

Disability Federation of Ireland, DFI

Submission on Ireland's National Reform Programme 2023

February 2023

Introduction

The Disability Federation of Ireland, DFI is a federation of disability organisations that represent and support people with disabilities and disabling conditions. Over 120 disability organisations across Ireland are affiliates or associates of DFI. DFI welcomes the opportunity to make a submission once again to Ireland's National Reform Programme, NRP.

In recent years Ireland has experienced a number of challenges. In particular these have included the COVID-19 pandemic, the need to support Ukrainians coming to Ireland as they flee war, the ongoing inflation and cost of living crisis, as well as the structural problems of the housing crisis and issues within the health service and system.

All of these issues have significant impacts on the quality of life of disabled people living in Ireland. Moreover, people with disabilities continue to live with significantly higher levels of poverty and social exclusion and extremely low levels of employment – in both areas Ireland performs well below EU averages, unlike other social indicators. Many disabled people also struggle to find suitable housing to live in, to be able to move around due to a lack of fully accessible, reliable and regular public transport, and experience significant waiting lists or lack of provision for health, community and social care supports necessary to enable them to live independently, equal to others.

These issues experienced at an individual level are being exacerbated by the impact of ongoing underfunding of voluntary disability organisations, coupled with significantly increased costs due to inflation. Disability organisations, like others operating in the health and social care area, are also experiencing a very serious recruitment and retention crisis, due to the fact that these organisations cannot compete with the better terms and conditions on offer in the public sector, and the lack of pay parity. Many DFI members have indicated that they have concerns over the sustainability of their organisation due to ongoing problems with retention of staff, indicating a serious risk for Ireland and its disabled citizens into the future.

Investing in people with disabilities is investing in Ireland's future

The 2016 census recorded 643,131 people with disabilities living across Ireland, making up 13.5% of the population. This number is likely to have increased in the intervening period, and we await updates from Census 2022 which will be released later this year. The National Disability

Authority previously estimated that by 2026 the number of people with disabilities will have increased by 20% from the Census 2016 figure due to demographic factors.¹ It is essential that the government begins planning for this future now or it will be both catastrophic for the people involved, and costly for the state in the future.

As Ireland emerges from the pandemic years, and seeks to plan more proactively for the future, it is imperative that we focus on those with the greatest need. The NRP should actively prioritise the needs of the 13.5% of people in Ireland who have a disability, and must invest significantly in health, social and community services and supports, and address the issues of poverty and low employment. While this may involve a short-term cost, it will prevent many further economic and social costs in the long term and thus ultimately be value for money².

A key social challenge: People with disabilities disproportionately at risk of poverty, exclusion, and deprivation

People with disabilities have lived with disproportionately high levels of poverty and low levels of employment for years. Ireland is one of the worst performing countries in the EU in both these areas, ranking with much less wealthy EU countries rather than the Western European countries we rank alongside on other social indicators. Those unable to work due a long-standing health condition (disability/illness) are five times more likely to live in consistent poverty compared to the national average.

More broadly, disabled people continue to struggle with a lack of sufficient support from the state, and due to the lack of a consistent inter-Departmental approach to disability issues, which by their very nature need to be tackled across Department briefs. Moreover the organisations across Ireland that provide support and services to disabled people, both voluntary and public sector, are underfunded and overstretched.

To understand the current status of disabled people, it is important to consider some statistics. For example:

 While on average 29.7% of the EU population with a disability was at risk of poverty or social exclusion (AROPE) in 2021, Ireland's rate

¹ Census 2016 and NDA (2018), Disability Statistics.

² See for example https://www.svp.ie/news-media/publications/social-justice-publications/the-hidden-cost-of-poverty.aspx for the hidden public service cost of poverty and exclusion

- was almost 10% higher, at 39.3%. Only Bulgaria, Latvia and Romania had higher AROPE rates in 2021 than Ireland.³
- The 2022 CSO Irish SILC Deprivation data shows that 42.7% of people unable to work due to long-standing health problems (disability) live in enforced deprivation. This is 2.5 times higher than the national average of 17.1%.
- The INDECON Cost of Disability report for the Department of Social Protection concluded that disabled people live with extra costs that vary from €8,700 - €12,300 per year.⁴
- 27% of the homeless population have a disability, double the rate among the general population (Census 2016).
- Only about 9% of people with disabilities, circa. 56,000 people, are supported through specialist disability services (Department of Health, Disability Capacity Review to 2032, 2021).
- Ireland's rate of employment for people with disabilities is almost 20% lower than EU averages (EDF 2020).
- More than 1,300 people with disabilities under the age of 65 are inappropriately placed in nursing homes (HSE, Nursing Home Support Scheme statistics)
- Disabled people wait longer on the social housing list. In 2020 the number of disabled people on the housing list declined by half as much (4.9%) as those without disabilities (9.9%). (Housing Agency, Summary of Social Housing Assessments)

Services to support disabled people: sustainability of voluntary disability organisations is threatened

A very significant amount of disability supports and services across Ireland are provided not by the state and the health care system directly, but by voluntary disability organisations. Unfortunately many of those organisations continue to struggle with funding deficits and with the impact of the broader healthcare staffing and recruitment crisis, which is particularly negatively impacting voluntary disability organisations.

The recruitment crisis exists primarily due to issues with insufficient pay and working conditions. The lack of pay parity for staff in Section 39 organisations with staff receiving better pay and conditions for similar roles in Section 38 organisations or the HSE, is extremely challenging for voluntary disability organisations. This is against a background of already

³ https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Disability statistics - poverty and income inequalities&oldid=561947#At risk of poverty or social exclusion

⁴ https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/

falling living standards for disabled people, and services that have often been incapable of even meeting existing needs over the past decade.

Voluntary disability organisations continue to be extremely concerned about their financial situation and viability. A survey of DFI members provides a snapshot of the issues experienced in voluntary disability organisations in relation to recruitment and retention. In total, 34 DFI member organisations responded to the survey. Some of the findings were:

- 59% of those who responded have concerns over the sustainability of their organisation due to retention of staff.
- 48% of those that responded have reduced the level of service they offer due to reduced staffing levels.
- 62% have run an unsuccessful recruitment campaign in the last 12 months and posts remains unfilled.
- 71% have lost experienced staff to the public sector.
- 57% have lost experienced staff to the private sector.
- 43% have lost experienced staff to non-healthcare related posts.
- 33% (over one in four) have lost experienced staff due to burnout.
- 70% have concerns regarding the additional risks their organisation is carrying due to staffing issues.

It is crucial to remember that almost 70% all services to support people with disabilities are provided by voluntary disability organisations. Many disability organisations may not be financially viable into the future if they are not supported. This would have a hugely negative impact on the people who rely on these services.

The UN CRPD: five years on, more progress needed

The Dáil unanimously agreed to ratify the United Nations Convention on the Rights of Persons with Disabilities, UN CRPD, in March 2018. The Convention commits states to a comprehensive set of actions which set out the changes necessary to support the equal participation, rights and inclusion of people with disabilities. This year marks the **fifth anniversary of the ratification of the UN CRPD**, and a chance to look back on the progress that has been made, and what work still needs to be

⁵ Disability Capacity Review https://www.gov.ie/en/publication/d3b2c-disability-capacity-review-to-2032-a-review-of-social-care-demand-and-capacity-requirements-to-2032/

done. Unfortunately, it is clear that progress has been slow, and there is still much to do to realise the rights outlined in the UN CRPD.

Since the ratification we have seen some strong commitments to improve disability supports, and changes to infrastructure and approaches to disability in Ireland. These have included new Ministerial briefs focused on disability, the creation of the new Department of Children, Equality, Disability, Integration and Youth, the Disability Matters Committee in the Oireachtas and the creation of the Disability Participation and Consultation Network.

The long-pending transfer of the HSE Disability Services Programme from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth, DCEDIY, is due to finally happen on March 1st. It is a welcome development, and offers positive opportunities for change. DFI has welcomed the placing of disability within a Department whose core brief includes equality, and the focus on a UN CRPD informed approach, as well as better coordination. On the other hand, concerns remain as to how the new areas of responsibility will be effectively integrated into DCEDIY's remit, and crucially how coordination will happen with the Department of Health, which will still have responsibility for key areas of mainstream health provision that many disabled people rely on, even more so than specialist disability services.

Ultimately DFI still believes that it would be optimal if the Department of An Taoiseach had overall responsibility for UN CRPD implementation, to ensure the required whole of government approach is adopted.

Given the levels of poverty, and lack of employment opportunities in Ireland for people with disabilities, the government should pay particular attention to Article 28 of the UN CRPD, on adequate standard of living and social protection. Ireland must ensure that its social protection system is adequately addressing the needs of people with disabilities, and keeping them out of poverty, including by addressing the extra costs of disability.

Ireland submitted its first report to the UN CRPD recently, and will be examined by the Committee for the first time in the coming years. Given the ongoing barriers to inclusion that disabled people face, and the positive opportunities for Ireland to change that situation, DFI believes that the UN CRPD should be a focus of the NRP. Ireland should explicitly allocate resources through the NRP to strengthen the ongoing work to implement the Convention, in particular in the areas outlined below.

Prioritising Disability in Ireland's NRP: Leave No-one Behind

As we have outlined, many people with disabilities lived precarious lives, struggling with poverty, lack of employment, unsuitable housing or lack of housing options and insufficient health and other public services. Ongoing systemic challenges and problems, like the housing, health and cost of living crises, have exacerbated the level of marginalisation experienced by disabled people and their families.

As we move towards a post-pandemic approach to EU Semester planning, a return to normal after the past few years, Ireland has the positive opportunity to build in specific supports, reforms and resources to support the 13.5% of people in Ireland who live with a disability, and their families. We must build a system that plans for the predicted 20% increase in the number of disabled people by 2026. While a focus on economic issues may arguably have been warranted in recent years, it is crucial that this year's NRP has a strong focus on social and community issues and challenges.

By prioritising and considering disability throughout Ireland's NRP, Ireland can also show commitment to making progress on the Sustainable Development Goals (SDGs). The central and transformative promise of the 2030 Agenda for Sustainable Development is to "leave no one behind". Ireland also promised to endeavour to reach the furthest behind first. To live up to these commitments Ireland will need to address the structural barriers to equal participation in society that disabled people experience, given the worsening levels of disability poverty, and the other problems already outlined. A focus on disabled people can in particular help Ireland to achieve Goal 1, to eliminate poverty, and Goal 10, to reduce inequality.

Such a focus would also strengthen Ireland's delivery on its EU Pillar of Social Rights commitments and responsibilities. The Pillar includes disability as a core concern. Principle 3 refers to equal opportunities, outlining the right to equal treatment and opportunities regarding employment, social protection, education, and access to public goods and services. It also explicitly calls for the fostering of equal opportunities for underrepresented groups (like disabled people). Principle 17 states that "People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs". The Principles also state that "everyone lacking sufficient resources has

the right to adequate minimum income benefits ensuring a life in dignity at all stages of life, and effective access to enabling goods and services".

DFI Recommendations for Ireland's 2023 NRP

Key General Recommendations

- The NRP should not just focus on economic growth and employment, but also on social development and progress on poverty.
- The needs of people with disabilities, one of the groups that are 'furthest behind', must be prioritised in the NRP.
- Given that 2023 is the five year anniversary of Ireland's ratification of the UN CRPD, Ireland should use the NRP to resource and progress full implementation of the UN CRPD.
- Invest in better and more comprehensive disability supports across a range of policy areas including employment, poverty, health and social care, housing, education and community services, as a means of future-proofing and building resilience in Ireland.
- In particular prioritise addressing the causes of the ongoing health and social care recruitment and retention crisis, that is causing huge problems for the delivery of services for disabled people.
- Ensure all budgetary and other relevant decisions are subject to meaningful and consultative equality proofing, including disability proofing in particular.

Specific Policy Area Recommendations

Health and Disability Services

The transition of roles and responsibilities for disability services from the Department of Health, DoH to the Department of Children, Equality, Disability, Integration and Youth, DCEDIY brings significant change. The current structure of service delivery is governed by the Transforming Lives programme, established to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland (2012). This programme delivered a targeted focus on reform of specialised disability social care services across congregated settings, day services, children services and personalised budget projects. The role of HIQA in the regulation of residential services for adults and children with disabilities has also been an important development since 2013.

Built around these policies, the core health disability budget has long been orientated towards traditional models of service. 85% of the specialist disability health budget funds residential and day services, 6 which support approximately 5% of people with disabilities. This funding model, and the structures that have been built around it, are out of touch with more innovative service models currently being delivered by community based voluntary disability organisations, and with the personcentred approach promoted by the UN CRPD. Unfortunately, as a result many disabled people experience a fragmented, duplicated, uncoordinated, and difficult to access system and set of supports.

DFI is calling for a dual process of policy reform and system review and redesign to recognise and respond to the changing demographic and service landscape of heath and social care in Ireland today.

To achieve this, a comprehensive, detailed assessment of needs and resources must be delivered. This should look beyond the system of data analysis available through the National Ability Supports System (NASS) database, in recognition of the wider profile of services provided to disabled people outside the silo of HSE disability services, across primary care, mental health and older persons services. Such system review would need to include a recognition of the existing depth of services and supports delivered at local, regional and national levels by voluntary disability organisations.

Key areas of concern

The learnings from COVID-19 must be built on to focus on ensuring a robust, resourced, preventative care model of support across the system of disability specialist services and social care. The government must priortise building and supporting a skilled workforce to deliver this model, addressing significant recruitment and retention challenges in the health sector. Interagency collaboration around workforce planning must be prioritised.

Increased and multiannual funding and models of transparent, uniform policies and procedures supporting equal access to services in line with demographic trends in disability and population growth is required to deliver disability services that are essential to the right to independent

⁶ Department of Health (2021). Disability Capacity Review to 2032: A Review of Social Care Demand and Capacity Requirements up to 2032.

living, including Personal Assistant Services, PAS, home support, alternative forms of respite, personalised budgets etc.

The government must look to international best practice across key areas of service delivery such as local area co-ordination, as a way of supporting people to participate in services and supports.

There remain over 1,300 people with disabilities under the age of 65 inappropriately placed in nursing homes. The Ombudsman's 2021 Wasted Lives report highlighted the experiences of some of these individuals and made recommendations to address this⁷. While Budgets 2021 and 2022 made some investment in this area, significantly more is needed.

Voluntary disability organisations services are facing significant workforce challenges. This is creating a huge risk to their ability to provide adequate services to adults and children with disabilities. The inequality in pay between Section 39 staff and equivalent staff working for Section 38 organisations and the HSE is one of the primary drivers of this crisis.

The issue of pay parity cannot be ignored and there is a need for this to be addressed by government so that Section 39 organisations are equally attractive workplaces for staff. Ireland is at full employment and the issue of supply of workers to fill posts is a disability sector-wide concern and must be addressed. This puts additional pressure on organisations to keep the workforce they have, under an environment in which they cannot compete with better pay and conditions elsewhere.

Over 90% of people with disabilities are supported through mainstream health and community services, rather than specialist disability services. Almost all people with disabilities will depend on access to mainstream health services as part of the management of their disability or health condition at some point. Ensuring integration between specialist disability services and mainstream health services so that the person's needs are responded to will be key in the context of the transfer of the HSE Disability Services programme to DCEDIY which is due to take place in March. There are ongoing issues with access to mainstream health services including staff shortages, long waiting lists and lack of funding and resources.

Early neuro-rehabilitation is vital to long-term recovery. The recovery window is at its optimum within the first two years for conditions such as acquired brain injury. Full implementation and resourcing of the

_

⁷ https://www.ombudsman.ie/publications/reports/wasted-lives/

⁸ Disability Capacity Review

Neurorehabilitation Strategy to create an integrated system that supports people throughout all stages of their journey should be a priority. As of the end of January 2023, 23,364 people were awaiting an outpatient appointment for neurology. 9,040 of these individuals have been waiting for longer than 12 months. Only 15% of patients have access to a community neurorehabilitation team, with only 2 of the promised 9 teams delivered across the 9 CHOs. Voluntary disability organisations play a vital role in the long term community rehabilitation of those with neurological conditions, however this is underappreciated and there is a lack of integrated care pathways. DFI and Neurological Alliance of Ireland have been working on a project with the HSE to map the role of voluntary organisations.

Investment in these crucial areas would be an investment in our future, and would save money in the long term. In particular, through the NRP, Ireland should:

- Ensure the UN CRPD is fully implemented across the government delivery of services and supports for people with disabilities.
- Facilitate timely reform of disability specific policy, recognising that Transforming Lives was developed prior to UN CRPD ratification, and does not adequately recognise either the current population of Ireland nor the profile of service delivery through voluntary disability organisations.
- Publish the Disability Capacity Review Action Plan and fund its implementation. The Disability Capacity Review found that to address both demographic changes, and unmet needs, disability spending to support those in receipt of funded services would need to be €800m-€1,250m higher than 2018 levels by 2032. It made recommendations for increased funding in a range of areas, which can be seen in the tables included as an Appendix to this submission.
- Address the deficit in data available to inform better service reform, design and delivery. There is a population of disabled people who are in effect excluded from accessing appropriate, timely intervention due to the lack of available data on their profile of need.
- Formally recognise and improve the integration of the role of the voluntary disability organisations in the delivery of disability specific services within the HSE system.

_

⁹ https://www.ntpf.ie/home/pdf//2020/09/nationalnumbers/out-patient/National02.pdf

¹⁰ Neurological Alliance of Ireland https://www.patientsdeservebetter.ie/#slider-0

- Support multiannual funding and regional HSE governance for effective, responsive and consistent service reform.
- Provide pay parity to staff in Section 39 organisations who are currently paid less than colleagues in equivalent roles in Section 38 organisations and the HSE, to address significant recruitment and retention challenges.
- Implement the Catherine Day Report¹¹ in full in collaboration with the Dialogue Forum, addressing multi-annual funding requirements, service level arrangement reform, partnership principles etc.
- Invest €26m to fully roll-out Specialist Clinical Rehabilitation Networks in every Community Health Organisation.
- Provide €17.5m funding for targeted community support packages to support people under-65 out of nursing homes and to continue work to prevent further admissions.

Poverty, Cost of Disability, Employment

The EU Commission has been highlighting concerns about Ireland's low disability employment rate and high poverty rates as part of the EU Semester process for years now. The 2022 Country Specific Report (CSR) for Ireland again emphasises specific concerns in this regard, concerns which DFI and other disability organisations have been calling on the government to prioritise for some time. The 2022 CSR noted that "the disability employment gap in Ireland was the largest in the EU, at 38.6%. These groups are also at an elevated risk of poverty and social exclusion." In the "Social scoreboard for Ireland" on page 47 of the report, the disability employment gap is the second worse ranking across the indicators tracked in the scoreboard, and Ireland is marked yellow for this indicator – "weak but improving". This scoreboard compares countries across the EU, and this is one of the only areas where Ireland is ranked below average – most other indicators are above or on average.

The CSR also highlights concerns about poverty, and again Ireland is underperforming here, relative to its wealth and development. The EU Commission notes that "concerns remain in relation to the availability of social services for disadvantaged groups, and the situation for homeless people, people with disabilities, single parent and low work intensity

¹¹ Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and social care services

https://commission.europa.eu/system/files/2022-06/2022-european-semester-country-reportireland_en.pdf p.15

households. In 2020, people with disabilities had an almost 14 pps higher chance of being at risk of poverty or social exclusion than the general population (33.9% versus 20%)"¹³.

At a national level, Ireland has made specific commitments on disability poverty and employment in the Roadmap to Social Inclusion, ie to:

- reduce the AROPE (At Risk of Poverty and Social Exclusion) rate from 36.9%, first to 28.7% (2025) and then to 22.7% (2030)
- increase the employment rate from 22.3%, first to 25% (2021) and then to 33% (2027).

However the Second Progress Report on the Roadmap show that despite these very clear targets, in fact things are disimproving. Ireland's AROPE rate actually *increased* in 2021 – going from 34% in 2020 to 38.9%¹⁴. Ireland ranks 24 of the EU 27, even though we are one of the wealthier countries in the EU, and our goal is to get to the top 10 EU countries by 2025. Given that Ireland's current AROPE rate is more than 10% higher than the 2025 goal, concerted action and resources will be needed to deliver this change.

The ongoing inflation and cost of living crisis has exacerbated the economic vulnerability faced by those who rely on our social protection system to survive. The 2022 CSO SILC Deprivation data paints an equally bleak picture. For example it shows that:

- 42.7% of people unable to work due to long-standing health problems (disability) live in enforced deprivation. This is 2.5 times higher than the national average of 17.1%.
- People unable to work due to long-standing health problems (disability) are most unable to afford to keep the home adequately warm (19.5%), compared with 5.7% of either employed or retired persons.
- People unable to work due to long-standing health problems (disability) are eight times more likely than the national average to be unable to afford a meal with meat, chicken, fish, or vegetarian equivalent every second day.

On disability employment Ireland is also performing badly, as the EU's CSR has again been flagging for a number of years. Ireland's rate of

¹³ https://commission.europa.eu/system/files/2022-06/2022-european-semester-country-reportireland en.pdf p48

¹⁴ https://www.gov.ie/en/organisation-information/be955a-social-inclusion-division/?referrer=http://www.gov.ie/socialinclusion/

employment for people with disabilities was almost 20% lower than EU averages in 2020, and there is no sign of this improving, although DFI does welcome recent initiatives in this regard, including the pilot of the 'early engagement' approach, and the ongoing review and reform of the Reasonable Accommodation Fund.

Another issue that perpetuates poverty is the additional cost of disability. The 2021 INDECON Report on the Cost of Disability, commissioned by the Department of Social Protection, provides significant and comprehensive policy evidence that people with disabilities have extra costs across a number of areas including mobility, transport, and communications, care and assistance services, equipment, aids and appliances, and medicine. The report concluded that "there are significant additional costs faced by individuals with a disability which are currently not met by existing programmes or by social welfare payments [our emphasis]."15 The report indicates extra costs in the range of €8,700-€12,300, and recommends tackling this through increased cash payments, enhanced access to services and targeted grant programmes. Disability and anti-poverty organisations have long called for a €20 weekly Cost of Disability payment as a first step in acknowledging these extra costs. The one-off Disability Support Grant in Budget 2023 was a welcome first acknowledgement by the social protection system of these costs, but ongoing, permanent and sufficient support will be needed into the future. This would also be a worthwhile investment as it would support many disabled people to enter the workforce and/or be more active in their community.

The general inadequacy of current social welfare rates was highlighted in recent years, when those unemployed due to the pandemic received a significantly higher level of social protection support to those unemployed for other reasons (including disability). Disability and anti-poverty organisations have for years called for a Minimum Essential Standard of Living, so that those relying on social protection are not condemned to poverty¹⁶.

The NRP should address these related issues. In its core recommendations, the EU Commission advised Ireland that when planning its expenditure it should take "into account continued temporary and targeted support to households and firms most vulnerable to energy price hikes" 17. Among those households would be those with disabled

¹⁵ https://www.gov.ie/en/publication/1d84e-the-cost-of-disability-in-ireland-research-report/

¹⁶ https://www.budgeting.ie/publications/mesl-2022/

¹⁷ https://commission.europa.eu/system/files/2022-05/2022-european-semester-csr-ireland en.pdf page 10

disabled family members, many of whom rely on Ireland's social protection system to survive.

In particular Ireland should:

- Develop a specific poverty reduction strategy for disabled people, given their disproportionately high poverty rates and the commitments in the Roadmap to Social Inclusion. Lay out the steps and actions to be taken each year to deliver the reduction targets, and allocate sufficient funding to 2025 to deliver them.
- Develop and resource a clear Action Plan to fully address the Cost of Disability over the next 3 years.
- Benchmark social welfare rates to a level above the poverty line, while taking the cost of disability into account. Use the Minimum Essential Standard of Living (MESL) recommendations as a guide for the level of social protection needed.
- Introduce a €20 Cost of Disability payment as an initial step to addressing the numerous extra costs associated with having a disability.
- Continue to prioritise targeted measures to support disabled people with the cost of living crisis.
- Ensure all budget decisions are subject to equality, gender and poverty proofing, specifically assessing their impact on disabled people, including taking into account the cost of disability.

Housing for All? Disability mainstreaming needed in housing policy

DFI and the Citizens Information jointly published a social policy report pm housing and disability last December, which found that people with disabilities face significant challenges when it comes to finding a suitable home to live in¹⁸. While acknowledging the severe housing crisis that Ireland has been experiencing, the report documents the disproportionate extent to which people with disabilities are failed by the system, and the range of challenges that they continue to experience in seeking to find a suitable home to live in.

Ireland is in an ongoing process of de-congregation and deinstitutionalisation for disabled individuals who historically lived in institutions, though progress has been slow even five years after the

¹⁸ https://www.disability-federation.ie/news/2022/12/07/people-with-disabilities-face-significant-challeng/

original 2018 deadline. There are also over 1,300 disabled people living in nursing homes, whose situation was highlighted by the Ombudsman's 'Wasted Lives' report. It is a concern that people under 65 are still entering nursing homes today due to a lack of alternative options. Decongregation for those in disability congregated settings and inappropriately placed in nursing homes must be further strengthened and resourced.

However, the vast majority of people with disabilities in Ireland live in the community, and experience many housing challenges in this context – mostly related to lack of sufficient resources, universally designed housing and joined up policy-making. People with disabilities should have the same options and opportunities to live in and be part of a community as everyone else. Article 19 of the UN CRPD commits signatories to "recognize the equal right of all persons with disabilities to live in the community, with choices equal to others." This is still not a reality for many people with disabilities in Ireland, who have very narrow and limited housing choices, if they have any choice at all.

Moreover, given the ongoing demographic trends that will see the number of people with a disability increasing by approximately 20% by 2026, ensuring that all housing policy factors in disability will be crucial to delivering sustainable development, effective strategic planning and the efficient delivery of well-planned homes in vibrant communities. The significant level of building due to take place under Housing for All must factor in disability and include universally designed and wheelchair liveable homes to future proof Ireland's housing stock. Well planned homes will be suitable for the whole life cycle, and accessible to all, and vibrant communities must include people with disabilities.

In this context the NRP should:

- Sufficiently fund, resource and implement the new National Housing Strategy for Disabled People 2022-2027.
- Increase the pace of decongregation of people with disabilities.
- Invest resources in supporting disabled people under 65 to move out of nursing homes, and to develop alternative support pathways to stop more people entering nursing homes.
- Address the problems in the system which prevent people from living independently, including the lack of funding for sufficient Personal Assistant and home support hours.
- Consider disability across all planning and housing initiatives and treat disability as a cross-cutting issue and objective, rather than a

- separate 'inclusion' objective. This should be continuously considered when delivering Housing for All.
- In particular, a move towards Universal Design++ and wheelchair liveable housing, and reform of Part M of the Building Regulations to set requirements for universal design will help to future-proof Ireland's housing stock.
- Increase the overall funding for Housing Adaptation Grants to support people to stay in their homes: raise the maximum grant amount, and factor the additional cost of disability into the means test thresholds.

Education and Skills, Young People

According to Census 2016 amongst people with disabilities aged 15 to 50, 13.7% had completed no education higher than primary level, compared to 4.2% of the general population. Also, 37% of people with disabilities aged 15 to 50 had completed third level education, compared to 53.4% of the general population. Research by AHEAD shows that in the last ten years the number of students with sensory disabilities has grown by less than half the rate of students with disabilities generally, so there is a need to focus on the barriers facing this particular cohort of students.

There are also ongoing issues with significant delays in assessments of need, which prevents children from getting the supports that they need. This also means that children of parents who can afford private assessments are more likely to get special education resources.

Ensuring that Further Education is accessible to students with disabilities is also a key concern. Further education courses can be more accessible for students with disabilities as a first step before higher education and/or employment. For adults who acquire disabilities further education courses can be a valuable way of retraining and regaining confidence, and can also offer a route back into education. However, supports for students with disabilities in further education are often underdeveloped in comparison to higher education.

Points of transition are a particularly challenging time in the lives of people with disabilities, as services and supports are not delivered in a joined-up way. Transitioning from early years education to primary school to secondary school to further/higher education to employment means

having to reapply for the same supports over and over again. A more joined up system is needed.

The financial barriers to engaging in education for people with disabilities also need to be overcome. There is a higher prevalence of students with disabilities in DEIS schools than non-DEIS schools, primarily due to the fact that people with disabilities are approximately twice as likely to experience poverty or social exclusion than the rest of the population. Students with disabilities also face additional costs to access education such as specialist transport, equipment, assistive technology etc.

The NRP should address these issues. In particular, it should:

- Fund a staff member at every Education and Training Board with the role of promoting disabled students' participation (cost: €1m).
- Allocate €2m for assistive technology supports, including a national network, loan library, national database, information system, training programme and peer support development programme.
- Extend the Fund for Students with Disabilities to students at all levels of Further Education, including part-time students.
- Invest €1.6m to appoint 20 additional National Educational Psychological Service, NEPS, psychologists.
- Invest in an education, training and employment support fund
- Extend the SUSI grant to part-time and postgraduate students
- Resource full implementation of the Education of Persons with Special Needs (EPSEN) Act 2004.

Regional and Community Development and Services

Facilitating people with disabilities to live equally in communities is just one part of an overall process towards equality and inclusion. Bricks and mortar, while necessary to achieve this, are not the only consideration. There is a real difference between living *in* the community and being *part* of the community.

Organisations who support these moves have reported an increase in social isolation for some people with disabilities now living in the community. There is also a balance to be struck between fulfilling health and physical care needs and ensuring that the recipients also have the same opportunity as others to influence and affect key decisions in their lives - both inside and outside the home.

Key funding decisions which shape the community we live in are increasingly being made through, and in partnership with, local government. The Reform of Local Government Act in 2014 opened the door to new decision-making structures at local level, tasked with the economic and community development of all 31 local authority areas in Ireland. These include decisions on how key rural and local development funding is spent, how local actions to address social exclusion are rolled out, as well as strategic decisions around infrastructure such as accessible public transport, employment training and education opportunities, as well as social and leisure activities.

Local Government is responsible for ensuring the participation and engagement of all local citizens in these decisions, and the ratification of the UN CRPD and Public Sector Duty requirements serve to reinforce those duties. To help make this a reality DFI recommends that the NRP;

- Increase the funding available both to Local Authorities and to community and voluntary groups to fund work to support people with disabilities at community and county level.
- Ireland should develop and implement participation and engagement strategies to support the inclusion and engagement of local citizens with disabilities in all plans and in local decision making.
- All plans and actions at local level should be disability proofed from point of development through implementation and evaluation.
- Implement the recommendations of the Loneliness Taskforce Report 2018 to combat social isolation.
- Fully implement the work of the Inter-Departmental Group at national level to support more joined up approaches locally. Greater connectivity and collaboration across all local agencies can maximise positive impacts at local and national levels.

Transport

As the world responds to climate change, there will inevitably be changes to our transportation networks. Some likely changes are fewer private cars, greener forms of public transport, and policies encouraging active travel. As these changes are made, and while the current transportation model and infrastructure remains in place, it is important that accessibility and universal design be a fundamental requirement and approach for all transportation modes – this will also future proof our transport infrastructure, in anticipation of an increasing older and disabled

population. Moreover, given ongoing accessibility issues, especially at rural level, disabled people sometimes cannot use public transport, and face significant extra costs due to needing to take an accessible taxi, for example.

To address this the NRP should;

- Mainstream an accessibility and universal design lens and approach in all areas of transport policy.
- All forms of public transport should be fully accessible and disability friendly. This must include training for staff on how to assist people with a wide variety of disabilities.
- Invest in increased accessibility and frequency of Local Link transport services.
- Proactively consult with and consider the concerns and needs of people with disabilities as regards all major changes to roads, footpaths, bike lanes and public transport.
- Urgently establish a Transport Support Scheme to replace the Mobility Allowance and other transport schemes as per the Ombudsman's longstanding recommendation.¹⁹

UN CRPD

Ireland has fallen behind many of its peer countries in ensuring the rights of people with disabilities, as is clear from this submission. In particular, this gap can be seen in employment, poverty, education, the extra cost of disability, health and PA services, and housing. The UN CRPD can be used as guidance to correct these inequities in Irish society, and delivering on it will help us achieve our SDG and EU Pillar of Social Rights targets also. Ireland should particularly focus on implementing the parts of the UN CRPD that address employment, an adequate standard of living, education, and independent living. Many of the other recommendations in this submission would contribute to this implementation. In addition, we recommend that Ireland:

- Pass and commence the Disability (Miscellaneous Provisions) Bill 2016.
- Requires each Department to prepare a plan to fully implement the UN CRPD in the policy areas within their remit.

20

¹⁹ https://www.ombudsman.ie/news/ombudsman-says-personal-t/index.xml

Conclusion

The social barriers that exist for people with disabilities are a societal responsibility, rather than one solely for the disability sector and the people affected. Given that people with disabilities make up 13.5% of the population in Ireland (ie one in eight people in the country), any NRP must explicitly consider disability. To create an Ireland where all can thrive and participate equally, much change is needed across the system of supports provided to disabled people.

in order to deliver for these people, their families and the communities all across the country that they live in, and to ensure inclusive development, significant change is needed. With 2023 being the five year anniversary of Ireland's ratification of the UN CRDP, Ireland has an opportunity to take leap forward by prioritising its implementation in the 2023 NRP.

There is a clear need to invest and future-proof our transport, housing and health infrastructure and services by mainstreaming a disability lens and approach, and by allocating sufficient resources through multiannual funding. It is also important to prioritise and tackle the social exclusion, low employment rates and economic vulnerability and deprivation that disabled people face in Ireland, which would have positive economic and social impacts. This year's NRP offers the opportunity to support the disabled people who live in every community, village and town across Ireland, and start to deliver on the vision of the UNCRPD.

Appendix

Tables from Disability Capacity Review, published in 2021.

The tables and the Capacity Review make recommendations for increased funding in a range of areas. These tables are on page 29 of the Review.

Table 1a: Estimate, additional annual funding required to meet demographic and unmet need – low

	Demography only			Demography + unmet need			
Type of disability service	2022	2027	2032	2022	2027	2032	
	€m	€m	€m	€m	€m	€m	
Residential - Minimum scenario	60	120	160	220	280	320	
Day services	8	30	60	40	60	90	
PA & home help	4	10	15	34	40	45	
Therapies	3	5	6	48	48	54	
Respite	2	3	4	18	21	25	
Community services	3	6	9	3	6	9	
Total (rounded)	80	170	250	350	450	550	

Estimates are indicative only. Totals may not add up due to rounding

Table 1b: Estimate, additional annual funding required to meet demographic and unmet need – high

	Demography only			Demography + unmet need		
Type of disability service	2022	2027	2032	2022	2027	2032
	€m	€m	€m	€m	€m	€m
Residential – Pre-recession scenario	60	120	160	400	500	550
Day services	40	140	250	70	170	280
PA & home help	4	10	15	34	40	45
Therapies	3	5	6	74	74	80
Respite	2	3	4	18	21	25
Community services	3	6	9	3	6	9
Total (rounded)	110	280	450	600	800	1,000

Estimates are indicative only. Totals may not add up due to rounding

DFI is about making Ireland fairer for people with disabilities.

We work to create an Ireland where everyone can thrive, where everyone is equally valued.

We do this by supporting people with disabilities and strengthening the disability movement.

There are over 120 member organisations in DFI. We also work with a growing number of other organisations that have a significant interest in people with disabilities.

DFI provides:

- Information
- Training and Support
- Networking
- Advocacy and Representation
- Research, Policy Development and Implementation
- Organisation and Management Development

Disability is a societal issue and DFI works with Government, and across all the social and economic strands and interests of society.

DFI, Fumbally Court, Fumbally Lane, Dublin 8

Tel: 01-4547978, Fax: 01-4547981 Email: info@disability-federation.ie Web: www.disability-federation.ie

Disability Federation of Ireland is a company limited by guarantee not

having share capital, registered in Dublin.

Registered No 140948, CHY No 6177, CRA No 20010584

