard operating procedure for Assessment of need (as of January 2020) has been widely criticized for its lack of comprehensiveness and person-centred approach whilst ignoring the negative impact it will have geographically where there are gaps in services.⁸

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 10.1 % of assessments were completed on time up to September 2019. CHO's 4 to 9 are the worst performing with only 2.8% to 8.9% of assessments being completed within legal timeframes.⁹

Lack of access to basic support services has forced many to seek costly therapies from the private sector. A survey carried out by Dyspraxia Ireland found that 82% of children were missing out on vital therapies due to waiting lists and 39% of families could not afford to pay for private therapies.¹⁰ This was echoed during Inclusion Ireland's consultation for this document where a significant number of people with disabilities stated that they or their families had paid, or were continuing to pay for therapies most noticeably Speech and Language and Mental Health supports.

Allied health supports

We know from reports that disability therapeutic services are understaffed to provide an optimum service to children with disabilities¹¹. In addition, the HSE report extensive waiting lists for therapies, child mental health services and Disability Act assessments. These waiting lists can run into years in certain areas of the country¹². For example, in psychology services 96% of people are seen within 12 months in CHO 8 but only 55%

⁶ The National Service Plan 2020

⁷ Dáil Eireann debate -Thursday, 14 Nov 2019 Vol. 989 No. 3 Minister of state at the department of Health Finian McGrath

⁸ The Psychological Society of Ireland(2018). Review of the Assessment of Need Standard Operating Procedure

⁹ HSE Performance Report Sept 2019

¹⁰ Dyspraxia Ireland Survey(2017).Economic Costs of Raising a child with Dyspraxia/DCD

¹¹ For example: NDA and Transforming Lives Working Group 1 indicate the system is hundreds of staff too low to cope with demand.

¹² HSE (2019) July – September 2019, Quarterly Profile, HSE

in CHO 7. CHO 4 contains the vast majority of children waiting more than 12 months for mental health services¹³.

Inclusion Ireland is aware from our case work that many children in the Dublin north area have not seen a therapist in years and may 'age out' of early intervention services without ever seeing a therapist. This does nothing to support these children, their parents, or their educators.

Waiting times for these assessments must be reduced so that children can get access to therapeutic supports in a timely manner. Early intervention is not only essential to health and wellbeing; it also entails significant cost benefits in later life supports.

Rights-based disability services

Alongside the implementation of the key reforms outlined in the Sláintecare report, Budget 2021 provides an opportunity to reform the existing spend on disability services.

Public expenditure on social care services to persons with disabilities is approaching €2billion per year. Much of this spend is tied up in the provision of 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.¹⁴" The introduction of New Directions in 2012 was welcomed as a measure to rectify this. It called for individualised services, inclusion in the community and an excellent standard of service provision. However, to date there has been minimal investment from the HSE to help introduce the identified goals of New Directions thus resulting in the current Day service model remaining largely unchanged.

After the widespread closure of Day services due to Covid-19, we have an opportunity to re-assess the current models of service in line with New Directions and the UNCRPD. Individualised, community-based services should not just be seen as a stop gap measure to address current Covid restrictions but rather as best practice and a chance to reform. The Personalised Budgets programme may be a favourable and cost-effective solution in providing person directed supports and services in a community setting. An expansion of the pilot programme may provide the

¹³ Ibid

¹⁴ Department of Health (2012). Value for Money and Policy Review of Disability Services in Ireland.

impetus needed to move away from the traditional, system-centred disability service practices that we have today.

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.

What people said in our consultation about health services

"I've never got speech and language therapy even though I could do with it. I am on a list, but I've heard nothing in 2 years."

"Thankfully, my experience has been fine because I pay for it to be that way. I pay thousands in private health care each year, crippling amounts, but I have to have it".

"The state should do more to look after our health, there's too many expectations on our families to look after us".

"Waiting lists for appointments are too long"

"We opted for private for our child as the stress of not being able to access medical care when required was too great."

"It would be a good idea if hospitals had training for their nurses and doctors on helping people with a disability, it would make people less worried and stressed about visiting the doctor."

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 for each of the next 3 years
4. Require the HSE to ring-fence 15% of the disability budget for personalised, community-based services to comply with the UNCRPD as a step towards making sure all services in receipt of public funding are compliant.
5. Expand the Personalised Budget pilot project in light of the current Covid-19 pandemic

Departments responsible:

Department of Health

Department of Children, Disability, Equality and Integration

Department of Public Expenditure and Reform

Mental health services for people with disabilities

The ratification of UNCRPD affirmed that all persons with a disability must enjoy the same fundamental human rights and basic freedoms as those without a disability.

With the publication of a new national mental health policy 'Sharing A Vision', it is timely that there is a focus on the provision of mental health supports for people with intellectual disabilities. The previous national mental health policy, *A Vision for Change* advocated for the development of 29 mental health teams for adults with ID nationally and 15 for children in 2007, and these teams would have 10 members each (290 team members in total for adults and 150 for children)¹². However, Mental Health Intellectual Disability (MHID) services remain at 33% for Adults and 12% for children of the level that was envisaged in *A Vision for Change*.

Families and people with intellectual disabilities tell us that they feel invisible and poorly treated by the Mental Health services and that they are struggling to access any kind of service when they experience a mental health crisis. Some areas have no MHID service or very limited service and 47.5% of adults with an Intellectual Disability over 40 have an emotional, nervous or psychiatric condition¹⁵. This is almost twice the rate of mental health problems of the general population.

The HSE's Mental Health Services have established a National MHID Programme, and a key part of the programme's work is the development and roll out of a targeted funding plan to establish a minimum basic service level. It is important that funding is immediately made available for this programme so that all people with an intellectual disability will have access to a basic minimum level of mental health service.

According to the United Nations, there is expected to be an increased need for mental health services worldwide as a result of Covid-19¹⁶. With

¹⁵ IDS, TILDA

¹⁶ United Nations (2020) Policy Brief: COVID-19 and the Need for Action on Mental Health

a potential mental health crisis looming, it is vital that the MHID programme is funded and that there is widespread access to emergency mental health supports and investment in building support services in communities around the country

Recommendation

1. Make adequate funding available for the HSE National Mental Health Intellectual Disability (MHID) Programme

Departments Responsible:

The Department of Health

Department of Children, Disability, Equality and Integration

3. Support Community Inclusion

Housing

Article 19 of the UNCRPD reaffirms the right of people with disabilities to live independently and be included in the community with the supports needed.

People with disabilities face many barriers when it comes to housing. As with the general population disabled people experience barriers in the form of the affordability of homes and the expensive nature of the rental market. However, people with disabilities experience many other barriers such as the lack of available accessible houses, being at an increased risk of poverty, difficulties navigating the social housing application process due to its inaccessible nature, and also issues regarding decision-making when they enter into tenancy agreements. One of the biggest barriers is access to support services that facilitate independent living, and the absence of a defined and transparent pathway to applying for these supports.

People with disabilities are twice as likely to experience homelessness as the general population¹⁷. Most people with intellectual disabilities live in

¹⁷ CSO

the family home and of this cohort 4,255 are over 35 and living with aging parents.

Deinstitutionalisation and community living

Despite successive Government's commitments to close all institutional settings by 2018, they and the HSE have so far failed to meet the yearly targets as set out in 'Time to Move On from Congregated Settings' report. The strategy was clear in recommending that all congregated settings would be closed within 7 years (by 2018)

In total 8,300 people live in residential services and an additional 1,500 people with a disability under the age of 65 live in nursing homes. Of the 8300 in a residential service up to 2,900 live in larger settings of 10 or more people.¹⁸

The UNCRPD is clear in its opposition to institutional living and on the right of persons with disabilities to a life in the community. Article 19 reaffirms the "equal right of all persons with disabilities to live in the community, with choices equal to others' and to "full inclusion and participation in the community"¹⁹.

It is therefore imperative that the Irish State ceases with the continued use of new admissions to these institutions which are a clear breach of domestic and international rights, and increases funding to accelerate the deinstitutionalisation process.

Pathways to Supports

One of the biggest barriers faced by people with intellectual disabilities when attempting to access social housing is the lack of availability of support services. Many people report being unable to get access to a social housing home due to the unavailability of support services, while others who need supports in their home have no way of applying for these supports²⁰.

There are many people in communities across Ireland who receive no support services from the HSE, and as a result find it is not possible to avail of social housing as they cannot access the required supports to live independently. Through our advocacy work Inclusion Ireland have found that many people report being highly placed on social housing waiting lists due to their disability but then cannot live in a local authority home due to support services not being available to facilitate them living there.

¹⁸ <https://www.hiqanews.com/the-experiences-of-people-with-disabilities-in-congregated-settings/>

¹⁹ Article 19, UNCRPD

²⁰ Inclusion Ireland (2019) Housing for People with Intellectual Disabilities, The lack of supports for Independent Living

This points to a clear breakdown in collaboration between the Department of Housing, Local Government and Heritage, The Department of Health and the HSE regarding coordination of support services, and this must be addressed as a matter of urgency.

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 not helped 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, only to then find there are no available homes that are accessible to their requirements. This is despite a commitment from the NDIS on accessible housing and universal design and the publication by the NDA of Universal Design Guidelines for Homes in Ireland.

What people said in our consultation about housing

“There should be more social housing so that people like us stand a chance at getting an affordable house”.

“All houses should be accessible so that anyone can live in it”.

“Local authorities don't include accessible housing and only provide it when HSE sanction necessary supports”

“The government need to address the issue for housing for persons with a disability. The long-term housing need of each individual requires careful assessment and should be provided close to town centres and all services”

“There should be more projects like the ‘Personal Budgets’ so that people get used to looking after their money and paying bills before they move into a house”.

Recommendations

1. Increase funding to accelerate the move of the remaining residents from institutions to homes in the community with the appropriate supports, within the next 5 years.
2. Ring-fence funding for accessible homes and support services to be made available for people with disabilities who have been allocated housing through local authority or Approved Housing Body (AHB's), or those who may need support to rent privately.

3. Invest in accessible social housing units, and require that any new build housing for use by local authorities will be universally designed and accessible to all

Departments responsible

Department of Housing, Local Government and Heritage

Department of Health

Department of Children, Disability, Equality and Integration

Employment

Article 27 of the UN Convention on the Rights of Persons with Disabilities 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.

Just 36% of people with disabilities of working age and 17% of people with an intellectual disability are in employment²¹ and this indicates a societal problem that needs to be urgently addressed using a range of strategies.

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.²² A job coach can be one such support.

The Comprehensive Employment Strategy also sets out the value of individualised support from a job coach in supporting people with intellectual disabilities to find and keep jobs²³. 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'.

²¹ CSO (2017). Census 2016

²² 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>

²³ Government of Ireland (2015). Comprehensive Employment Strategy for People with Disabilities 2015-2024

The 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 are due to cease in mid-2021, and 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.

The progress of the Ability Programme and any potential future roll-out nationally of this programme would be supported by developing capacity within Intreo offices across the country. Such a step is supported by Action 2.2 of the Second Action Plan of the CES which outlines that capacity must be built to support people with disabilities to get into and maintain employment²⁴.

According to recent figures in results broken down by broad age group, the CSO have said the new Covid-19 adjusted measure of unemployment is 52.8% for those aged 15 to 24 years and 24.8% for those aged 25 to 74 years.²⁵ As the effects of the Covid-19 period become clearer and the data trends related to employment become available, it is vital that people with intellectual disabilities are not left behind in any future drives to get people back into employment.

It is imperative that the Department does not allow the progress made in recent years with schemes such as the Ability Programme to be lost as a result of the Covid-19 period. People with disabilities must be given equal opportunities to regain and maintain employment in the coming months and years.

²⁴ Comprehensive Employment Strategy Phase Two Action Plan 2019- 2021

²⁵ DEASP consultative committee communication as of 10.06.20

What people said in our consultation about employment

"The government need to invest in us and helps us become more skilled. We need more training and support"

" Our bosses in work need to know how to support us in work. We can do more and do a good job. They are afraid of letting us do more because we might make a mistake, but we are hard workers".

"Provide the same opportunities for people with a disability to return to work"

"All businesses should be encouraged to do training courses on dealing with people with disabilities and be encouraged to employ them"

Recommendations

1. Ring-fence funding to mainstream the good practice and learning arising from the evaluation of the "Ability Programme".
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 Social Protection, Community, and Rural Development and the Islands

Department of Enterprise, Trade and Employment

Cost of Disability

The UNCRPD, is clear on the need to eradicate poverty for persons with disabilities. Article 28, which is concerned with an adequate standard of living and social protection, requires States to "ensure access by persons with disabilities...to social protection programmes and poverty reduction programmes".

Research on minimum incomes indicates that current social welfare rates and minimum wages are not sufficient to provide a minimum essential standard of living for some sectors of the population²⁶. In Ireland, people with disabilities are more than three times as likely to experience

²⁶ https://www.budgeting.ie/download/pdf/mesl_2019_update_report.pdf

consistent poverty as the general population²⁷. Persons with a disability experience much higher rates of deprivation which means they go without some of the basic necessities for living²⁸.

Persons with disabilities 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 are estimated as being between €207-€276 per week²⁹.

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

The recent introduction of the Covid-19 Pandemic Unemployment Payment (PUP) and its set rate of €350 per week has given an indication of the income needed to have an adequate standard of living during this Covid-19 period. The recognition from Government that without the introduction of such a payment, many individuals and families across the country would be at risk of sustained poverty means that more sustained action must now be taken to address those groups, such as people with a disability, who are consistently at risk of, or experiencing poverty.

The ongoing research being carried out by Indecon through tender from the Department is to be welcomed. This research is due to be published by the end of 2020, and it is hoped that it 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.

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 benefit payment, similar in nature to the Personal Independence Payment in the UK should be introduced to support mobility and daily living.

Inclusion Ireland notes that in the Department's 'Roadmap for Social Inclusion', there are targets outlined to reduce the percentage of people with disability at risk of poverty or social exclusion from a rate of 36.9% in 2018 to no more than 28.7% for the year 2025 and to no more

²⁷ In 2017, 24% of people with disabilities experienced consistent poverty as compared with 6.7% of the general population.

²⁸ CSO (2019). SILC 2017.

²⁹ Cullinan, J., Gannon, B. and Lyons, S. (2008) Estimating the Economic Cost of Disability in Ireland. ESRI

than 22.7% by 2030³⁰. However, more progress must be made and research into the costs of disability should inform what appropriate actions need to be taken to improve these targets.

What people said in our consultation about cost of disability

“I have to pay for taxi’s all the time because I find it hard to stand and wait for the bus and some bus stops don’t have any seats”.

“Yes the costs are higher, medical, heating, outings, car expenses as can’t use public transport. People with disabilities should be getting more than 203 a week and also they shouldn't be means tested for their disability allowance or medical card.”

“For a child with disability there are hidden costs for families particularly in terms of social outlets, diet requirements, premiums attached to one to one lessons (example swimming) as group activities might not work, transport as public transport might not work, clothes etc. ”

“Childcare is a huge cost ...and then the more obvious direct costs around education, health and procuring therapies and tutors, transport to and from same to try recover ground lost by an unsupportive system. To improve these there should be a more supportive system, better ambition and expectations and accountability”

Recommendations

1. Introduce an individually assessed, non-means tested cost of disability payment to offset the additional costs associated with having a disability.
2. Improve targets for reducing poverty as set out in the ‘Roadmap for Social Inclusion’

Departments Responsible:

Department of Social Protection, Community, and Rural Development and the Islands

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

³⁰ Roadmap for Social Inclusion 2020 - 2025

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 2021, issues frequently raised include: information such as timetables not being in accessible 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 persistent issue for people with intellectual disabilities but it does not appear to be a public service priority.

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.

Improved disability awareness

In our consultations many people commented on the poor access and basic infrastructure of transport services, in particular on buses and trains. This takes the form of a lack of wheelchair space on buses or use of that space for buggies. One issue that arose repeatedly in rural areas was difficulties associated with restricted and inconsistent scheduling or low frequency of services.

Many adults and children with intellectual disabilities also use public transport to go to school or attend Adult Day Services. Some describe a good experience, a regular, familiar service with friendly drivers and good assistance. However, several say that disability awareness and training, for staff and the general public would help improve access and understanding for people with an intellectual disability or autism using public transport.

Article 8³¹, part 2 (d) of the UNCRPD places an obligation on State parties to engage in promoting awareness raising programmes for people with disabilities. In our consultations around transport many people felt that there was a need for an awareness raising campaign around the needs

³¹ Article 8, UNCRPD

and rights of people with disabilities so that transport workers as well as other passengers could better understand and support people.

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. A common issue arising from our consultations was the lack of public transport services in rural areas. Many reported they have no access to any form of public transport, while others spoke of the difficulties posed by the long distance to bus stops or train stations, infrequent services or service provision and planning which is undependable.

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.

What people said in our consultation about transport

"I can't read the timetable for the bus or LUAS so I never know when the next one is coming. They should have a voice that reads it out".

"They've changed the bus routes in my area so now I have to get 2 buses to the club".

"There's always a big gap when you are trying to get on the train. I had to ask someone to help me".

"Some transport, especially buses, do not have access for people who wheelchair users"

"Provide transport in the rural community"

"There is no public transport where we live, it is impossible to function without a car."

"The fact that only one wheelchair user can be on a bus at any one time is ridiculous, especially if buses are every hour as your friend would be left on the side of the road"

Recommendations:

1. Invest resources to ensure that there is full accessibility across transport services. 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. Invest so that the NTA can engage in a public awareness raising campaign to promote the rights of people with disabilities and their needs relating to transport
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 Climate Action, Communication Networks and Transport

4. Enable equality and participation

Assisted Decision-Making

The Assisted Decision-Making (Capacity) Act 2015 was enacted at the end of 2015 but has yet to be fully commenced. 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 very slow. In its 2019 annual report, the Mental Health Commission stated that progress had finally been made “towards agreeing a costed, time-bound plan for commencement... Key outstanding issues included clarity on fundamental aspects of the 2015 Act and Regulations from the Department of Health”. The Director of the DSS ³², has said that the service will need additional funding and draft legislation will also need to

³² Irish Examiner 22nd May

be passed to enable the organisation to implement its 24-month plan to open in 2022.

Full commencement is essential to ensuring that individuals with disabilities have the support to exercise decision-making and choice in their lives. In 2020, Ireland will report on its compliance with the United Nations Convention on the Rights of Persons with Disabilities, following ratification in March 2018. The full commencement of the 2015 Act and operationalisation of the DSS plays a key role in the State's compliance with the Convention.

The Mental Health Commission report also stated that over 1,250 people have been made wards of court since the Act was passed. The Commission also commented that the ongoing effect of not commencing the act is that "hundreds of people continue to be taken into wardship, thousands of people remain vulnerable to financial and other forms of abuse and hundreds of thousands of people lack the formal frameworks to plan ahead, and to be supported to the fullest extent to make decisions about their own lives."³³

It is now essential that outstanding issues delaying the commencement of the Act be urgently resolved by the Department of Health, and that the Director of the Decision Support Service is given adequate resources in Budget 2021 to execute their 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.

What people said in our consultation about decision making

"The full enactment is needed of the assisted decision making capacity act."

"More self-advocacy groups needed in day services to empower people to make choices around issues that affect them, also people appointed to assist decision making process"

"People with disability need support to make their own decisions, to be able to stand up and voice their opinion, to be heard"

"Will the opening of the DSS, provide the necessary training and support for people with an intellectual disability?"

"They should do training for our families because sometimes they won't let us make our own choices. My family don't want me to have a boyfriend, but I really want one"

³³ Mental Health Commission Annual Report 2019 p.44

Recommendations

1. Invest the resources needed for 2021 to cover both operational and project costs in order to fully operationalise the Decision Support Service in order to fully commence the Assisted Decision Making (Capacity) Act

Departments responsible

Department of Justice

Department of Health

Department of Children, Disability, Equality and Integration

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 at local/regional (CHO) and national level.

The Covid-19 Pandemic has shone a stark light on the quality and extent of supports and services available to people with disabilities. The voice, experience and participation of people with disabilities and their supporters is essential to the process of driving and delivering effective reform in line with the Value for Money review and facilitating the inclusion and integration of people with disabilities within the wider community.

Despite the importance of this plan to the social inclusion of people with disabilities, no significant funding was allocated for its implementation in the HSE's service plan for 2020.

Funding must be provided to the HSE to make substantive progress towards the implementation of the Plan for Effective Participation in 2021. This should include funding for independent support to develop, test and disseminate tools, accessible resources, training materials and models of good practice for participation. This work would be developed in close co-operation and consultation with people with disabilities, their supporters and service providers.

Recommendation

1. Provide funding for the HSE to make substantive progress towards the implementation of the Plan for Effective Participation in 2021

Department responsible

Department of Health

Department of Children, Disability, Equality and Integration

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”³⁴.

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”.

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 highlighted concerns about the National Advocacy Service (NAS) for many years. NAS does not have statutory powers, there are too few advocates resulting in long waiting lists. Furthermore, there is no national, statutory service providing advocacy for children.

³⁴ 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

There has also been the addition of the Patient Advocacy Service and while this service is welcome it will represent yet another strand of advocacy that must be connected by a strategic approach.

Inclusion Ireland has consistently criticised the fragmented nature of advocacy provision and called for a cohesive strategy.

The seminal document on advocacy 'Jigsaw of Advocacy' recognises that there are 5 distinct models of advocacy, namely;

- Self-advocacy covering both general self-advocacy and group advocacy for people with disabilities
- Peer advocacy covering family and community advocacy
- Personal / professional advocacy covering legal advocacy, patient advocacy
- Citizen advocacy
- Public policy advocacy

Safeguarding Ireland recently³⁵ identified illustrative examples of organisations delivering or supporting these models of advocacy. There is no consistent source of core funding for these organisations with the Department of Employment Affairs and Social Protection, HSE, Department of Health and the Department of Rural and Community Development (through the Scheme to Support National Organisations) all among the funders.

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. These developments all lend themselves to a risk to advocacy.

Inclusion Ireland is calling for the Department of Social Protection, Community and Rural Development and the Islands as the lead department in advocacy provision and the Department of Justice as the department responsible for working towards an equal and inclusive society³⁶ to work together to ensure an advocacy strategy is developed and implemented.

A National Advocacy Authority should be established that has responsibility for the development of the national advocacy strategy.

³⁵ Independent Advocacy in Ireland Current Context and Future Challenge

³⁶ Department of Justice Strategy Statement 2016-2019

What people said in our consultation about advocacy and participation

"We need more training and support to learn how to speak up for ourselves and know more about our rights"

"I want to feel respected and by that, I mean trusted to make my own decisions about my life and have control of my life".

" We should have more chances to meet people from the Government ourselves rather than other people doing the talking for us".

"I can get out there in my community and help people too. People think they need to help me all the time".

Recommendations

1. Establish a National Advocacy Authority (NAA)
2. Consultation with disabled people and others on a national advocacy strategy

Departments responsible

Department of Children, Disability, Equality and Integration

Department of Justice

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Government of Ireland

**For further information, contact;
Robert Murtagh, Advocacy (Policy) Coordinator, Inclusion Ireland.**

01 855 98 91 / robert@inclusionireland.ie