



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Housing, Planning, Community and Local Government

**On Ireland 2040 Plan: The National Planning
Framework**

March 2017

This document is written in font 12 Verdana in line with Inclusion Ireland plain English guidelines.

1. 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.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

“What sort of place should Ireland be in 2040 and what do we need to do to achieve this?”

This is the question posed in the Ireland 2040 Plan consultation paper. The development of this plan provides an opportunity to ensure that the Ireland of twenty years' time is a place that is inclusive of all people living in Ireland.

While progress has been made in recent years to include people with disabilities, it cannot be said that Ireland in 2017 is an inclusive place for all.

Many people with disabilities experience social and economic inequality. They still find themselves living in segregated spaces, apart from

mainstream communities. They often find themselves excluded from the life of their community, due to poor accessibility of physical spaces, poor provision of accessible transport and a general failure to include people with disabilities in the formulation of public policy.

To ensure that Ireland is an inclusive place for all its people in the future, it is necessary to pay attention to the needs of people with disabilities in the development of this plan and in all plans that will stem from it.

It is important to strike a balance between physical and economic development and social development. All are key for a thriving, inclusive society. The Ireland 2040 Plan and other strategies that stem from it must be aligned with social policies and should be inclusive of the diverse range of people living in Ireland.

3. Towards an inclusive National Planning Framework (NPF)

3.1 Ireland 2040. Our Plan: Issues and Choices

The consultation paper – Issues and Choices – published by the Department sets out some of the emerging policy choices that need to be considered. The Minister’s foreword highlights ‘the values we share as a society...’, the importance of ‘our sense of belonging to both community and place...the value we place on social justice...inclusion and fair play...’¹.

The paper argues against a ‘business as usual’ approach and maintains that a fundamental shift in how we do ‘place making’ in Ireland is required to improve communities and quality of life for those living within them.

¹ Department of Housing, Planning, Community and Local Government (2017). *Ireland 2040: Our Plan. Issues and Choices*. Consultation paper, p15.

However, there is little acknowledgement in the paper of the diversity of people living in communities across Ireland and people with disabilities are all but invisible in the document. There is little or no reference to what inclusive communities would look like and how they can be developed.

There is no mention of the need to align planning strategies with responsibilities under the Public Sector Duty, despite the fact that it requires public bodies in Ireland to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans.

Overall, the document fails to acknowledge the current social and economic inequalities that exist in different areas of the country and among different societal groups, and poses no solutions as to how these might be addressed in the future.

3.2 Inclusive Consultation

In a democratic and inclusive consultation process, the diverse population of people with disabilities would be supported to have their voices heard. It is important that people with disabilities have an opportunity to take part in the consultation process on the Ireland 2040 Plan as it progresses.

Consultation documents should be made available in accessible formats such as plain English, easy to read, short videos and braille. When the draft plan goes on public display, venues should be accessible and locations accessible by public transport. The Department might also give consideration to meeting with groups of disabled people around the country.

In reflecting our own values as an organisation, Inclusion Ireland engaged with people with disabilities in compiling this submission. Their views on key issues are dispersed throughout this paper.

Recommendations:

- Ensure that the NPF takes note of the changing profile of people with disabilities in Ireland
- Equality proof the Plan and subsequent strategies as they emerge to ensure that people with disabilities and other marginalised groups are protected against poverty and social exclusion
- Ensure that the NPF is aligned with the Public Sector Duty, provided for under the Human Rights and Equality Commission Act 2014
- Ensure that the consultation process is inclusive of and accessible to people with disabilities

4. Inclusive communities - Key outcomes for 2040.

Envisioning the kind of society that we would like to have in 2040 is helpful in working out what needs to be done to achieve that vision. Inclusion Ireland would like to see the following broad outcomes for people with disabilities emerge over the next number of years.

- People with disabilities live in their own homes in the community
- People with disabilities participate in the life of the community
- People with disabilities have the best possible health and wellbeing

- People with disabilities have opportunities to engage in education, training and employment

4.1 People with disabilities live in their own homes in the community

The UN Convention on the Rights of Persons with Disabilities, Article 19, reaffirms the right of people with disabilities to “have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”.

Article 19 about choice has two important aspects; the right to exercise one’s choice on an equal basis with others and having the same options available to choose from as others in the community.

In Ireland in 2040 we need to ensure that all people with disabilities, whatever level of support they may require have an opportunity to live in an inclusive community of their choosing.

The availability of appropriate housing in Ireland is already at crisis point. By 2019, the remaining two to three thousand people currently living in congregated settings across Ireland will need to be accommodated in suitable, community based accommodation, in line with the HSE policy, Time to Move on from Congregated Settings.

The Ireland 2040 Plan will need to cater for their housing needs and also for the many people with disabilities currently living in other types of housing that may wish to live in their own home in the community. In an inclusive, equal society, young people with disabilities would be supported to make the transition from the family home to an independent setting like all young people.

Planning for inclusive housing would:

- Include people with disabilities in the creation of housing policies
- Value diversity
- Value the voice of the person and his/her will and preference
- Promote a collaborative approach to housing in the local community, building on the capacity of national and local structures
- Connect people with facilities and services they need to build a secure, meaningful and productive life
- Ensure that people live close to jobs, public transport, schools, health centres, and supports that are necessary for an independent life

The Department's own strategy statement for the period 2016-2019 acknowledges legal obligations under the Public Sector Duty. The provision of housing for people with disabilities is recognised as one of the key areas in which an equality and human rights focus is needed. It is important that housing planning and policy identifies and addresses the housing needs of people with disabilities over the next number of years.

Full commencement of the Assisted Decision Making (Capacity) Act 2015 is also required to support people with intellectual disabilities to live in the community and to enter into the kinds of arrangements that this entails, such as tenancy and mortgage agreements. The ADM also provides a mechanism for people to live in their own home as they age by providing structures to support people to make decisions relating to property, other than Ward of Court or the Fair Deal scheme.

Housing and the community – what people said

- We want to see people with disabilities having the ability to choose where they live, who they live with and what house they want to live in.
- We hope that in the future people with disabilities will be active members of their community, being supported to live independently when needed and to be seen as equals by others.
- We do not want to see any people with disabilities living in institutions in the future.
- We would like to see housing planning place more of a focus on providing buildings with greater accessibility for people with disabilities and for planning to have input from those with disabilities when they are being planned and constructed.
- We would also like to see older people not put into nursing homes, but supported to live independently in the community if they can.

Recommendations:

- The NPF and subsequent strategies that emerge from it, should make a commitment to plan and provide for inclusive housing in communities for all people with disabilities
- Housing policy should be aligned with the commitments in Time to Move on from Congregated Settings; the National Housing Strategy for People with a Disability; and the Public Sector Duty
- Housing policy should reflect the principles of the Assisted Decision Making (Capacity) Act 2015

- People with disabilities should be consulted and included in the planning and development of housing policy

4.2 People with disabilities participate in the life of the community

4.2.1 Poverty and social exclusion

People with disabilities are more likely to experience poverty and deprivation than non-disabled people. This has a negative impact on their ability to take part in the life of the community.

With reduced disposal income and less money to spend on social activities, people with disabilities experience isolation and exclusion from community life.

According to a recent EU report, over 50% of people with disabilities in Ireland are at risk of poverty or social exclusion². At EU level, people with disabilities report experiencing barriers to leisure, to mobility, to transport, to accessing buildings, to education, training and employment and to paying for essential goods³.

4.2.2 Accessible communities

The Programme for Partnership Government made a commitment to “support people with disabilities in maximising their potential, by removing barriers which impact on access to services, education, work or healthcare⁴.”

² European Institute for Gender Equality (2016). *Poverty, gender and intersecting inequalities in the EU Review of the implementation of Area A: Women and Poverty of the Beijing Platform for Action*. Brussels: EIGE

³ Ibid

⁴ Programme for Partnership Government (2016).

People with disabilities experience many physical barriers to their full enjoyment of the community, such as lack of accessible transport or public spaces or lack of accessible toilet facilities.

Universal design refers to designing and building environments that can be accessed, understood and used by all people to the greatest extent possible regardless of their age, size or disability⁵. It is a fundamental condition of good design rather than a special consideration for a minority of people. The principles of universal design should be incorporated at all levels of Ireland's planning strategy.

Changing Places

Currently in Ireland, many people are actively excluded from towns, cities and communities through a lack of fully accessible toilet facilities.

Standard disabled toilets do not meet the needs of all people with disabilities – and, indeed, other mobility issues including multiple sclerosis, motor neurone disease and the elderly – as some people need extra facilities to use the toilet.

Changing Places facilities are different from mainstream accessible toilets in that they include both a hoist and a height-adjustable changing bench. They have been designed to put health, safety and dignity concerns of the person with a disability and the carer to the fore.

As it currently stands, there are only a small number of fully accessible toilet facilities in Ireland including Trinity College Dublin, Dublin Airport Áras an Uachtaráin and The Lime Tree Theatre in Limerick.

Some work has already started at Government level around rolling out Changing Places toilets around Ireland. The Office of Public Works (OPW) has made a commitment to carry out appraisals of tourist centres Farmleigh House, Dublin Castle, Glendalough Visitor Centre, the National Gallery and Clonmacnoise Heritage Centre to incorporate fully accessible

⁵ The Disability Act 2005

toilets. The OPW unveiled the first of this series of installations at Áras an Uachtaráin in May 2016.

Access to public toilet facilities is a basic requirement for people to be able to participate in the life in the community and any inclusive place based strategy should include a plan to expand fully accessible toilet facilities across the country.

Transport

Accessible transport is vital to enable people with disabilities to get around their community and across the country, to attend school, college or work and to generally participate in the life of the community. It is a key driver of inclusion in the community.

The need for accessibility in transport encompasses the whole journey experience – from accessible timetables and information to accessible public transport infrastructure, disability aware staff and accessible parking.

Recent figures indicate that more than one in four people with disabilities do not use public transport due to accessibility reasons; nearly half of Bus Éireann's fleet is not deemed accessible and only 5% of licensed vehicles were deemed accessible in 2015⁶.

⁶ Disable Inequality (2016). *Transport and Disability Factsheet*.

Transport: What people said

- We would like to see better infrastructure in local areas so that people with disabilities can avail of public transport and travel with greater ease.
- We want all buses, trains and taxis in Ireland to have fully accessible wheelchair ramps for people with disabilities.
- We want all private transport operators to take bus passes in the future as at the moment only public operators provide this.
- We would like to see timetables and transport information being much more accessible and easy to read throughout Ireland's transport network for people with disabilities.
- We would like to see future planning of transport infrastructure place more importance on people with disabilities, listening to what they have to say.

4.2.3 Participation of people with disabilities in decision making

Being included in the community also means having a say in decisions that affect that community. In deciding the planning priorities for the next twenty years, it is vital that all people in Ireland are included in decision making processes. It is not just a matter of holding an open consultation, but of really including people in all aspects of the policy planning, development and implementation processes.

Currently, participation in decision making for people with disabilities and their families is minimal at best. Working Group 3 of the Transforming Lives programme (set up to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland), will shortly present its plan, entitled 'Ordinary Lives in Ordinary Places' – a plan for

effective participation in decision making for people with disabilities and families.

The plan will help support the emergence of decision making fora for people with disabilities and families and will support them to participate in decision making at local, regional and national levels.

Going forward, it is important that people with disabilities and families are engaged in decisions that impact on their lives early and at every stage of the process, with regard to service provision and all other decisions in civic, social, political, economic and cultural spheres.

Participation in the community – what people said

- Community means meeting friends and neighbours and engaging in local services, like doctors, hairdressers, using public transport, going to the church or cinema.
- It means volunteering and participating in community classes, activities and supports.
- People with disabilities experience barriers to being included in the community, including a lack of support to get out and do things, poor or no public transport, cuts to funding and benefits and poor attitudes that other people have.
- We want to be part of communities just as much as everyone else. We want to be asked to be involved and we want to contribute to all facets of life.

Recommendations:

- The NPF needs to acknowledge the connection between poverty and social exclusion for people with disabilities and make a plan to address this

- A strategy to deliver an accessible and integrated transport system for people with disabilities, across urban and rural areas is urgently needed
- Planning should incorporate universal design principles
- Changing places, fully accessible toilets, should be installed across the country in both urban and rural areas, with a changing places facility in every major tourist site or civic, social or cultural centre by 2040
- The recommendations of Transforming Lives, Working Group 3 on supporting effective participation of people with disabilities in decision making should be adopted
- Policy on transport and tourism should take account of legal obligations under the Public Sector Duty

4.3 People with disabilities have the best possible health and wellbeing

4.3.1 Access to health and wellbeing services

A recent study on quality of life among different social groups revealed that 55% of adults with a disability experienced multiple quality of life challenges - more than three times that of the general population⁷.

The study also found that 53% of children who have a parent with a disability experience multiple quality of life challenges. Poor health and

⁷ Watson, D., Maître, B., Whelan, C., & Russell, H. (2016). *Social Risk and Social Class Patterns in Poverty and Quality of Life in Ireland*. Dublin: ESRI and DSP.

mental distress were among the main reasons that quality of life is lower for people with disabilities.

Access to quality services and supports would help to address the health and wellbeing issues experienced by children and adults with disabilities.

It is the intention of public policy that all children with support needs should be able to avail of services on a local geographic basis close to home regardless of their disability, their school location or the location of a service provider from whom their family is receiving services⁸. However, the provision and availability of services and supports currently varies across the country.

Research by Inclusion Ireland has demonstrated that access to speech and language therapy very much depends on where you live with an estimated 1 Speech and Language Therapist for every 83 children with complex needs in Wicklow and 1 for every 388 children in Wexford⁹.

Similarly, access to respite or short break services varies across the country, from a median of 32 nights in Galway/Roscommon/Mayo to 14 nights in parts of the North-West and South-East in 2015¹⁰.

4.3.2 Positive aging

The consultation paper published by the Department rightly points out that Ireland needs to plan for the needs of a growing population.

According to the Central Statistics Office (CSO), the population of over 65's is set to double in less than 30 years. The CSO estimates that there will be about 20,000 more people over the age of 65 every year until 2040. There is a strong link between ageing and acquired disabilities and public policy needs to plan for how to support this growing population.

⁸ Conroy, P. (2014). *The case of speech and language therapy*. Dublin: Inclusion Ireland.

⁹ Ibid

¹⁰ Health Research Board (2016). *NIDD 2015 Annual Report*.

Future planning policy also needs to take into account the changing profile of people with disabilities in Ireland. In keeping with general population trends, people with disabilities are living longer. While this is good news, it has an impact on policy and service provision.

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS - TILDA) reported some significant findings concerning people with disabilities and aging. According to the IDS-TILDA, as they aged people with disabilities were more likely to experience:

- Vision and mobility challenges
- A higher prevalence rate for falls
- An increased risk of dementia among people with Down Syndrome
- A higher incidence of mental health and emotional health issues, particularly for those living in residential centres

The study findings show a gender dimension to aging with women more likely than men to experience social exclusion, loneliness, cardio-metabolic disease, eye conditions, pain, or be overweight or obese.

Keeping older adults healthy and active as vital members of their communities is an emerging challenge for our society. If our older people are to have a 'sense of belonging' and place then we need to look at new models of living.

In Europe there is increasing focus on intergenerational learning and the constructive relationships that develop among all generations which contribute to the social cohesion of communities. When thinking of 'new infrastructure' the NPF should look towards models of intergenerational learning and living. This is increasingly urgent in terms of changing demographics.

Recommendations:

- The Plan needs to acknowledge the inequalities in health and wellbeing experienced by people with disabilities and find ways of addressing this
- The NPF should be aligned with the programme of Progressing Disability Services for Children and Young People
- There is a need to plan and provide for an equitable level of services and supports across the country
- The NPF should be aligned with the mental health policy, a Vision for Change
- The Plan should include the need for research on different models of intergenerational living

4.4 People with disabilities have opportunities to engage in education, training and employment

4.4.1 Education and training

Through our advocacy work, parents have reported to Inclusion Ireland some of the place and space barriers to education that children and young people experience. These include barriers in school enrolment policies for children with a disability which mean that children often cannot attend their local school.

The aim of Ireland's educational strategy should be to ensure full inclusiveness for persons with intellectual disabilities. All children should be supported to reach their potential and this involves a commitment from the government to accept that all children are entitled to an

education and to provide resources and supports to students with special educational needs or disabilities.

All schools should be fully accessible, as should school tours, excursions, trips abroad and sports. There should be a strong focus on the use of technology in the classroom. Technology will change and improve over the next 20 years and the most up to date technology and eLearning tools should be readily available. This will facilitate personalised learning using different devices, different programs and techniques based on student's own abilities and preferences.

Education – What people said

Accessing courses in third level colleges and universities

- We want colleges and universities to invest in inclusive courses for people with intellectual disabilities. We believe that people with disabilities should be able to pursue a school and college education just like everyone else in society, and that they should be properly supported to achieve this.

Career Guidance

- We would like there to be more career guidance in schools for people with disabilities. This helps students plan for their future and supports them while they are attending school and college.
- There should also be career guidance professionals for adults too and they should have experience of working with people with disabilities.

Reading and writing

- Students in Ireland need assistance in learning to read and write. It is not uncommon for people with disabilities to struggle when it comes to reading and writing at school age, resulting in them being unable to develop this skill into adulthood
- It is important that schools and universities provide extra support to those with disabilities both at school age and following into adult life in order to ensure they can develop this skill and understand day-to-day issues. People need the opportunity to learn about reading and writing no matter what age they are.

Choice of support

- We hope that people with disabilities will receive more support in their courses and will have the ability to choose people that support them. It is important to recognise the relationship the person has with their support person is central to learning.

4.4.2 Employment

Having a job is accepted as essential in order for persons with disabilities to participate in mainstream society and take an active part in the community. Having a job helps to combat the institutional and systemic causes of poverty and social exclusion.

However, the labour participation rates for people with disabilities are extremely low with only three out of 10 adults with a disability of a working age having a job. Data from the Health Research Board (HRB) indicates that only 1% of adults registered with the National Intellectual Disability Database (NIDD) are in open employment¹¹.

More than one third of people with a disability who are not in employment would like to have a job if the circumstances were right. Among young adults, this figure is higher at almost two thirds of young adults.

People with disabilities experience many barriers in accessing employment. These include financial barriers, negative societal attitudes, the education system and lack of opportunity. However, there are also physical and environmental barriers.

A recent analysis of the Quarterly National Household Survey shows that people with disabilities living outside the Dublin or Mid-East areas have a lower chance of entering employment¹². This illustrates the importance of taking a whole of government approach and ensuring that employment policy is aligned with other policies, such as policy on transport and local development.

Reasonable accommodation is essential for people with disabilities to be encouraged to enter the workforce and to ensure consistency in the labour market. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Employment Equality Acts 1998–2015

¹¹ Health Research Board (2015). *Annual Report of the National Intellectual Disability Database Committee 2014*. Dublin: HRB.

¹² Watson, D., Lawless, M. & Maître, B. (2017). *Employment transitions among people with disabilities in Ireland. An analysis of the QNHS*. Dublin: ESRI.

require employers to reasonably accommodate employees with disabilities.

'Reasonable accommodation' is interpreted as accommodation that will create the conditions to ensure the enjoyment of equal rights in the given situation.

Reasonable accommodation means necessary and appropriate modification and adjustments, not imposing a disproportionate or undue burden, where needed in a particular case, to ensure people with disabilities can exercise their rights and freedoms on an equal basis as others (UNCRPD).

Adapting the premises or equipment, for example, by installing wheelchair ramps, providing special computers for the visually impaired or installing loop systems are some ways in which the physical barriers to employment can be addressed.

Recommendations:

- The NPF should acknowledge the barriers to accessing education experienced by children with disabilities
- Planning should take account of the need to provide supports for people with disabilities and carers to access further education, training and employment
- The Department should be cognisant of the principle of reasonable accommodation when planning for the future employment needs of the population
- The Department should work with other government departments to implement a scheme to support the making of reasonable accommodations by employers

- The Department should work with other relevant government departments to ensure that the obligations under the Public Sector Duty are met in the areas of education, training and employment

5. Conclusion

Between now and 2040, many decisions will be made about how we run our society and how everyone in that society can participate fully in every facet of life. It is essential that people with disabilities and families are included in these decision making processes.

There is little evidence that the needs of people with disabilities or the barriers they experience have been considered in the development of the National Planning Framework so far.

The forthcoming NPF and other strategies arising from it as well as the consultation process should be equality proofed so that they are inclusive of all people in Ireland and acknowledge the different realities they face.

The strategy must include measures and targets to address the inequalities currently faced by people with disabilities and their participation in communities across Ireland.

Finally, planning for the future should be guided by a vision of the Ireland that we would like to see – an Ireland that acknowledges and values diversity and includes all its people.