

Overview of UNCRPD Article 25 in Ireland

Right to Health

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Údarás Náisiúnta Míchumais
National Disability Authority

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Background to the UNCRPD Article review papers

The National Disability Authority (NDA) are developing a series of in-depth papers on individual United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articles. These papers detail the main data available relevant to specific Articles and provides an overview of key policies, programmes, services, supports and data that exist in the Irish context. They are not a critique of what is currently in place but rather a record of what exists. Nevertheless, there are instances where certain gaps or concerns are highlighted, including those advised by the NDA or other stakeholders.

These papers were primarily developed through desk research. However, the papers were also informed by the NDA's own work, updates and discussions at Departmental Disability Consultative Committees, the National Disability Inclusion Strategy Steering Group, and other relevant committees. They were also informed by interactions with the Disability Stakeholders Group and with persons with disabilities, particularly through participation on a range of working and advisory groups across Government Departments on areas related to NDIS actions. Given their factual nature a more direct consultation process with persons with disabilities was not conducted. However, the NDA conducts periodic consultations on issues related to articles of the UNCRPD and seeks to include the lived experience of persons with disabilities individually and through their representative bodies in our work.

The purpose of the papers are multiple. They were developed initially to support the development of the State Party report to the UNCRPD Committee. In line with the NDA's anticipated new statutory function under the UNCRPD, they are also intended to be useful to support the development by the Irish Human Rights and Equality Commission (IHREC) of the State's parallel report to the UNCRPD Committee. They will also be used internally as reference papers within the NDA. The NDA has published these documents on our website to make them available to a wider audience to support any work underway to develop shadow reports on implementation of UNCRPD in Ireland.

Due to the the changing nature of policies, programmes, services, supports and data these reports will date and we will endeavour to update them periodically to reflect any changes. The papers are not intended to be exhaustive but seek to provide a broad overview of the main issues of relevance to each article.

In the first instance five articles were reviewed and are available at <https://nda.ie/publications/others/uncrpd/series-of-papers-on-individual-united-nations-convention-on-the-rights-of-persons-with-disabilities-uncrpd-articles.html>

These were selected to reflect some of the main topics of concern to the stakeholders noted above and to include some of the cross-cutting issues such as children and women with disabilities. It is intended that the NDA will develop further papers during 2021 and 2022.

- Article 7, Children with Disabilities
- Article 8, Awareness Raising
- Article 26, Work and employment
- Article 28, Adequate Standard of Living and Social Protection
- Article 31, Statistics and Data Collection

Introduction

The ratification of the UNCRPD by Ireland in 2018 with a specific article on health providers an impetus to focus on the rights of people with disabilities to access appropriate health care.

Following the convention text below this paper then examines the situation of people with disabilities in relation to accessing appropriate health care, looking at key data and research, policies, legislation, and then looking at some specific areas such as access to tertiary care and primary care and preventative and public health programmes.

In Ireland the delivery of health and social care is the responsibility of the Department of Health (in terms of policy and strategy) and the Health Services Executive (in terms of service delivery and service commissioning). However, this paper is largely focused on health and health care rather than social care. Social care is / will be dealt with in other NDA UNCRPD papers.

Convention text

Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to

other persons, including in the area of sexual and reproductive health and population-based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people's own communities, including in rural areas;

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Type of Right

The right to health is a social right and is therefore subject to progressive realisation.

Key data and statistics

Health profile of people with disabilities

Mortality rates

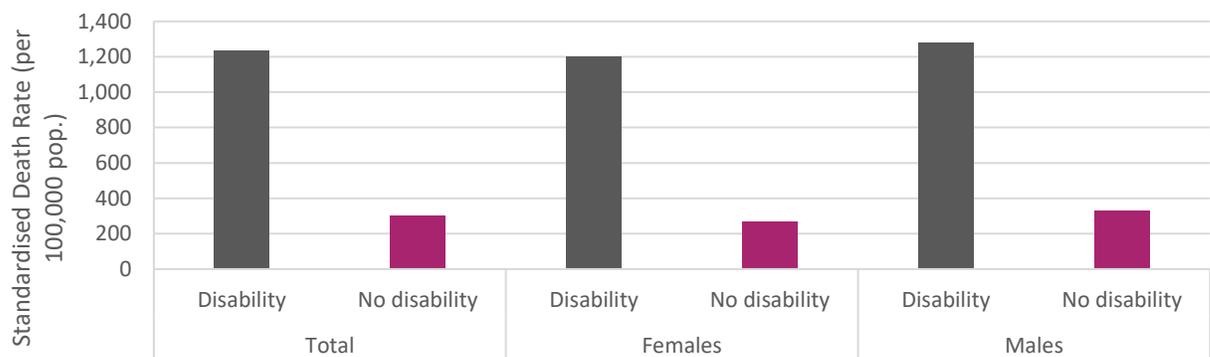
In 2019, the Central Statistics Office published analyses of the characteristics of people who died in the twelve month period following the 2016 Census.¹ It uses standardised mortality rates which take into account different characteristics such as age so that rates can be compared across groups. The standardised mortality

¹ Central Statistics Office (2019) **Mortality Differentials in Ireland 2016-2017**, available at <https://www.cso.ie/en/releasesandpublications/in/mdi/mortalitydifferentialsinireland2016-2017/>.

rate for persons with a disability was 1,232 per 100,000 people in 2016-2017 (1,197 for females and 1,280 for males). The rate for persons without a disability was lower at 302 per 100,000 people (268 for females and 329 for males) (see Figure 1 below). Because persons with disabilities make up only 13.5% of the population, the absolute numbers of persons without disabilities dying is higher than those with a disability. However, the standardised mortality rate for:

- persons with disabilities was 4.1 times higher than that of persons without disabilities,
- females with a disability was 4.5 times higher than that of females without a disability, and
- males with a disability was 3.9 times higher than that of males without a disability²

Figure 1. Standardised Death Rates 2016-2017 by Sex and Disability



An increase in relative standardised mortality rates for persons with disabilities compared to persons without disabilities may possibly reflect a lack of access to health or social care or poorer quality health and social care for persons with disabilities.³ The NDA has observed that this particular analysis may raise more questions than it answers and plans to look at it in more detail. Due to some changes in methodology, these data are not directly comparable to a similar analysis conducted after the last census in 2006-2007.⁴

² National Disability Authority (2020) **Mid-term Review of Progress under the National Disability Inclusion Strategy Indicators**, Dublin: NDA.

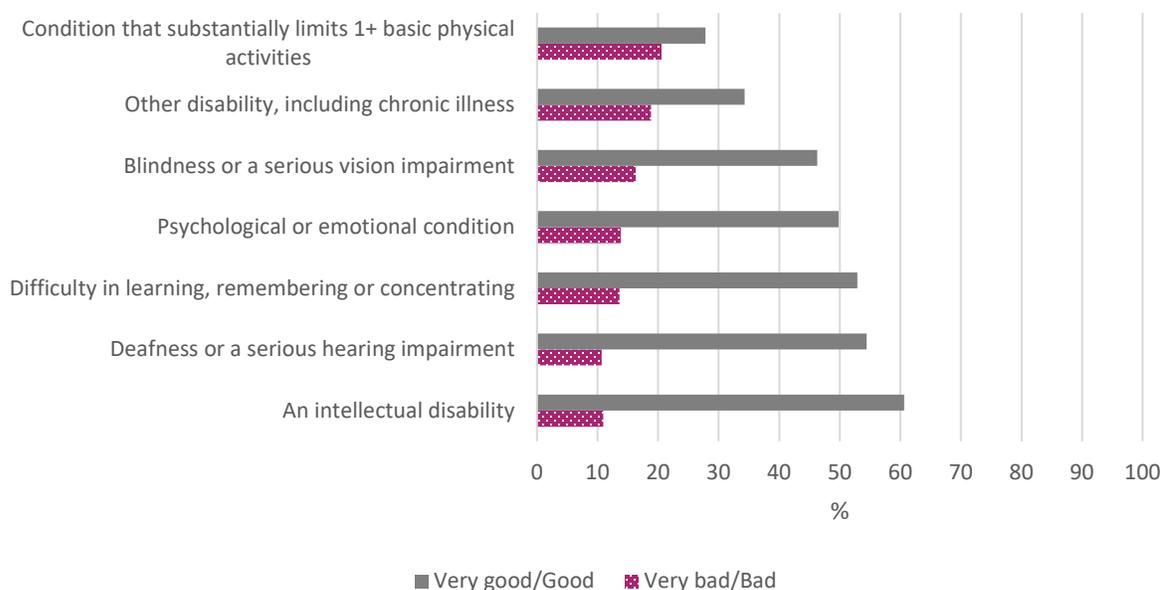
³ ibid

⁴ According to the CSO there were variations in the matching rate across the various age-groups. In particular there was a significantly lower match rate for deaths in the 20 - 54 year

Self-reported health

Information available through the Central Statistics Office shows that there is a stark difference in the percentage of persons with and without disabilities with regards to how they report their general health (Figure 2, CSO Census 2016).⁵ Almost every person (92.7%) without a disability reports their health as being good or very good. This compares to 51.2% of persons with a disability. Similarly, 0.1% of persons without a disability report their health as bad or very bad, compared to 11.0% of persons with a disability. When looking at self-reported general health of people with different types of disabilities, people with a condition that substantially limits one or more basic physical activity and people with other disabilities including chronic illness are more likely to report having bad or very bad health (Figure 2). People with intellectual disabilities are least likely to report bad or very bad health.

Figure 2. General health of people according to type of disability in 2016



age-groups. This may lead to over-estimation of life expectancy values since the matched mortality records will have less deaths at younger ages than the overall mortality file. Furthermore, since new matching methods, data sources and life table graduation methods have been used in this release, the current statistics are not directly comparable with the previous Mortality Differentials statistics for 2006/2007.

⁵ National Disability Authority (2020) **Mid-term Review of Progress under the National Disability Inclusion Strategy Indicators**, Dublin: NDA.

Levels of health screening

In 2019, the Irish Health Survey found that persons with a disability had higher or similar levels of health screening than persons without a disability.⁶ 14% percent of women with a disability had a mammogram in the previous 12 months compared to 13% of persons without a disability. Corresponding figures for cervical smear test were 17% versus 20% and for a blood pressure check the figures were 88% versus 65. Wave 3 of the Intellectual Disability Supplement to TILDA (**IDS-TILDA**) found that rates of flu vaccination amongst people with an intellectual disability over the age of 40 were 90.9%, substantially greater than for the general older population, where 47.5% were reported to have had a flu vaccination.⁷ Participants reported accessing health screening services including prostate cancer checks (77.1%) and breast checks (77.3%). Levels of breast checks among women with intellectual disabilities were comparable with the general older population. In Wave 3 of TILDA, 64.6% of older adult women in the general population reported that they check their breasts for lumps regularly and 54.7% of older adult women in Ireland reported that they had a mammogram since their last interview, comparable to 57.2% of IDS-TILDA participants. Rates for cholesterol checks were found to be higher among IDS-TILDA participants than for the older general population.

The NDA's research on decongregation⁸ also indicates that people in residential settings – both community and institutional – are the subject of very regular health monitoring. In addition to regular check-ups with GPs and psychiatric/psychology services, individuals' weight is usually monitored and this can lead to staff exercising control over their diets, particularly in congregated / institutional settings. The research suggest that while some residents require careful monitoring due to poor or unstable health, others are healthy and fit and do not need, and perhaps do not want, their health to be closely monitored⁹.

Levels of polypharmacy

It is possible that a by-product of higher levels of health monitoring amongst persons with a disability is the poly-pharmacy experienced by many, which can result in unwanted side effects and negatively impact health outcome.

⁶ Central Statistics Office (2021). Figures provided by the CSO to the NDA.

⁷ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, p.106.

⁸ NDA (2021) Moving In, Moving On. Due to be published by end of 2021.

⁹ NDA (2021) Moving In, Moving On. Due to be published by end of 2021.

The IDS-TILDA report finds that polypharmacy was high amongst Wave 3 participants at 39.5% and excessive polypharmacy at 32.7%, with 47.4% of those taking 3-4 medications at Wave 2 having progressed to taking 5-9 medications (polypharmacy) at Wave 3.¹⁰

More people with an intellectual disability (72%) aged over 40 were taking five or more medications compared to 32% of people without an intellectual disability aged over 55. This may be a result of the higher health needs of those with an intellectual disability or communications challenges in the relationship between healthcare provider and the individual, and the NDA advises that this area would require further work and examination.

Health outcomes

The Positive Ageing Indicators report¹¹ shows older people with intellectual disabilities have worse health than older people without a disability, with 65% of people aged over 55 having a chronic disease compared to 79% of people with an intellectual disability aged over 40.

Initial findings from the NDA's work on decongregation indicates that some of the positive health outcomes that have flowed from deinstitutionalisation are not related to medical input, but rather relate to increased physical activity, quieter calmer environments, eating a more varied diet with more fresh food etc.

Discrimination in healthcare

Research undertaken by the Economic and Social Research Institute and the Irish Human Rights and Equality Commission found that people with disabilities were most likely to report discrimination when accessing health services, though the situation changed considerably over time. In 2004, one-in-four reports of discrimination made by people with disabilities in the Equality module of the Quarterly National Household Survey related to health services, but this figure fell to 21% in 2010 and 19% in 2014.¹²

¹⁰ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, p.78.

¹¹ McGlinchey, E., McCallion, P., McDermott, S., Foley, M., Burke, E.A., O'Donovan, M-A., McCausland, D., Gibney, S., McCarron, M. (2019) **Positive Ageing Indicators for People with an Intellectual Disability 2018**, Dublin: Trinity Centre for Ageing and Intellectual Disability.

¹² Economic and Social Research Institute and the Irish Human Rights and Equality Commission (2018) **Disability and Discrimination in Ireland: Evidence from the QNHS Equality Modules 2004, 2010, 2014**, Dublin: ESRI & IHREC, p.26.

The research attributes the higher degree of likelihood of discrimination in this area to the fact that people with disabilities interact with health services on a much more frequent basis than those without disabilities, and therefore have a greater prospect of exposure to potential discrimination.¹³ The NDA notes that it is unclear what particular health services or aspect of the health service is giving rise to discrimination against people with disabilities (e.g. primary, specialised or acute care) or in what part of the process of accessing healthcare services the discrimination is encountered (e.g. in obtaining an appointment, in gaining physical access to services, time spent on the waiting list, quality of care and aftercare). The ERSI research on disability and discrimination doesn't look at intersectionality and discrimination. Intersectionality and the Irish health services is discussed further below. Further exploration in this regard may be necessary.

Irish Healthcare System

Ireland's healthcare system is characterised by a complex mixture of public and private delivery and financing, and multiple eligibility tiers.

Public Healthcare System

Entitlement

Under the provisions of the Health Act 1970 (as amended), entitlement to public health services in Ireland is primarily based on residency and means. Any person, regardless of nationality, who is accepted as being ordinarily resident in Ireland, is entitled to either full eligibility or limited eligibility for public health services.

Persons who are ordinarily resident and who satisfy a means test, and therefore with full eligibility, receive a 'Medical Card'.¹⁴ The Medical Card provides free access to a range of services including general practitioner services, prescribed drugs and medicines, all in-patient public hospital services in public wards including consultants services, all out-patient public hospital services including consultants services, certain dental services, ophthalmic and aural services and appliances and a maternity and infant care service.

From 1st December 2018, the medical card earnings disregard for persons in receipt of Disability Allowance was significantly increased, from €120 to €427 per week. As a result, the earnings of someone in receipt of Disability Allowance that can be disregarded under the medical card assessment process has increased

¹³ *ibid*, p.x.

¹⁴ For more information, see the website of the Health Service Executive at <https://www2.hse.ie/medical-cards/>.

from €6,240 a year to €22,204.¹⁵ In practical terms, this measure has enabled persons in receipt of a Disability Allowance payment to have a greater earnings capacity and still retain their medical card.

Those whose income is above the maximum threshold for eligibility may be granted a Discretionary Medical Card. In deciding whether to make such a grant, the HSE considers whether expenditure on personal medical expenses, and/or medical expenses for dependents, would result in 'undue financial hardship' being placed on the applicant.¹⁶ In practice, this scheme covers people with disabilities and medical conditions who have significant medical expenses.

Persons not eligible for any Medical Card, may satisfy the means test for a General Practitioner or GP visit card. The GP visit card allows a person to visit a participating family doctor for free, although it does not cover hospital charges, GP out-of-hours services or prescribed drugs.¹⁷ All persons under the age of 6 years and over the age of 70 years are eligible for a GP visit card. Budget 2022 contained a commitment to expanding eligibility for the GP visit card to children up to 7 years of age.

At the end of 2020, 1,613,015 people in Ireland held a medical card and 533,379 held a GP visit card; in total, 2,146,430 held either card, 43% of the population.¹⁸

Persons with limited eligibility (those not awarded a medical card or GP visit card) are eligible for in-patient and outpatient public hospital services including consultant services, subject to certain charges.

State agencies and regulators of services

Health Service Executive

Statutory responsibility for the provision of health services is vested in the Health Service Executive under the Health Act 2004 which provides that the Health Service Executive has the responsibility to manage and deliver, or arrange to be delivered on its behalf, health and personal social services. The HSE funds public hospitals and certain social care services directly under its authority, and is also

¹⁵ Department of Health, New Medical Card Measures to Remove Barriers to Work for People with Disabilities – over 250% increase in earnings disregard, 30 November 2018

<<https://www.gov.ie/en/press-release/c4f82d-new-medical-card-measures-to-remove-barriers-to-work-for-people-with/>>.

¹⁶ HSE (2019) **Medical Card and GP Visit Card National Assessment Guidelines**, Dublin: HSE, p.36.

¹⁷ For more information, see the website of the Health Service Executive at <https://www2.hse.ie/services/gp-visit-cards/gp-visit-cards.html>

¹⁸ HSE (2021) **National Service Plan 2021**, Dublin: HSE, p.139.

the channel for state funding to voluntary organisations and other organisations that provide health and personal social care services. These are defined under Sections 38 and 39 of the Health Act 2004. Section 38 and 39 organisations, which are wholly or largely funded by the State, are generally autonomous in terms of governance arrangements.

In 2019, an Independent Review Group published a report which examined the role of voluntary organisations in public health and personal social care settings and made recommendations on the future evolution of their role. The recommendations addressed issues such as ownership and control of state funded assets, governance arrangements, the mapping of service provision by voluntary providers, and the development of a list of essential services which the state would fund.¹⁹

Health Information and Quality Authority (HIQA)

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive continuous improvement in Ireland's health and personal social care services, monitor the safety and quality of these services and promote person-centred care for the benefit of the public. The Authority's mandate extends across the quality and safety of the public, private (within its social care function) and voluntary sectors. Reporting to the Minister for Health and the Minister for Children, Equality, Disability, Integration and Youth, the Health Information and Quality Authority has statutory responsibility for:

- Setting Standards for Health and Social Services;
- Registering and inspecting residential centres for older people and residential disability centres;
- Monitoring the quality and safety of health and personal social care services; and
- Investigating as necessary serious concerns about the health and welfare of people who use these services.

Mental Health Commission & Inspectorate of Mental Health Services

The functions of the Mental Health Commission are to promote, encourage, and foster the maintenance of high standards and good practices in the delivery of mental health services and to take all reasonable steps to protect the interests of detained patients.

¹⁹ Department of Health (2019) **Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services**, Dublin: DoH.

The Inspectorate of Mental Health Services is required by law to visit and inspect every approved centre annually and, as the Inspectorate thinks appropriate, to visit and inspect any other premises where mental health services are being provided. As part of the inspection process, the functions of the Inspectorate include ascertaining the degree of compliance by approved centres with any applicable Code of Practice or statutory regulations.

Private healthcare system

Alongside the public healthcare system, Ireland has a voluntary private health insurance market. The supplementary element of private health insurance in Ireland provides cover for hospital services, while the complementary element provides partial reimbursement of fees for day-to-day medical expenses including, inter alia, visits to GPs, physiotherapists, opticians, dentists and alternative practitioners, as well as A&E charges. The average premium paid per insured person in 2020 was €1,142.²⁰

All private health insurance providers are registered with and regulated by the Health Insurance Authority. Based on CSO population estimates, the percentage of the population with inpatient health insurance plans stood at 46% at the end of December 2019.²¹ According to the Health Insurance Authority, among the key drivers of demand for private health insurance in Ireland are the perceived high costs of medical treatment and a lack of confidence in the standard of, and access to, public health services.²²

The NDA is aware that the Irish health system has been criticised for being a two-tier system, whereby private patients receive preferential treatment. One of the key issues that leads to such criticism is the degree of overlap between the public and private funding and delivery of healthcare in Ireland.²³

The total number of people with disabilities with private health insurance is not clear. According to the IDS-TILDA Wave 3 report, private health insurance was low for people with an intellectual disability at 0.5% compared with 35% reported

²⁰ Health Insurance Authority (2021) **Annual Report 2020**, Dublin: HIA.

²¹ Health Insurance Authority, Market Figures, December 2019
<<https://www.hia.ie/sites/default/files/Market%20Figures%20Dec%202019.pdf>>.

²² Health Insurance Authority (2018) **The Irish Healthcare System: An Historical and Comparative Review**, Dublin: HIA, p.53.

²³ Health Insurance Authority (2018) **The Irish Healthcare System: An Historical and Comparative Review**, Dublin: HIA, p.47.

for the TILDA population.²⁴ However, almost all older people with an intellectual disability had access to a medical or GP card (95.3%), compared with 38% of the general older population.

The Health Insurance Acts (1994 – 2015) provide a legislative basis for the four principles of private health insurance in Ireland. These principles are:

- lifetime community rating
- open enrolment
- lifetime cover
- minimum benefit

The legislative framework is designed to ensure that people pay the same premium for the same cover regardless of age, gender or health status.

Part 4 of the Disability Act, 2005 provides protections in relation to the health insurance industry (and other sectors) using genetic test results to inform decisions around an individual's cover or premium.

The European Commission has noted that the Irish healthcare system is commonly referred to as 'two-tiered' because people with private health insurance (or who are otherwise able to pay) obtain faster access to diagnostics and hospital treatments, even from public providers.²⁵ At the end of July 2021 there were 567, 584 people on hospital outpatient waiting lists²⁶ and 69, 597 on hospital inpatient / Day case waiting lists²⁷. Though it should be noted that Covid-19 related disruption to the health services has inflated these figures.

²⁴ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, p.103.

²⁵ European Commission (2017) **State of Health in the EU Ireland Country Health Profile 2017**, Brussels: EC, p.7.

²⁶ National Treatment Purchase Fund, 2021a, Outpatient by Hospital as at 29/07/2021 <https://www.ntpf.ie/home/pdf//2021/07/nationalnumbers/out-patient/National01.pdf>

²⁷ National Treatment Purchase Fund , 2021b, Inpatient/Day Case as at 29/07/2021 <https://www.ntpf.ie/home/pdf//2021/07/nationalnumbers/in-patient/National01.pdf>

Policy landscape

Sláintecare

The Oireachtas Committee on the Future of Healthcare was established to devise cross-party agreement on a single, long-term vision for health and social care and the direction of health policy in Ireland. The committee produced the **Sláintecare Report**, which was adopted by the government and published in May 2017.²⁸ The Sláintecare vision is to achieve a universal single-tier health and social care system where everyone has equal access to services based on need, and not ability to pay. According to the report, health care delivery should take place in primary care and social settings meeting patients' care needs in an integrated way across sectors. The report identifies measures structured around the domains of population health, entitlement and access, care integration, funding and governance.

The implementation costs are estimated to amount to €5.8 billion over a ten-year period as a result of service expansion and required investment in infrastructure and eHealth.

The Sláintecare Action Plan committed to conducting a Disability Capacity Review. The Disability Capacity Review was published by the Department of Health in 2021 (discussed further below) and identifies the need for increased investment in disability services of between 550 and 1 000 million up to 2032.

Healthy Ireland

Healthy Ireland – A Framework for Improved Health and Wellbeing 2013– 2025 is the national framework for action to improve the health and wellbeing of the people of Ireland.²⁹ Healthy Ireland takes a whole-of-government and whole-of-society approach to improving health and wellbeing and the quality of people's lives. It focuses on prevention, reducing inequalities and keeping people healthier for longer.

Drugs and Alcohol

Reducing Harm, Supporting Recovery lays out the direction of government policy on drug and alcohol use until 2025.³⁰ The strategy aims to provide an

²⁸ Committee on the Future of Healthcare (2018) **Sláintecare**, Dublin: Houses of the Oireachtas.

²⁹ Department of Health (2013) **Healthy Ireland – A Framework for Improved Health and Wellbeing 2013– 2025**, Dublin: DoH.

³⁰ Department of Health (2019) **Reducing Harm, Supporting Recovery 2017-2025**, Dublin: DoH.

integrated public health approach to drug and alcohol use, focused on promoting healthier lifestyles within society. The strategy contains a 50 point Action Plan from 2017 to 2020, and provides the scope to develop further actions between 2021 and 2025 to ensure the continued relevance of the strategy to emerging needs into the future.

The Strategy recognises the link between substance misuse and mental health issues, and also identifies a link between substance misuse and early school leaving, and states that persons with learning disabilities are at risk in this regard. One of the actions detailed in the strategy relates to improving access to services for people who have a co-occurring mental health and substance use problem.

National Trauma Policy

In 2018, the Trauma Steering Group published a trauma policy for Ireland. The report recommends the establishment of an inclusive trauma system, where a network of facilities and services co-ordinate in the care of injured patients along standardised pathways.³¹ The primary aim of the development of a **Trauma System for Ireland** is to improve patient outcomes by reducing preventable death and disability from both intentional and unintentional injuries.

National Cancer Strategy 2017-2026

The **National Cancer Strategy** recognises that patients with cancer can experience cancer-related distress and outlines a proposed model of hospital-community psycho-oncology and psycho-social care.³² Psycho-oncology commitments detailed in the Strategy include the appointment of a National Clinical Lead for Psycho-oncology in order to drive the delivery of networked services and establishment of a dedicated service within each designated cancer centre to address the psychosocial needs of patients with cancer and their families, which will operate through a hub and spoke model.³³

Patient Safety Strategy 2019-2024

The HSE's Patient Safety Strategy seeks to improve the safety of all patients by identifying and reducing preventable harm within the health and social care system.³⁴ Commitment No.4 seeks to reduce common causes of patient harm and one of the patient safety improvement priorities in this regard is to improve patient safety for those with disabilities and mental health issues.

³¹ Department of Health (2018) **A Trauma System for Ireland**, Dublin: DoH.

³² Department of Health (2017) **National Cancer Strategy 2017-2026**, Dublin: DoH, p.91.

³³ Department of Health (2017) **National Cancer Strategy 2017-2026**, Dublin: DoH, p.91.

³⁴ Health Service Executive (2019) **Patient Safety Strategy 2019-2024**, Dublin: HSE.

In 2019 an independent Patient Advocacy Service was established to support those wishing to make a complaint about their experience of the public health service; and provide support to patients who may have been affected by a patient safety incident.³⁵

National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland

The National Strategy and Policy, originally intended to cover the period 2011-2015, outlines a national framework for the provision of neuro-rehabilitation services in Ireland.³⁶ An Implementation Framework for the Strategy, covering the period 2019-2021, describes the design and service delivery required to implement the Strategy.³⁷

Disability Services

According to the HSE 2020 Service Plan, disability services seek to support and enable people with disabilities to live the life of their choosing in their own homes, in accommodation that is designed and / or adapted as necessary to meet their needs, enabling them to live ordinary lives in ordinary places as independently as possible.³⁸ HSE disability services include a range of health, social care and community services such as personal assistance services, home care, respite care, residential care and day care (some of these are dealt with in the Article 19 and Article 27 papers in this series).

The total budget allocated to disability services in 2019 was €1,915.8 million, while the 2020 budget increased to €2,049.5 million.³⁹ The Chairperson of Working Group I of the Transforming Lives programme and the NDA undertook forecasting work in order to estimate the demand for HSE-funded disability services up to 2026.⁴⁰ The report estimates that current expenditure needs to increase by approximately 19-35%, and capital spending requirements

³⁵ Patient Advocacy Service - <https://www.patientadvocacyservice.ie/>

³⁶ Department of Children and Health (2011) **National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland**, Dublin: DoCH.

³⁷ Health Service Executive (2019) **National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland: Implementation Framework 2019-2021**, Dublin: HSE.

³⁸ Health Service Executive (2019) **National Service Plan 2020**, Dublin: HSE, p.56.

³⁹ Ibid, p.110.

⁴⁰ Working Group I (2018) **Transforming Lives: Report on Future Needs for Disability Services**, Dublin: Working Group I.

need to increase by between €100-€300 million. The report notes that gross spending on disability services fell between 2009 and 2016, at a time when the population requiring services grew, which has resulted in significant areas of unmet need, spanning residential, respite, therapy and other services.

Disability Capacity Review

In July 2021 the Department of Health published Disability Capacity Review to 2032 - A Review of Disability Social Care Demand and Capacity Requirements up to 2032. The Capacity Review sets out the implications of demographic change and of meeting unmet demand for disability services. The costs of meeting both the changing demographic profile and unmet need is estimated to be between 550 million and 1000 million by 2032 over current expenditure levels.

The NDA is also aware of the calls of disability service providers of the need to provide more funding to the sector.

Therapy services

The HSE provides a range of therapy services to adults with disabilities including speech and language therapy, occupational therapy and physiotherapy. Based on unmet need recorded on the disability databases, provision of adult therapy services would need to double from its 2016 level to meet current demand.⁴¹ As the number of staff currently providing such services is not known, and service providers suggest that the expansion to date of children's therapy services has been achieved partly through cutting services for adults, it is not possible to put any firm figures on the cost of meeting this shortfall. However, by extrapolating ratios from children's services on staff numbers per service user, an additional 480 staff are required now, and a further 100 by 2026.⁴²

Respite care

Respite care services are provided both directly by the HSE and by funded service providers. Respite is provided to people with disabilities through overnight, short-term or holiday stays in an approved centre. The HSE 2020 Service Plan allocated an additional €5million to respite services. In 2020, it is anticipated that 166,183 nights respite care (2019: 182,506) and 33,712 day only respite sessions (2019: 32,662) will be provided, benefiting 6,060 people with

⁴¹ Ibid, p.10.

⁴² Ibid, p.63.

disabilities (2019: 6,559).⁴³ At the end of September 2019, 16,856 nights respite care had been provided, and 79,911 day only respite sessions.⁴⁴

Respite care estimates from the Health Research Board show that about 1,600 people with intellectual disabilities will require a service by 2021. Assuming a further 10% for additional respite provision for people with physical and sensory disabilities at the median stay of 17 nights, it is estimated that an additional €11 million in current expenditure is required for extra respite provision (from 2017 levels), and additional capital expenditure of €10million.⁴⁵

Respite services for children and adults with a disability are covered by the National Standards for Residential Services for Children and Adults with Disabilities and subject to inspection and registration with HIQA⁴⁶, however there is no national policy framework around the provision of respite services.

In 2019, the NDA commissioned research which explored the experiences of users of disability respite services.⁴⁷ Overall, participants were very satisfied with their respite services and rated the quality highly. There were high levels of satisfaction with staff, the comfort of bedrooms and social spaces, and many participants spoke about the importance of respite in terms of their own wellbeing and independence, as well as building new relationships. The negative aspects of respite included being away from family, some negative interactions with staff and lack of accessibility and transport associated with respite houses and centres in rural locations. Participants also noted that respite services are limited, with some waiting more than two years from the point of referral. Some participants also expressed concerns about the lack of choice in terms of the respite they received, or the frequency of their respite service.

Accessible and disability-sensitive healthcare

The HSE's **National Guidelines on Accessible Health and Social Care Services** provide practical guidance to all health and social care staff about how they can provide accessible services.⁴⁸ The guidelines outline how to deliver

⁴³ Health Service Executive (2019) **National Service Plan 2020**, Dublin: HSE, p.137.

⁴⁴ Health Service Executive (2019) **Performance Profile July – September 2019 Quarterly Report**, Dublin: HSE, p.26.

⁴⁵ Working Group 1 (2018) **Transforming Lives: Report on Future Needs for Disability Services**, Dublin: Working Group 1, p.9.

⁴⁶ HIQA (2013) **National Standards for Residential Services for Children and Adults with Disabilities**, Dublin: HIQA.

⁴⁷ National Disability Authority (2019) **Exploring the Experiences of Users of Disability Respite Services in Ireland**, Dublin: NDA.

⁴⁸ Health Service Executive (2016) **National Guidelines on Accessible Health and Social Care Services**, Dublin: HSE & NDA.

disability-friendly services, how to make premises accessible, how to accommodate additional needs of people with disabilities, and how to communicate with people with disabilities in ways that are appropriate to their needs.

The **Dementia Friendly Hospital Guidelines from a Universal Design Approach** provide detailed guidance in relation to dementia specific design issues and the Universal Design (UD) of acute hospitals in Ireland.⁴⁹ The HSE has also appointed a National Specialist in Accessibility who provides guidance, advice and strategic support in the promotion of access for people with disabilities. The purpose of the role is also to develop a strategic framework for the HSE on the implementation of Part 3 of the Disability Act 2005, which places an obligation on public bodies to make their buildings and services accessible.⁵⁰

An omnibus survey carried out by Ipsos MRBI for the NDA in 2011 examined the accessibility of community facilities. The research revealed that community facilities that had the lowest perceived access among disability households was the doctor's surgery.⁵¹ At the time just over a third (34%) of physical disability households reported that they could not access their local doctor's surgery without having to go up or down steps. Previous NDA commissioned reports have also highlighted that not all General Practitioner surgeries are accessible⁵².

Healthcare professionals

A variety of education, training and capacity-building materials are available to HSE healthcare professionals on disability-related issues. For instance, the HSE has developed Practice Guidance for Mental Health Services, which is supported by an extensive training programme.⁵³ There is also an eLearning module on the New Directions policy for all management and frontline staff working

⁴⁹ Grey, T., Xidous, D., Kennelly, S., Mahon, S., Mannion, V., de Freine, P., Dockrell, D., de Siún, A., Murphy, N., Craddock, G., O'Neill, D. (2018) **Dementia Friendly Hospitals from a Universal Design Approach: Design Guidelines**, Dublin: HRB.

⁵⁰ More information is available on the HSE website at the following link:
<https://www.hse.ie/eng/about/who/qid/person-family-engagement/universal-access/>.

⁵¹ Ipsos MRBI (2011) **Survey on National Disability Strategy Indicators 2011**, Dublin: NDA, p.12.

⁵² Pillinger, J. (2012) Review of literature and guidelines on accessibility in healthcare that underpin the National Guidelines on Accessible Primary, Community and Hospital Services. Dublin: NDA.

⁵³ Health Service Executive (2017) **Best Practice Guidance for Mental Health Services**, Dublin: HSE.

in HSE funded Adult Day Services.⁵⁴ The HSE is currently developing training and capacity building materials to assist staff in dealing with the implications of the Assisted Decision Making (Capacity) Act 2015.

Primary Care

Primary Care Therapies

Primary care services cover many of the health or social care services available in the community, outside of the hospital setting. Primary care therapy services include physiotherapy, speech and language therapy and occupational therapy. The numbers detailed in Table 1 and 2 below relate to all persons seeking access to primary care therapies, not just persons with a disability.

⁵⁴ The eLearning Module for New Directions - Putting New Directions into Practice was launched in September 2019 and can be accessed on the HSElanD online learning and development portal.

Table 1: Assessment Waiting List

Physiotherapy	Expected Activity / Target	January – December 2019
Number seen	581,661	568,736
Total number waiting	34,023	38,177
% waiting less than 12 weeks	-	50.2%
Number waiting more than 52 weeks	-	3,051
Occupational Therapy		
Number seen	356,314	382,219
Total number waiting	31,220	34,343
% waiting less than 12 weeks	-	26.7%
Number waiting more than 52 weeks	-	10,017
Speech and Language Therapy		
Number seen	279,803	273,639
Total number waiting	14,236	16,710
Number waiting more than 52 weeks	-	1,410

Source: HSE Performance Report, October – December 2019⁵⁵

Table 2: Treatment Waiting List

Speech & Language Therapy	Expected Activity / Target	January – December 2019
Total number waiting	7,939	9,039
Number waiting more than 52 weeks	-	1,617

Source: HSE Performance Report, October – December 2019⁵⁶

⁵⁵ More up to date figures are available but they have been significantly impacted by measures taken to respond to Covid 19. The Q4 2019 figures are quoted as they are the most recent pre-pandemic figures available.

⁵⁶ See footnote 55 above.

Oral Health

Key data and statistics

National Oral Health Survey

The NDA notes that a National Oral Health Survey of adults with an intellectual disability was undertaken in 2003. It comprised of 281 adults with an intellectual disability in 27 residential care units and was carried out by 10 teams of dentists and dental nurses.⁵⁷ It found that:

- Treatment of decayed teeth by extraction is more common among adults with an intellectual disability than in adults from the general population
- Loss of all natural teeth is much more common in adults with an intellectual disability than adults in the general population; 61% of adults with an intellectual disability in full time residential care aged 55+ years had no natural teeth compared to 41% of adults aged 65+ years in the general population. The majority of the adults with an intellectual disability who are missing all their own natural teeth do not wear dentures and have been assessed by the dentists as not being suitable for dentures
- The vast majority of adults examined as part of this study had gingivitis (early gum disease)

The study recommended that both primary and secondary dental services for adults with an intellectual disability in residential care in Ireland be expanded, and that training be provided to care staff in oral health care for adults with an intellectual disability.

IDS-TILDA

Results of Wave 3 of the Intellectual Disability Supplement to TILDA (**IDS-TILDA**), a longitudinal study researching ageing in Ireland among people with an intellectual disability aged 40 and over, found that⁵⁸:

- 28.3% participants reported that they had no teeth at all. In contrast, only 16.9% of Wave 3 TILDA participants reported total tooth loss
- When total tooth loss occurred, 67.8% of people with intellectual disability without any teeth did not receive prosthetic dentures to restore function.

⁵⁷ Crowley, E. et al. (2005) **Oral Health of Adults with an Intellectual Disability in Residential Care in Ireland 2003**, Dublin: Department of Health.

⁵⁸ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, pp.76-77.

Conversely, this did not occur among the TILDA Wave 3 sample, where only 5.3% of those without teeth were without dentures

- As with the general population, tooth loss increased with age among participants with an intellectual disability. Only 7% of people under 50 years were edentulous (without teeth), compared to 23.1% of those aged 50-64 years and 50.6% of those aged 65+ years
- The frequency of total tooth loss also increased across residential settings; 19.6% of those living independently / with family were edentulous, compared to 23% in community group homes and 36.3% in residential care
- Self-reported oral health was almost identical in the TILDA and IDS-TILDA samples. IDS-TILDA saw 39.4% of participants reporting excellent or very good oral health. This compared to 39.5% in TILDA. Despite poorer oral conditions, people with intellectual disabilities were just as likely to be happy with their oral health.

Oral health services

Primary oral healthcare services for medical card holders (including for medical card holders with a disability) are provided by local dentists and their teams. The dentist is the first point of contact for all oral healthcare services, and most oral healthcare is delivered in this primary oral healthcare setting. Community oral healthcare services provide services to vulnerable people, including persons with a disability, referred from their local dentist for episodic care. However, in some cases – such as for people living in residential care or for people with moderate to profound disabilities – services may be provided long term by community oral healthcare services.⁵⁹

Policy and regulatory landscape

Oral Health and Disability: the way forward

In 2005, the NDA, the Dental Health Foundation and Trinity College Dublin published a position paper entitled “**Oral Health and Disability: the way forward**” outlining ten recommendations for enhancing the oral health of people with disabilities.⁶⁰ Recommendations included conducting research into the needs and preferences of people with disabilities, their family members and carers regarding oral health service provision, conducting research and developing practice on the building of competence in oral health care for people with

⁵⁹ Department of Health (2019) **Smile agus Sláinte – National Oral Health Policy**, Dublin: DoH, p.14.

⁶⁰ National Disability Authority, Dental Health Foundation and Trinity College, Dublin (2005) **Oral Health and Disability: the way forward**, Dublin: NDA, DHF & TCD.

disabilities; and promoting debate on progressing the mainstreaming of provision whilst ensuring the development of specialist knowledge and skills.

National Oral Health Policy, Smile agus Sláinte (2019)

The Second Goal of the **National Oral Health Policy, Smile agus Sláinte**, is to reduce oral health inequalities across the population in Ireland by enabling vulnerable groups to access oral healthcare and improve their oral health.⁶¹ According to the Policy, this will be accomplished by providing appropriate additional support for persons with moderate and profound disabilities. Facilitating vulnerable people, to access mainstream oral healthcare locally, in parallel with their peers, is a core principle of the Policy.⁶²

Actions included in the Strategy include the development of oral health promotion programmes for people with disabilities in residential settings (Action 7) and the development of a pathfinder survey in order to assess the oral health needs of vulnerable groups, with an initial focus on residential centres.

HIQA standards

HIQA has established standards of care for older people, and for people with disabilities living in residential care. For older people, the need for primary dental care provision is highlighted in HIQA's National Standards for Residential Care Settings for Older People in Ireland (Standard 4.1.3).⁶³ For persons with disabilities, HIQA's National Standards for Residential Services for Children and Adults with Disabilities provide that each person should have access to screening, early detection and the full range of universal health and welfare services in the community, including oral services (Standard 4.1.3).⁶⁴

Sexual & Reproductive Health

Sexual Health

Key data and statistics

Research jointly commissioned by the National Disability Authority and the Crisis Pregnancy Agency in 2008 found that sexual healthcare and engaging in sexual relationships for those with intellectual disabilities is complicated by legal and

⁶¹ Department of Health (2019) **Smile agus Sláinte – National Oral Health Policy**, Dublin: DoH.

⁶² Ibid p.47.

⁶³ HIQA (2016) **National Standards for Residential Care Settings for Older People in Ireland**, Dublin: HIQA, p.58.

⁶⁴ HIQA (2013) **National Standards for Residential Services for Children and Adults with Disabilities**, Dublin: HIQA, p.38 and 87.

technical issues surrounding capacity to consent, both to medical treatment (including contraception) and to sexual intercourse.⁶⁵ The legal framework around people with intellectual disabilities having consensual sexual relationships was changed by the Criminal Law (Sexual Offences) Act 2017. Negative attitudes to sexual activity among people with intellectual disabilities, a desire to protect people with intellectual disabilities from exploitation and a lack of specialised care to support participation in decision-making can compromise the level of sexual health support received.

The research also found that patterns of contraceptive use amongst women with intellectual disability differs widely from that of the non-disabled population. The Pill, Depot Medroxyprogesterone Acetate and IUDs are the only methods used by most women with learning disabilities, with barrier methods being reported as unheard of. It has been argued that the prescribing of these particular methods of contraception assumes that women with learning disabilities are incapable or unreliable when it comes to contraceptive decision-making and managing their fertility.⁶⁶

Policy landscape

The **National Sexual Health Strategy 2015–2020** aims to improve sexual health and wellbeing and reduce negative sexual health outcomes.⁶⁷ The Strategy identifies persons with an intellectual disability as one of vulnerable groups that require targeted support to improve their sexual health and wellbeing. Actions outlined in the Strategy for at-risk and vulnerable groups include:

- Developing an evidence-informed response to targeting those most at risk of negative sexual health outcomes
- Ensuring that all campaigns and interventions targeting those most at risk of negative sexual health outcomes will be inclusive with regard to the diversity of sexual experiences and identities
- Developing and maintaining positive prevention, access to condoms, testing, targeted education and outreach
- Identifying and establishing links with other relevant strategies, particularly those relating to vulnerable and at-risk groups, to ensure their sexual health needs are addressed

⁶⁵ O'Connor, J. (2008) **Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy**, Dublin: NDA and Crisis Pregnancy Agency.

⁶⁶ Ibid, p.5.

⁶⁷ Department of Health (2015) **National Sexual Health Strategy 2015–2020**, Dublin: DoH.

A Mid-Term Review of the Strategy provided no detail regarding the specific progress which has been achieved in terms of improving the sexual health and wellbeing of persons with an intellectual disability, who are considered one of the “at-risk groups” under the Strategy.⁶⁸ However, information received from the Department of Health indicates that it funds and co-ordinates a range of trainings to build the capacity of parents and of professionals to meet the relationship and sexuality education needs of children, young people and adults with physical and intellectual disabilities.⁶⁹ For instance, the Sexual Health and Crisis Pregnancy Programme funds the Irish Family Planning Association to deliver their Speak Easy Plus programme to parents of young people with disabilities, as well as professionals working with people with disabilities. Speak Easy Plus helps parents, carers and professionals to support children with regard to their relationship and sexuality education needs.

The NDA is aware that some stakeholders have expressed concern that harmful and stereotypical myths with respect to sexuality and disability, coupled with over protective laws and poor service provision, have resulted in the exclusion of people with disabilities from services designed to meet individual needs of achieving sexual health.⁷⁰ Other stakeholders have raised concerns regarding inequalities for people with intellectual disabilities in accessing maternity services and contraception.⁷¹

Reproductive and Maternal Health

Key data and statistics

There is currently no national level data collection and monitoring of perinatal mental health complications in Ireland.⁷² Of approximately 1,500 mothers reviewed by the liaison perinatal mental health team in the Coombe Women & Infants University Hospital in 2013, 25% were diagnosed with antenatal depression, and a further 42% were diagnosed with postnatal depression.⁷³

⁶⁸ Health Service Executive (2018) **Mid-Term Review of the Implementation of the National Sexual Health Strategy**, Dublin: HSE.

⁶⁹ Correspondence received from the Department of Health, April 2020.

⁷⁰ Irish Family Planning Association, Sexuality and Disability: Briefing Report, available at https://www.ifpa.ie/sites/default/files/documents/briefings/disability_and_sexuality_briefing_report.pdf

⁷¹ Inclusion Ireland, Inclusion Ireland joins ‘Together for Yes’, available at <http://www.inclusionireland.ie/sites/default/files/attach/news-item/1680/inclusion-ireland-together-yes.pdf>

⁷² Department of Health (2016) **Creating a Better Future Together: National Maternity Strategy 2016–2026**, Dublin: DoH, p.44.

⁷³ Coombe Women and Infants University Hospital (2014) **Coombe Women and Infants University Hospital Annual Clinical Report 2013**, Dublin: Coombe Hospital.

Existing research

The NDA commissioned a series of research reports, in a joint initiative with the National Women's Council of Ireland, to explore the strengths and weaknesses of publicly funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. The research was carried out by a team of researchers from the School of Nursing and Midwifery in Trinity College, Dublin.⁷⁴

- The first report from this project, **Women with Disabilities: barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood**, is a review of literature, both national and international, identifying the challenges that women with disabilities face in accessing health services during pregnancy, childbirth and early motherhood. The report also documents factors, identified in the literature, which facilitate access to these health services for women with disabilities.
- The second report from the project, **Women with Disabilities: policies governing procedure and practice in service provision in Ireland during pregnancy, childbirth and early motherhood**, is a review of policy governing maternity service provision for women with disabilities in Ireland and in 9 other jurisdictions. The report also contains the findings from a survey conducted with all 19 publicly-funded maternity hospitals/units in Ireland to identify the existence of policies in these facilities.
- The third report from the project, **The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood**, is a detailed exploration of women's views and experiences of the services they received during pregnancy, childbirth and early motherhood. The report also sets out findings of focus group discussions with service providers and professionals in the field.

The findings from the third study demonstrate that women's experiences of the publicly-funded maternity services are varied, with weaknesses and strengths identified. Issues identified included lack of specialist services within the maternity care sector, difficulties communicating with healthcare staff, particularly for

⁷⁴ All three reports are available on the NDA website at the following link:
<http://nda.ie/Publications/Health/Pregnancy/Pregnancy-childbirth-early-motherhood-project.html>.

women with sensory disabilities, stigma of healthcare staff, particularly towards women with mental health issues, and a perceived fragmented approach to care.⁷⁵

Research on women with intellectual disabilities experiencing crisis pregnancies has found that there is a lack of empirical evidence on the individual experience of crisis pregnancy, pregnancy and childbirth among women with intellectual disability, to inform professional practice. There is limited research related to how a woman with intellectual disability conceptualises her pregnancy and whether it was unplanned, unwanted or a crisis for her. The research that does exist suggests that the number of women with intellectual disability having children is increasing and that when a woman announces her pregnancy, the reactions of people close to her are almost exclusively negative.⁷⁶

Other challenges faced by women with an intellectual disability experiencing pregnancy and parenthood include accessing sexual health information, accessing sexual health services, inadequate information and negative attitudes to pregnancy and parenthood among service providers and the wider community.

The NDA is aware that the Centre for Disability Law and Policy at NUI Galway are currently working on a project, “**Re(al) Productive Justice**”, the objective of which is to make visible the experiences of disabled people seeking reproductive justice. They are examining a range of issues around fertility, contraception, abortion, pregnancy and childbirth, and intend to create a toolkit of best practice for health and social care professionals.⁷⁷

In 2020 HIQA published the findings of the National Maternity Experience Survey⁷⁸ which reported on the experience of maternity care in Ireland. The survey was completed by 3,204 mothers, and 217 of these (6.8%) indicated that they had a long-term disability, illness or condition. The survey asked mothers about their experiences through the full pathway of maternity care, including antenatal care, care during labour and birth, care in hospital after birth, specialised care if their baby was in a neonatal unit, care for feeding their baby, care at home after birth, and their overall experience of maternity care. The

⁷⁵ School of Nursing and Midwifery, Trinity College Dublin (2010) **The Strengths and Weaknesses of Publicly-funded Irish Health Services Provided to Women with Disabilities in Relation to Pregnancy, Childbirth and Early Motherhood**, Dublin: NDA.

⁷⁶ O'Connor, J. (2008) **Literature Review on Provision of Appropriate and Accessible Support to People with an Intellectual Disability who are Experiencing Crisis Pregnancy**, Dublin: NDA and Crisis Pregnancy Agency, p.18.

⁷⁷ More information is available at the Re(al) Productive Justice website <http://realproductivejustice.com/>.

⁷⁸ HIQA, 2020, National Maternity Experience Survey <https://www.hiqa.ie/hiqa-news-updates/results-new-national-survey-show-most-women-have-positive-experience-irelands>

National Disability Authority has conducted a secondary analysis of the data to compare the experiences of maternity services of women with disabilities and those without a disability.⁷⁹ This analysis found that women with disabilities generally had quite positive maternity experiences and the areas where they reported particularly strong or weak care were largely the same as those without disabilities. However, they did report less positive care experiences than those without disabilities in a number of areas, including for example, on feeling treated with respect and dignity, feeling involved in decisions in their care, having their questions answered in a way they understood, and receiving enough information at different points of the maternity journey.⁸⁰

The HSE has developed a suite of quality improvement plans based on the National Maternity Experience Survey's findings.⁸¹ The NDA report makes a series of recommendations, including ways in which current or planned quality improvement initiatives can adequately address the needs of women with disabilities or additional care needs. The concern is that initiatives which aren't accessible to all women may serve to perpetuate or exacerbate existing differences in the care experiences of those with and without disabilities.

Policy landscape

Ireland's national maternity strategy, **Creating a Better Future Together: National Maternity Strategy 2016–2026**, contains very few references to disability, but places considerable focus on mental health. In terms of disability, the Strategy outlines the need to ensure that antenatal care is accessible to people with disabilities and that antenatal education places focused attention on women with disabilities. Actions related to mental health are outlined in the National Maternity Strategy Implementation Plan.⁸² Actions include identifying women with a history of a mental health condition early and ensuring that midwives work collaboratively with mental health and other services; training health care professionals involved in antenatal and postnatal care to identify women at risk of developing or experiencing emotional or mental health difficulties in the perinatal period; and adopting a multidisciplinary approach to

⁷⁹ National Disability Authority (2021) **Experiences of Women with Long-Term Disabilities, Illnesses or Conditions in their Journey through Maternity Services in Ireland**, Dublin: NDA. <https://nda.ie/publications/health/pregnancy/experiences-of-women-with-disabilities-in-their-journey-through-maternity-services-in-ireland.html>

⁸⁰ Please see report for full findings.

⁸¹ See <https://yourexperience.ie/wp-content/uploads/2020/10/HSE-RESPONSE-TO-NMES-2020.pdf>

⁸² Department of Health (2017) **National Maternity Strategy Implementation Plan**, Dublin: DoH.

assessment and support for women at risk of developing or experiencing emotional or mental health difficulties in the perinatal period.

The HSE's Specialist Perinatal Mental Health Service Model of Care was launched in November 2017 and includes a model for an overall perinatal mental health service clinical pathway. This provides for screening for mental health problems such as depression, anxiety, psychosis at the first visit to the maternity service, called the booking visit. The project is currently at implementation stage with full time services available in the Rotunda and National Maternity Hospitals for the first time, with services currently being developed in Limerick, Cork and Galway.⁸³

HIQA has expressed concern about the “limited progress” the HSE has made in advancing the Strategy and called for a more comprehensive, time-bound and costed implementation plan.⁸⁴

Breastfeeding in a Healthy Ireland – Health Service Breastfeeding Action Plan 2016-2021

The Breastfeeding Action Plan sets out the priority areas to be addressed over the next 5 years to improve breastfeeding supports, to enable more mothers in Ireland to breastfeed and to improve health outcomes for mothers and children in Ireland.⁸⁵ It does not contain any disability or mental health-specific actions.

Mental Health

Key data and statistics

Prevalence of mental health issues

The 2019 Irish Health Survey found that 43% of persons with disabilities report some form of depression, well above the State average of 14%.⁸⁶ The NDA notes that it is important to disaggregate this finding by type of disability and exclude

⁸³ Walsh, K. (2019) **Women's Health in Ireland**, Dublin, NWCI, DoH and HSE, p.22.

⁸⁴ HIQA (2020) **Overview report of HIQA's monitoring programme against the National Standards for Safer Better Maternity Services, with a focus on obstetric emergencies**, Dublin: HIQA, p.60.

⁸⁵ Health Service Executive (2016) **Breastfeeding in a Healthy Ireland – Health Service Breastfeeding Action Plan 2016-2021**, Dublin: HSE.

⁸⁶ Central Statistics Office (2020) **Irish Health Survey 2019**, Dublin: CSO.
<https://www.cso.ie/en/releasesandpublications/ep/p-ihsd/irishhealthsurvey2019-personswithdisabilities/introductionandkeyfindings/>

those with a mental health related disability only to see if this difference persists.

⁸⁷

The NDA's 2017 National Survey of Public Attitudes to Disability in Ireland found that a higher proportion of people with a disability felt downhearted and depressed than people without a disability (18% v 4%).⁸⁸ People with disabilities had a statistically significantly lower mean satisfaction with life score (7.3) and a lower mean happiness score (7.4) compared to people without disabilities (8.0 and 8.2 respectively).

The IDS-TILDA study reveals that the prevalence of emotional, nervous and psychiatric conditions amongst people with intellectual disabilities over the age of 40 is high, with almost 52% of participants reporting having received a diagnosis.⁸⁹ Depression (15.8%), anxiety (32.4%) and mood disorders (15.1%) were the main contributors to poor mental health. This compares with the TILDA finding that 13% of people experienced 'case-level' symptoms for anxiety.

In-patient mental health facilities

At the end of 2020, there were 2,657 in-patient beds in approved centres across the country, 713 adult beds in the independent sector, 103 registered forensic beds and 79 mental health intellectual disability beds.⁹⁰ By way of comparison, at the end of 2019, there were 2,703 in-patient beds in approved centres across the country, 687 adult beds in the independent sector, 103 registered forensic beds and 96 mental health intellectual disability beds.⁹¹

An analysis of admissions to Irish psychiatric units and hospitals found that there was an equal proportion of male and female admissions (all), with males having a slightly higher rate of all admissions, at 361.4 per 100,000 compared with 340.7 for females.⁹²

⁸⁷ National Disability Authority (2020) **Mid-term Review of Progress under the National Disability Inclusion Strategy Indicators**, Dublin: NDA.

⁸⁸ National Disability Authority (2017) **National Survey of Public Attitudes to Disability in Ireland 2017**, Dublin: NDA, p.60.

⁸⁹ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, pp.5-6.

⁹⁰ Mental Health Commission (2021) **Annual Report 2020**, Dublin: MHC, p.17.

⁹¹ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.17.

⁹² Daly, A. & Craig, S. (2020) **Activities of Irish Psychiatric Units and Hospitals 2019: Main Findings**, HRB Statistics Series 41.

In 2019, there were 2,390 involuntary admissions to psychiatric hospitals. Of those involuntarily admitted, 54% were men and 46% were women.⁹³ If a person is admitted to hospital involuntarily, they are entitled to have the detention order reviewed by a mental health tribunal within 21 days of their admission.⁹⁴ The Mental Health Commission is responsible for establishing these tribunals and each tribunal comprises three people – a solicitor or barrister as chair, a consultant psychiatrist and a lay person. The function of the mental health tribunal is to either revoke or affirm an admission or renewal order. In 2019, 12% (245) of tribunal hearings resulted in a revocation of the admission or renewal order.⁹⁵

On 28 November 2018, the Mental Health Commission conducted an in-patient census across all of its regulated in-patient mental health services (approved centres).⁹⁶ This included all residents who were in-patient in the unit, absent without leave, on approved leave, or transferred to another facility (e.g. a general hospital) but not discharged. The census revealed that there were 2,345 residents, 52% male and 47% female. This figure represented a national occupancy rate of 84%.

The primary diagnosis of 39% of residents was schizophrenia disorders, 19% had depressive disorders, 12% had organic disorders (including dementia), 7% had mania and 4% had personality disorders. 52% had been admitted less than three months beforehand, 41% were admitted longer than six months, 29% were admitted for more than two years and 18% were admitted for over five years.⁹⁷

Seclusion was used in 42% of approved centres in 2018⁹⁸ and 43% in 2019.⁹⁹ A 2019 report shows that seclusion was used in 42% of approved centres in 2018 41% in 2017 and, as compared to 42% in 2016.¹⁰⁰ There were 1,392 episodes of seclusion in 2017, a decrease from the 1,475 episodes in 2016, but which again increased in 2018 to 1,799. The seclusion involved 646 individuals in 2017 and 760 people were secluded in 2018. In 2017 and 2018, more male residents than

⁹³ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.37.

⁹⁴ Mental Health Act 2001, section 18.

⁹⁵ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.37.

⁹⁶ Ibid, p.30.

⁹⁷ Ibid, p.30.

⁹⁸ Mental Health Commission (2019) **The Use of Restrictive Practices in Approved Centres**, Dublin: MHC, p.4.

⁹⁹ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.30.

¹⁰⁰ Mental Health Commission (2019) **The Use of Restrictive Practices in Approved Centres**, Dublin: MHC, p.4.

female residents were secluded (63% and 65% respectively). In 2017, there were 211 episodes where a person was locked in seclusion for over 24 hours. In 2018, this rose to 317 episodes. In 2017, there were 49 episodes where a person was locked in seclusion for over 72 hours. This compares to 81 episodes in 2018.¹⁰¹

Physical restraint was used in 89% of approved centres in 2019¹⁰², 85% in 2018 and 81% in 2017.¹⁰³ In 2019, 50% of physical restraints were compliant with the Code of Practice on Physical Restraint, a significant improvement from 2016 where the rate of compliance was 22%.¹⁰⁴ There were 4,773 episodes of physical restraint in 2017 and 5,665 in 2018. This was a year-on-year increase from 3,525 in 2016. 1,125 people were physically restrained in 2017 and 1,207 in 2018. More male residents than female residents were physically restrained (53.9% male in 2017 and 51% male in 2018). 86.8% of episodes of physical restraint in 2017 and 87.6% in 2018 lasted for less than 15 minutes.¹⁰⁵

In 2018, the Mental Health Commission estimated that 1,200 people lived in 118 24-hour supervised mental health residences.¹⁰⁶ In 2019, 33% of 18 residences inspected had 10 or more beds,¹⁰⁷ while that figure stood at 43% of 54 residences inspected in 2018.¹⁰⁸

In January 2019, there were 35 local Mental Health forums across nine CHO areas.¹⁰⁹ These fora act as a resource for service users and family members, carers and supporters to voice their experiences, raise issues and be consulted and involved in mental health services developments in their area.

¹⁰¹ Mental Health Commission (2019) **The Use of Restrictive Practices in Approved Centres**, Dublin: MHC, p.4.

¹⁰² Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.30.

¹⁰³ Mental Health Commission (2019) **The Use of Restrictive Practices in Approved Centres**, Dublin: MHC, p.5.

¹⁰⁴ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.76.

¹⁰⁵ Mental Health Commission (2019) **The Use of Restrictive Practices in Approved Centres**, Dublin: MHC, p.5.

¹⁰⁶ Mental Health Commission (2019) **Annual Report 2018**, Dublin: MHC, p.69.

¹⁰⁷ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.78.

¹⁰⁸ National Disability Authority (2020) **Mid-term Review of Progress under the National Disability Inclusion Strategy Indicators**, Dublin: NDA.

¹⁰⁹ National Disability Authority (2020) **Mid-term Review of Progress under the National Disability Inclusion Strategy Indicators**, Dublin: NDA.

In 2019, 563 deaths of people using mental health services were reported to the Mental Health Commission.¹¹⁰ 166 of these related to regulated services (approved centres), while 397 related to other community mental health services. While death by suicide may only be determined by a Coroner’s inquest, which may take place a number of months after the death, 168 deaths were reported to the Commission by the service as ‘suspected suicides’.¹¹¹

Community Mental Healthcare

The number of referrals and consultations for general adult mental health services and psychiatry of later life services are outlined in Tables 3 and 4 below.

Table 3: General Adult Mental Health services

	Expected Activity / Target	January – December 2019
Number of referrals received	43,819	43,680
Number of referrals seen	28,716	26,878
% seen within 12 weeks	75%	72.9%

Source: HSE Performance Report, October – December 2019¹¹²

Table 4: Psychiatry of Later Life services

	Expected Activity / Target	January – December 2019
Number of referrals received	12,455	12,423
Number of referrals seen	8,896	8,921
% seen within 12 weeks	95%	94%

Source: HSE Performance Report, October – December 2019¹¹³

¹¹⁰ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.26.

¹¹¹ Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.26.

¹¹² See footnote 55 above

¹¹³ See footnote 55 above

Existing research

Mental Health Reform's report **My Voice Matters** explores people's experiences of using community and in-patient mental health services. The evidence indicates that the experiences of service users are mixed. It was noted that some participants experienced services consistent with aspects of national policy and standards. This is reflected in reports by participants of the following: positive experiences with mental health staff; feeling listened to; being treated with dignity and respect; being provided opportunities to be involved in their own care; having a recovery/care plan; being involved in conversations about recovery and being referred to talking therapies by mental health services.¹¹⁴

However, a large majority of participants reported having no individual recovery/care plan and a high focus on medication as part of their treatment and care. Only a minority reported being involved as much as they would like in decisions about the medication they take; many reported that their Community Mental Health Team did not talk to them about recovery or how their mental health difficulty affects other areas of their life, and less than half felt that they were always treated with dignity and respect by community mental health services.¹¹⁵

The NDA notes that, in 2011, the Mental Health Commission published the findings of '**Your Views of Mental Health Inpatient Services**', a survey which examined 710 service users' experiences of their stay across 28 approved centres.¹¹⁶ A large majority (84.4%) of respondents stated that they were satisfied overall with the service they received. Those who reported not having a discharge plan when leaving the hospital were approximately twice as likely to be dissatisfied overall with the service they received. Health status following hospital stay was a significant predictor of overall satisfaction, with those scoring higher on health status reporting greater satisfaction. 73.4% of respondents reported some level of improvement in their health status following their hospital stay and 68.1% indicated that they had either Excellent, Very Good, or Good current perceived health status at the time of survey completion. A key priority identified for the improvement of patient care was increasing patient participation in care.

¹¹⁴ Mental Health Reform (2019) **My Voice Matters: Report on a National Consultation with Mental Health Service Users**, Dublin: MHC, p.26.

¹¹⁵ Mental Health Reform (2019) **My Voice Matters: Report on a National Consultation with Mental Health Service Users**, Dublin: MHC, p.26.

¹¹⁶ Mental Health Commission (2011) **Your Views of Mental Health Inpatient Services**, MHC: Dublin.

A discussion paper published by the Mental Health Commission on **Access to Acute Mental Health Beds in Ireland** found that while the number of acute mental health beds available was in accordance with Ireland's previous mental health policy (A Vision for Change), a number of factors complicated access.¹¹⁷ Data demonstrated a dearth of crisis houses, high support hostels and rehabilitation units. Of note, 12.3% of acute beds were occupied by people resident for 6 months or longer, pointing to a lack of appropriate alternative services. Similarly, no CHO was meeting the recommended number of dedicated older-age adult acute beds. In addition, only 33% of acute units operated at the recognised level of less than 85% occupancy with 25% having an occupancy rate of over 100%.

Mental Health services

HSE specialist mental health services are provided in local community areas. These services include acute inpatient services, day hospitals, outpatient clinics, community-based mental health teams (including CAMHs, general adult and psychiatry of later life services), mental health of intellectual disability, community residential and continuing care residential services. Sub-specialties include rehabilitation and recovery, eating disorders, liaison psychiatry and perinatal mental health.

Currently, Child and Adult Mental Health Services (CAMHs) serve young people aged up to 18 years, general adult community mental health services are for those aged 18 to 64 years and psychiatry of later life provides services for those aged 65 years and over. In 2021, the HSE anticipates that 23,042 adults will access general community health services, 7,388 adults will access Psychiatry of Later Life mental health services and 9,338 young people will access CAMHS services.¹¹⁸

The HSE has reported that difficulties in recruiting and retaining skilled staff continues to be a significant challenge, with some services reporting risks as a result. Concerns have been expressed by CHOs that current financial constraints mean that while essential services, such as inpatient services, are maintained, strategic developments and preventative interventions in the community cannot be progressed, resulting in people's needs escalating such that they may require inpatient services.¹¹⁹ From 2020 Covid related absences impacted on capacity to

¹¹⁷ Mental Health Commission (2020) **Access to Acute Mental Health Beds in Ireland**, Dublin: MHC.

¹¹⁸ Health Service Executive (2021) **National Service Plan 2021**, Dublin: HSE, p.143.

¹¹⁹ Health Service Executive (2019) **Performance Profile July – September 2019 Quarterly Report**, Dublin: HSE, p.34.

deliver services. For example, Covid related absences were recorded in January 2021 as over 3,000 Whole Time Equivalents¹²⁰.

The total budget allocated to mental health services in 2019 was €995.7 million. The 2020 budget was €1,031.3 million.¹²¹

Mental Health Act 2001

The Mental Health Act 2001 provides a framework within which people who have a “mental disorder” and require treatment or protection can be cared for and treated. The legislation puts in place mechanisms by which the standards, care and treatment in mental health services can be monitored, inspected and regulated. The Act provides for the establishment of the Mental Health Commission as an independent statutory body to promote, encourage and foster the establishment and maintenance of high standards and good practice in the delivery of mental health services and to protect the interests of people detained under the 2001 Act. It also provides for the establishment of the Office of the Inspector of Mental Health Services.

The NDA has called for the 2001 Act to be audited and updated to render it compliant with the UNCRPD. Some of the issues identified by the NDA as requiring improvement in the 2001 Act include the removal of “intellectual disability” from the definition of “mental disorder” and dealing with the omission of children from the legislation.¹²²

In 2012, an Expert Group was appointed to review the Mental Health Act 2001 and subsequently made a series of recommendations to update the existing legislation. The report of the Expert Group was published in 2015 and set out a series of recommendations (165 in total) to update the Act in full.¹²³ However, the NDA notes that analysis by Mental Health Reform suggests that just two of the Expert Group’s recommendations have come into effect to date.¹²⁴

¹²⁰ Health Service Executive (2021) Performance Profile October to December 2020. p 33

¹²¹ Health Service Executive (2019) **National Service Plan 2020**, Dublin: HSE, p.110.

¹²² National Disability Authority, NDA Submission on the Review of the Mental Health Act 2001, <<http://nda.ie/Publications/Health/Submissions-on-Health/NDA-Submission-on-the-Review-of-the-Mental-Health-Act-2001-HTML-Format-1.html>>.

¹²³ Department of Health (2015) **Report of the Expert Group Review of the Mental Health Act, 2001**, Dublin: DoH.

¹²⁴ Mental Health Reform, Briefing Note on Reform of the Mental Health Act 2001, <<https://www.mentalhealthreform.ie/news/briefing-note-on-reform-of-the-mental-health-act-2001/>>.

First, the Mental Health (Amendment) Act 2015 provides that Electroconvulsive Therapy (ECT) and medication (administered for over three months) can only be administered to an involuntary patient without consent where it has been determined that the patient is unable to consent to the treatment. Secondly, the Mental Health (Renewal Orders) Act 2018 implemented one of the recommendations by stipulating that the involuntary detention of a person under a 'renewal order' cannot exceed a period of 6 months at any given time. In addition, a person who is detained against their will under a renewal order can now apply for a review of their detention at or after three months from the date the renewal order was made.

The NDA notes that the Oireachtas Joint Committee for the Future of Mental Health Care published a final report in October 2018, which also recommended amendments to the Mental Health Act 2001. These included to: 'provide for the regulation of all premises where mental health services are provided and to strengthen the Mental Health Commission's powers to impose penalties on service providers where they are found to be noncompliant with the regulations'.¹²⁵

A Prospective Evaluation of the Operation and Effects of the Mental Health Act 2001 from the Viewpoints of Service Users and Health Professionals found that the implementation of the 2001 Act in clinical practice succeeds in achieving certain basic goals such as ensuring that care is delivered to individuals experiencing a 'mental disorder' and safeguarding certain human rights whilst that care is delivered coercively.¹²⁶ However, key difficulties were identified in areas such as the community assessment and transfer of individuals to hospital, lack of information and emotional support at critical points in the process and with the adversarial nature of mental health tribunals.

The National Disability Inclusion Strategy 2017-2021 commits the Department of Health to amending the Mental Health Act 2001:

- to deal in a more complete and comprehensive manner with the operation of advance healthcare directives in the area of mental health in the longer term [action 62]

¹²⁵ Oireachtas Joint Committee for the Future of Mental Health Care (2018) **Final Report**, Dublin: Houses of the Oireachtas.

¹²⁶ College of Medicine, Nursing and Health Sciences, National University of Ireland, Galway (2017) **A Prospective Evaluation of the Operation and Effects of the Mental Health Act 2001 from the Viewpoints of Service Users and Health Professionals**, Galway: NUIG.

- to align the 2001 Act with the Assisted Decision-Making (Capacity) Act and the Expert Group report on Review of the Mental Health Act 2001 [action 13]
- to require the Inspector of Mental Health Services to conduct annual inspections of 24-hour staffed community residences [action 95]¹²⁷

However, the NDA notes that progress on delivering these commitments has been slower than anticipated. The Draft Heads of Bill were finalised and submitted to the Mental Health Commission for detailed review in July 2019.¹²⁸ The Department of Health initiated a public consultation on the Mental Health Act 2001 in early 2021. In November 2021, the Oireachtas Sub Committee on Mental Health commenced pre-legislative scrutiny of the general scheme of the Mental Health (Amendment) Bill.

The NDA further notes that, in April 2019, as a result of the COVID-19 pandemic, emergency legislation was introduced which made changes to the Mental Health Act 2001 and the operation of Mental Health Tribunals. The Emergency Measures in the Public Interest (Covid-19) Act 2020 provides that, when the need arises, the Mental Health Commission is authorised to appoint a lawyer from its existing panel of tribunal chairs to act as a one-person tribunal. According to the Mental Health Commission, the rationale for this measure is that it may not always be possible to convene a three-person tribunal during the public health emergency.¹²⁹ It also provides that the 21 day time limit within which an admission or renewal order should be reviewed, can be extended by 14 days, and can be extended by a further 14 days in certain circumstances.

Policy landscape

Sharing the Vision: A Mental Health Policy for Everyone

A refreshed mental health policy, entitled **Sharing the Vision**, was published in 2020. The new policy replaces, **A Vision for Change**, which was launched in 2006, and which came to an end in 2016.¹³⁰ The policy sets out current and future service priorities and includes a time-bound implementation plan as well as an Implementation Monitoring Committee (the Chairperson and membership of the

¹²⁷ Department of Justice and Equality (2017) **National Disability Inclusion Strategy 2017-2021**, Dublin: DJE.

¹²⁸ December 2019 NDIS traffic light report.

¹²⁹ Mental Health Commission, “Mental Health Commission welcomes safeguards for involuntary patients during Covid-19 crisis”, <https://www.mhcirl.ie/File/PR_300320.pdf>.

¹³⁰ Government of Ireland (2006) **A Vision for Change: A Report of the Expert Group on Mental Health Policy**, Dublin: Stationery Office.

Committee were announced in late 2020)¹³¹. The programme lays out recommendations for a “whole-of-government” approach to mental health services, and centres on four domains, namely:

1. Promotion, Prevention and Early Intervention
2. Service Access, Co-ordination and Continuity of Care
3. Social Inclusion
4. Accountability and Continuous Improvement

The refresh process leading to the publication of *Sharing the Vision* consisted of a number of steps. For instance, in February 2017, a report on the expert review of ‘A Vision for Change’ was published.¹³² It reviewed the implementation of ‘A Vision for Change’ and looked at international best practice. It covered the state of mental health services in Ireland today, including societal issues, prevention, recovery, social inclusion, governance and financing. It did not present recommendations but provided an evidence base on which future policy might be set. Key points from the review included the importance of prioritising mental health as a major societal issue, recognising the importance of primary prevention and the promotion of positive mental health, placing a strong focus on recovery and on the social inclusion of people with mental health difficulties more generally, and harnessing the potential of eMental Health.

Suicide prevention

Connecting for Life is the national strategy to reduce suicide over the period 2015–2020.¹³³ *Connecting for Life* sets out a vision of an Ireland where fewer lives are lost through suicide, and where communities and individuals are empowered to improve their mental health and wellbeing.

The defined outcomes of the strategy are:

- Reduced suicide rate in the whole population and amongst specified priority groups

¹³¹ Department of Health, 2020, Press Release- Minister for Mental Health and Older People announces appointment of independent chair for ‘Sharing the Vision’ National Implementation and Monitoring Committee. <https://www.gov.ie/en/press-release/b5c3a-minister-for-mental-health-and-older-people-announces-appointment-of-independent-chair-for-sharing-the-vision-national-implementation-and-monitoring-committee/>

¹³² Work Research Centre and London School of Economics (2017) **Evidence Review to Inform the Parameters for a Refresh of A Vision for Change (AVFC)**, Dublin: DoH.

¹³³ Department of Health (2015) **Connecting for Life: Ireland’s National Strategy to Reduce Suicide 2015-2020**, Dublin: DoH.

- Reduced rate of presentations of self-harm in the whole population and amongst specified priority groups

As outlined in the Strategy, particular demographic groups have consistently been shown by both national and international research evidence to have increased risk of suicidal behaviour including people with mental health issues. The Strategy further notes that there is potentially increased vulnerability to suicidal behaviour amongst people with a disability, however the research evidence is either less consistent or limited. The Strategy details a range of actions related to addressing mental health issues.

The Connecting for Life Evaluation Advisory Group undertook an independent Interim Review of the Strategy to assess the progress achieved by the 22 government departments/ state agencies in delivering on their commitments under the strategy, and to identify potential for improvements and risks to full-implementation and sustainability. Of the seven goals, the Evaluation Advisory Group was of the view that overall, moderate progress had been achieved in respect of four goals, good progress in respect of two goals and limited progress in respect of one goal.¹³⁴ The Group recommended that the Department of Health should extend the timeframe and funding of Connecting for Life to 2024, and to this end, the HSE National Office for Suicide Prevention should develop a Connecting for Life Implementation Plan for the period 2020-22.

Regulatory landscape

24-hour, supervised mental health residences are not regulated by the Mental Health Commission, despite the stated concerns of the Inspector of Mental Health Services. However, although 24-hour supervised residence are not regulated, the Inspector of Mental Hospitals can inspect them and has done so since 2005.¹³⁵

The Inspector of Mental Health Services visits and inspects every approved mental health centre at least once a year. The Inspector rates compliance against 31 Regulations, Part 4 of the Mental Health Act 2001, four Codes of Practice and two Statutory Rules. In 2019, 78% of centres complied with the national regulations.¹³⁶ This compares to 79% compliance in 2018, and 76% compliance in 2017. A number of areas showed consistently high compliance across all services.

¹³⁴ Health Service Executive (2019) **Connecting for Life: Interim Strategy Review**, Dublin: HSE.

¹³⁵ Mental Health Commission (2019) **2018 Inspection of 24-hour Supervised Residences for People with Mental Illness**, Dublin: MHC, p.3.

¹³⁶ Mental Health Commission (2021) **Annual Report 2020**, Dublin: MHC, p.4 and Mental Health Commission (2020) **Annual Report 2019**, Dublin: MHC, p.18.

These include resident identifiers (100%), health and safety (100%), and communication (97%). However, some noted areas of concern included staffing and general health, relating to the physical health of residents.¹³⁷

The Commission took 17 enforcement actions relating to 13 approved centres in 2020. This compares with 40 enforcement actions in 2019 and 44 enforcement actions in 2018.¹³⁸

Physical Health

Obesity

Key data and statistics

Wave 3 of the IDS-TILDA study found that 79.7% of participants were overweight or obese, similar to rates reported by TILDA for the general older population (79%).¹³⁹ Higher levels of overweight and obesity were identified in those aged 50-64 years at 80.6% compared to 77.6% in those 65 years and over. Those with a mild/ moderate level of intellectual disability presented with greater levels of obesity at 87.5% versus 64.3% for those in the severe/profound disability.¹⁴⁰ Females had higher prevalence of overweight and obesity compared to males at 83.1% versus 75.9% respectively. Females with a mild level of intellectual disability showed the highest levels of overweight and obesity at 89.1%.

Policy landscape

A Healthy Weight for Ireland is Ireland's Obesity Policy and Action Plan for the period 2016-2025.¹⁴¹ It was launched in September 2016 under the auspices of the Healthy Ireland agenda, and aims to reverse obesity trends, prevent health complications and reduce the overall burden for individuals, families, the health system, and the wider society and economy. The Strategy notes that people with a disability are one of the groups most at risk of obesity. It also notes that obesity can impact on mental health.

¹³⁷ Ibid, p.19.

¹³⁸ Ibid, p.24.

¹³⁹ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, p.59.

¹⁴⁰ Ibid

¹⁴¹ Department of Health (2016) **A Healthy Weight for Ireland: Obesity Policy and Action Plan 2016 – 2025**, Dublin: DoH.

The Strategy prescribes 'Ten Steps Forward' to tackle obesity. Step 6 is as follows: “Mobilise the health services to better prevent and address overweight and obesity through effective community-based health promotion programmes, training and skills development and through enhanced systems for detection and referrals of overweight and obese patients at primary care level.” Under this Step, the HSE is required to develop and integrate evidence-based, effective, community-based health promotion programmes targeted at high-risk groups within all community health organisations.¹⁴²

Health Needs of People with Specific Disabilities

People with Dementia

Key data and statistics

The total number of people with dementia in Ireland was estimated to range from 39 272 and 55 266 in 2018 (depending on measure used). The incidence of dementia in Ireland has increased as the population has aged. It is estimated to increase by nearly 8000 new cases per year¹⁴³.

Wave 3 of the IDS-TILDA study shows that the prevalence of dementia in participants is high, with 9.1% of people with an intellectual disability over the age of 40 having a diagnosis of Alzheimer’s disease or dementia.¹⁴⁴ In Wave 3, 35.5% of people with Down syndrome had a doctor’s diagnosis of dementia, compared to 3.4% of those with intellectual disability from other aetiologies.

Policy landscape

The **Irish National Dementia Strategy** was launched in December 2014.¹⁴⁵ The Strategy aims to improve dementia care to allow people with dementia to live well for as long as possible and have services and supports delivered as well as possible. A National Dementia Office was established in the HSE in 2015 to drive the Strategy’s implementation.

¹⁴² Department of Health (2016) **A Healthy Weight for Ireland: Obesity Policy and Action Plan 2016 – 2025**, Dublin: DoH, p.47.

¹⁴³ Pierse, T., O’ Shea, E., & Carney, P. (2019). Estimates of the prevalence, incidence and severity of dementia in Ireland. **Irish Journal of Psychological Medicine**, 36(2)

¹⁴⁴ School of Nursing and Midwifery, Trinity College Dublin (2017) **Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland: Wave 3 IDS-TILDA**, p.80.

¹⁴⁵ Department of Health (2014) **The Irish National Dementia Strategy**, Dublin: DoH.

A mid-term review of the Strategy (May 2018) noted that good progress has been made on implementing many of the Strategy's 35 priority and additional actions but that additional financial and staffing resources will be required in the areas of diagnosis, post-diagnostic supports, primary care, acute care, home care and housing if the Strategy is to be fully implemented.¹⁴⁶

People with Autism

Key data and statistics

In 2018, the Department of Health published a research report entitled "Estimating prevalence of Autism Spectrum Disorder (ASD) in the Irish Population: A review of data sources and epidemiological studies" with a view to supporting the direction of future policy decisions and to autism proof the health services. The paper describes the complexity of the changing classification of autism over many decades and developments in relation to screening and diagnostic instruments for autism. The paper, drawing on a variety of sources, concludes that there is a robust case for estimating a prevalence rate of autism in children of 1-1.5% for the purposes of planning policy and services in Ireland.¹⁴⁷

The second report is entitled: "Review of the Irish Health Services for Individuals with Autism Spectrum Disorders" reviewed current services for autistic people and identified examples of good practice that can be replicated wider in the health service.¹⁴⁸

The HSE also commissioned a national review to identify pathways of care for individuals with Autism, entitled a **National Review of Autism Services Past, Present and Way Forward**.¹⁴⁹ It made a series of recommendations to ensure a more consistent national approach to care. In addition, the NDA has published research on **Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community**. Although evidence is limited, it seems as though some level of specialist services will be required for adults with autism without an Intellectual Disability living in the community to ensure that they have a good

¹⁴⁶ Department of Health (2018) **Mid-Term Review of the implementation of the National Dementia Strategy**, Dublin: DoH.

¹⁴⁷ Department of Health (2018) **Estimating prevalence of Autism Spectrum Disorder (ASD) in the Irish Population: A review of data sources and epidemiological studies**, Dublin: DoH, p.6.

¹⁴⁸ Health Service Executive (2018) **Review of the Irish Health Services for Individuals with Autism Spectrum Disorders**, Dublin: HSE.

¹⁴⁹ Health Service Executive (2012) **National Review of Autism Services Past, Present and Way Forward**, Dublin: HSE.

quality of life and can meet their life goals.¹⁵⁰ The report makes a number of recommendations, including that a clear pathway to diagnosis be identified for adults who are suspected to be on the autistic spectrum.

Policy landscape

€2 million was allocated to the Autism Plan in Budget 2020. The NDA notes that, over the period 2019-2020, this funding will be used in a number of priority areas:

- to implement a programme of awareness raising that can provide a better information resource for children and parents about what supports are available
- a campaign to assist in creating awareness of the challenges, needs and experiences of people with autism
- to build capacity and competence amongst key professionals working with autism – including a national training programme for clinicians and the implementation of a tiered model of assessment in order to improve access to and responses by services for those with ASD¹⁵¹

Healthcare Technology and Research

Health Research

Health Research Regulations

The Health Research Regulations 2018 were published as a section of Data Protection legislation following the introduction of General Data Protection Regulation.¹⁵² These regulations outline how personal data should be processed and managed in the carrying out of health research; define health research for the purposes of the legislation; describe how to obtain a “consent declaration” for research that includes participants who are unable to explicitly provide consent; along with some other responsibilities.

¹⁵⁰ National Disability Authority (2017) **Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community**, Dublin: NDA.

¹⁵¹ Department of Health, Minister Harris announces €2 million funding for Autism Plan, 14 October 2019 <<https://www.gov.ie/en/news/4b6d68-minister-harris-announces-2-million-funding-for-autism-plan/>>.

¹⁵² **Data Protection Act 2018 (Section 36(2)) (Health Research) Regulations 2018**, SI No.314 of 2018.

The NDA has advised that there is a legislative gap regarding the participation of people who lack capacity in health research and have advised that this matter could be best addressed by way of an amendment to the Assisted Decision Making (Capacity) Act 2015.

National Research Ethics Committees Bill

The Department of Health has published the General Scheme of the National Research Ethics Committees Bill which will provide for the establishment of a National Research Ethics Committee.¹⁵³ According to the Department, the proposed legislation plans to develop a streamlined, regulated and fit-for-purpose model for the ethical review of health research projects. The NDA provided some initial observations on the General Scheme. A National Office for Research Ethics Committees was established in 2020.

eHealth, Telecare and Telehealth

An eHealth – Strategy for Ireland was published in December 2013.¹⁵⁴ eHealth Ireland and the role of the Chief Information Officer were established in 2014 and are responsible for implementing the eHealth strategy and driving eHealth initiatives. The European Commission have noted that the development of a national Electronic Health Record (E.H.R.), along with the development of the Individual Health Identifier (I.H.I), are essential elements to ensure that patient data can be securely connected and shared within the health service.¹⁵⁵

In 2018, the NDA published a working paper based on a synthesis of three previous phases of research commissioned by the NDA in 2014, 2016 and 2017, exploring some of the main issues around telecare and telehealth provision, and examples of good practice in other jurisdictions.¹⁵⁶ Entitled **Effective implementation and monitoring of telehealth and telecare in Ireland: learning from international best practice**, the working paper outlines the key learning, opportunities and pitfalls that should inform the effective implementation and monitoring of telehealth and telecare in Ireland. These include embedding universal design into telehealth and telecare, the need for cultural change within the health and social care sector, upskilling staff and

¹⁵³ Available at the following link: <https://www.gov.ie/en/press-release/0e11c1-minister-for-health-publishes-new-bill-to-reform-the-research-ethic/>.

¹⁵⁴ Department of Health (2013) **eHealth Strategy for Ireland**, Dublin: DoH.

¹⁵⁵ European Commission (2019) **Ireland Health Care & Long-Term Care Systems**, Brussels: EC, p.139.

¹⁵⁶ National Disability Authority (2018) **Effective implementation and monitoring of telehealth and telecare in Ireland: learning from international best practice**, Dublin: NDA.

enhancing Wi-Fi capabilities. There was a significant expansion of telehealth and telecare during the Covid-19 lockdowns in Ireland. This will be discussed in more detail below.

Intersectional Barriers and Challenges of Persons with Disabilities

Older Persons with Disabilities

The **National Positive Ageing Strategy** aims “to act as a catalyst for action and innovation to promote the health, wellbeing and quality of life of people as they age in Ireland by focusing attention on issues relevant to older people across the policy development and service delivery process.”¹⁵⁷ The Strategy identifies four National Goals to address key aspects of older people’s lives.

National Goal 2 commits to supporting people as they age to maintain, improve or manage their physical and mental health and wellbeing, with one of the objectives thereunder (Objective 2.1) to prevent and reduce disability, chronic disease and premature mortality as people age by supporting the development and implementation of policies to reduce associated lifestyle factors. A number of areas for action are identified under Objective 2.1, including mental health (anxiety, depression, dementia) and mental capacity, falls and fractures prevention, and physical activity.¹⁵⁸ These Action Areas set the strategic direction for activity rather than prescribe the specific measures to be taken to progress the implementation of the Strategy.

Men with Disabilities

Key data and statistics

Research has been undertaken exploring the factors underpinning the high suicide rates among middle-aged men at risk of marginalisation. Particular risk factors identified that are associated with increased psychological distress among more marginalised groups of middle-aged men include: mid-life transitions; decreasing life and career opportunities; unfulfilled aspirations and expectations; deteriorating physical health; increasing pressures associated with the provider role at middle-age; societal challenges to middle-aged masculinity; and rejection

¹⁵⁷ Department of Health (2013) **The National Positive Ageing Strategy**, Dublin: DoH.

¹⁵⁸ Ibid, pp.52-53.

and isolation.¹⁵⁹ The stigma attached to mental health and to men seeking support was also highlighted as a significant issue.

Policy landscape

One of the four themes of **Healthy Ireland: Men 2017-2021, the National Men's Health Action Plan** is to “Contribute to the implementation of the priority programmes for Healthy Ireland - healthy eating and active living, wellbeing and mental health, positive ageing, alcohol, tobacco free, and healthy childhood - with a particular emphasis on reducing health inequalities between different sub-populations of men”.¹⁶⁰ Relevant actions under Theme 2 include:

- Support the implementation of the ‘Connecting for Life’ Implementation Plan by developing and implementing new initiatives (e.g. with middle-aged men) that promote positive mental health and resilience among at risk groups of men
- Support the HSE’s Plan for Wellbeing and Mental Health by continuing to implement and expand existing initiatives (e.g. Engaging Young Men, Mojo Project, 7 Key Questions) to promote positive mental health and resilience among at risk groups of men
- Develop and implement new initiatives targeted at engaging Traveller men, with a particular focus on mental health and resilience building

Women with Disabilities

Existing research

Research commissioned by the National Women’s Council of Ireland, the HSE and the Department of Health on **Women’s Health in Ireland** found that because women have different life experiences and socio-economic realities to men, the mental health symptoms they present with, are also often different, as are their pathways into services, and their treatment needs.¹⁶¹ Statistically more women than men report mental health problems, linked to this more women than men engage in self-harm. Women are also more likely to attempt suicide (with men more likely to die by suicide). Hospitalisation rates are somewhat lower for women than men for a variety of diagnoses. The research also noted

¹⁵⁹ O’Donnell, S. & Richardson, N. (2018) **Middle Aged Men and Suicide in Ireland**, Dublin: DoH.

¹⁶⁰ Department of Health (2017) **Healthy Ireland: Men 2017-2021, the National Men's Health Action Plan**, Dublin: DoH.

¹⁶¹ Walsh, K. (2019) **Women’s Health in Ireland**, Dublin, NWCI, DoH and HSE, p.81.

that women with disabilities have lower uptake of health promotion and health screening services than women in general.

Policy landscape

The **National Strategy for Women and Girls 2017-2020** is a cross-government strategy that aims to create ‘an Ireland where all women enjoy equality with men and can achieve their full potential, while enjoying a safe and fulfilling life’.¹⁶² To drive this goal across the health sector, the Strategy contains a formal commitment to develop a Women’s Health Action Plan under Objective Two: Advance the Physical and Mental Health and Wellbeing of Women and Girls.

A new Women's Health Taskforce was established in September 2019 by the Department of Health to improve women’s health outcomes and experiences of healthcare. The Taskforce has been established for a two year period and will meet every 4-6 weeks. The first action will be to lead a ‘radical listening’ exercise that will invite women in Ireland to share their experiences of and solutions for the health system. This data combined with the available evidence will form the basis for future policy and action to improve women’s health in Ireland.¹⁶³

Ethnic Minorities with Disabilities

The **Second National Intercultural Health Strategy 2018-2023** states that there is limited information available in respect of the numbers of minority ethnic service users requiring or accessing disability services.¹⁶⁴ One of the strategic objectives under Goal 2 is to address health inequalities relevant to service users in relation to disability and mental health. Actions committed to in this regard include:

- Establishing links with relevant HSE structures to explore the extent and nature of disability within the cohort of minority ethnic service users and associated needs for appropriate care and rehabilitation
- Collecting and publishing disaggregated data (by sex and complemented by disability) to inform policies and programmes and address inequities

¹⁶² Government of Ireland (2017) **National Strategy for Women and Girls 2017-2020**, Dublin: Stationery Office.

¹⁶³ More information on the Women’s Health Taskforce is available at the following link: <https://www.gov.ie/en/campaigns/-womens-health/>.

¹⁶⁴ Health Service Executive (2018) **Second National Intercultural Health Strategy 2018-2023**, Dublin: HSE.

- Promoting and supporting research into the mental health needs of service users from minority ethnic communities
- Working towards development of a comprehensive model in respect of provision of culturally competent assessment and treatment that is tailored to the unique mental health needs of vulnerable service users from diverse ethnic and cultural backgrounds and with a range of unique care needs
- Working with relevant organisations to explore and tackle the issue of mental health stigma among minority ethnic communities and the promotion of psychological wellbeing.

The Mental Health Commission and Mental Health Reform have published guidelines for mental health services and staff on working with people from ethnic minority communities.¹⁶⁵ The guidelines are structured around six themes, including respect for diverse beliefs and values, communication and language supports, and mental health training.

The report also identifies a range of barriers that people from ethnic minority groups experience in accessing mental health services including a lack of understanding among mental health professionals of the social and cultural context for people from ethnic minority groups, including experiences of poverty, racism, discrimination and other types of social exclusion; a lack of understanding among people from ethnic minority communities about mental health services and how to access them; issues of mistrust of mental health services among people from ethnic minority groups; and a range of communication and language barriers, including lack of good quality interpretation services.¹⁶⁶

Asylum-Seekers with Disabilities

Persons in the system, including those with disabilities, have access to mainstream health and social care services. Those who reside in Direct Provision are provided with a medical card and those who reside outside Direct Provision and fall within the relevant income thresholds are also entitled to a medical card.

In 2015, the Working Group Report to Government on Improvements to the Protection Process, including Direct Provision and Supports to Asylum Seekers (otherwise known as the McMahon report) made some important

¹⁶⁵ Mental Health Commission & Mental Health Reform (2016) **Ethnic Minorities and Mental Health: Guidelines for mental health services and staff on working with people from ethnic minority communities**, Dublin: MHC & MHR.

¹⁶⁶ Mental Health Commission & Mental Health Reform (2016) **Ethnic Minorities and Mental Health: Guidelines for mental health services and staff on working with people from ethnic minority communities**, Dublin: MHC & MHR, p.4.

recommendations for changing the asylum system, including specific recommendations relating to healthcare. It noted that international protection applicants experience higher levels of self-reported symptoms of depression than persons granted refugee status, and suffer higher rates of anxiety and depressive disorders than other sections of society.¹⁶⁷ It also been noted that there is no dedicated national strategy to meet the unique mental health needs of protection applicants.¹⁶⁸

The McMahon report recommended that all staff working in Direct Provision accommodation centres should be provided with mental health awareness training by the HSE. Information from the June 2017 Final Progress Report indicates that this work has commenced on this action but was not yet completed.¹⁶⁹

Roma with Disabilities

Roma in Ireland: A National Needs Assessment sought to establish how best to improve state agencies' interaction with the Roma community in Ireland. The assessment was undertaken by Pavee Point Traveller and Roma Centre, in partnership with the Department of Justice and Equality.¹⁷⁰ The report highlights the prevalence of mental health issues within the Roma community; over half (51.3%) of 108 respondents reported more than 14 days of the previous month when their mental health was not good. The report recommends that mental health outcomes for Roma be improved by ensuring that health service staff are supported to respond effectively to their needs.

¹⁶⁷ Department of Justice and Equality (2015) **Working Group Report to Government on Improvements to the Protection Process, including Direct Provision and Supports to Asylum Seekers**, Dublin: DJE.

¹⁶⁸ Nwachukwu, I., Browne, D. and Tobin, J. (2009), "The Mental Health Service Requirements for Asylum Seekers and Refugees in Ireland", Working Group of the Faculty of Adult Psychiatry Executive Committee.

¹⁶⁹ Department of Justice and Equality (2017) **Report of the Working Group to Report to Government on Improvements to the Protection Process, including Direct Provision and Supports for Asylum Seekers - Third and Final Progress Report on the Implementation of the Report's Recommendations**, Dublin: DJE, p.19.

¹⁷⁰ Pavee Point and Department of Justice and Equality (2018) **Roma in Ireland: A National Needs Assessment**, Dublin: Pavee Point and DJE.

Travellers with Disabilities

In 2010, the **All Ireland Traveller Health Study, Our Geels**, was published.¹⁷¹ It showed that 62.7% of Traveller women and 59.4% Traveller men reported that their mental health was not good for one or more days in the last 30 days. In addition, 56% of Travellers reported that poor physical & mental health restricted their normal daily activities. Suicide amongst Travellers is 6 times the rate of the general population, accounting for approximately 11% of all Traveller deaths. The data showed that while mental health services were available, they were often perceived as inadequate.

The study also found that 90% of Travellers said they had not used mental health services in the previous twelve months and many perceived mental health services to be inadequate.¹⁷² In particular, the study found that Travellers tended not to use available counselling services due to a lack of culturally appropriate provision and social stigma.

The NDA notes that there have been calls for the publication of a National Traveller Health Action Plan in line with commitments under the National Traveller and Roma Inclusion Strategy.¹⁷³

Migrants with Disabilities

The NDA notes that research has been undertaken examining the mental health experiences of a sample of migrant women in Ireland and their access to services.¹⁷⁴ The study, entitled **Let's Talk: Mental Health Experiences of Migrant Women**, shows that the women were affected by traumatic experiences in their country of origin or during their journey to Ireland, however at the time of the interview, current stressors, especially for the asylum seekers played a more significant role in determining their mental health. The study identified the key barriers to accessing mental health services including: cultural beliefs about mental health involving notions of stigma and shame, language barriers and lack of information and inadequate service provision. Recommendations included the provision of outreach psychosocial services in

¹⁷¹ Department of Health (2010) **All Ireland Traveller Health Study, Our Geels**, Dublin: DoH.

¹⁷² Quirke, B. (2010) **Selected Findings and Recommendations from the All-Ireland Traveller Health Study - Our Geels**, Dublin: Pavee Point

¹⁷³ Pavee Point, Pavee Point Manifesto for General Election 2020, <<https://www.paveepoint.ie/pavee-point-manifesto-ge-2020/>>.

¹⁷⁴ Akidwa (2020) **Let's Talk: Mental Health Experiences of Migrant Women**, Dublin: Akidwa.

Direct Provision that build trust and ensure regular contact and consistency of support for international protection applicants.

Funded through the NDA's Research Promotion Scheme, a small-scale UCD study on **Assessment of Psychiatric and Psychological Needs Among Help Seeking Migrants in Dublin** investigated the problems presented and health care needs of migrants with mental health difficulties who sought help in the Mater Hospital, Dublin and compared them to those of native Irish who sought such help.¹⁷⁵ This study found that migrants were significantly more likely than Irish individuals to fulfil diagnostic criteria for post-traumatic stress disorder and less likely to fulfil diagnostic criteria for alcohol dependence syndrome. There was no difference between migrant and Irish groups in rates of schizophrenia, bipolar affective disorder, depression or anxiety. However, the authors concluded that the low rate of schizophrenia diagnoses compared to international studies may indicate that migrants in need are not accessing mental health services.

The study revealed that the majority of migrants believed that their illness was primarily caused by the traumatic events they experienced in their home countries. Many also lacked knowledge about Western psychiatric diagnoses, disagreed with their diagnosis, and had sought alternative treatment, therapy or care from outside the psychiatric services, such as herbalists, traditional Chinese doctors and Sheik healers.

LGBTI+ with Disabilities

The Health Service Executive in its 2009 report **LGBT Health** highlighted that LGBT people experience inequities in access to and within health services which can lead to reluctance to engage with mainstream health services.¹⁷⁶ It also concluded that LGBT people are at a heightened mental health risk because of the stresses created by stigmatisation, marginalisation and discrimination.

Key findings of the 2009 study **Supporting LGBT Lives**, which explored the mental health and wellbeing of LGBT people, included the following:

- 27% had self-harmed and 85% of these did so more than once

¹⁷⁵ Kelly, F., Kelly, B. and Ryan, D. (2008) **Assessment of Psychiatric and Psychological Needs Among Help Seeking Migrants in Dublin**, Dublin: UCD.

¹⁷⁶ Health Service Executive (2009) **LGBT Health**, Dublin: HSE.

- 18% had attempted suicide and 85% saw their first attempt as related to stresses associated with their LGBT identity (e.g. fear of rejection by family or friends)
- Over a third of those aged 25 years and under had thought seriously about ending their lives within the past year and over 50% had done so at some time
- The three most common LGBT-specific stresses identified were: fear of rejection when considering coming out; negative school experiences; and experiences of harassment and victimisation¹⁷⁷

In 2015, a national study was conducted of the mental health and wellbeing of LGBTI+ people living in Ireland.¹⁷⁸ The findings of the **LGBTIreland Report** illustrated that a significant proportion of LGBTI+ people experience mental health difficulties. Across LGBTI groups, between 12-35% of participants recorded scores indicating severe or extremely severe depression, anxiety, and stress. Levels of severe or extremely severe stress, anxiety and depression were 4 times higher among 14-18 year old LGBTI teens in comparison to a similar age group (12-19 year) in the My World national youth mental health study. Additionally, intersex people had the highest scores for depression, anxiety and stress followed by transgender and bisexual people.

The **National LGBTI+ Inclusion Strategy 2019-2021** commits the Department of Health and HSE to providing LGBTI+ awareness training to staff working in mental health services nationally.¹⁷⁹ This action is to commence in Q4 2020. One of the goals of the **LGBTI+ National Youth Strategy 2018-2020** is to improve the mental health of LGBTI+ young people, which includes as an action the development of targeted early intervention initiatives and services to reduce the risk of mental health problems for LGBTI+ young people, including suicide and self-harm.¹⁸⁰ The Department of Children and Youth Affairs is also required to develop research into the factors that support positive mental health

¹⁷⁷ Mayock, P., Kitching, K., Bryan, A. & Carr, N. (2009) **Supporting LGBT Lives: A Study of the Mental Health and Wellbeing of Lesbian, Gay, Bisexual and Transgender People**, Dublin: GLEN and BeLonG To.

¹⁷⁸ Higgins, A. et al. (2016) **The LGBTIreland Report: national study of the mental health and wellbeing of lesbian, gay, bisexual, transgender and intersex people in Ireland**, Dublin: GLEN and BeLonG To.

¹⁷⁹ Government of Ireland (2019) **National LGBTI+ Inclusion Strategy 2019-2021**, Dublin: Department of Justice, p.22.

¹⁸⁰ Department of Children and Youth Affairs (2018) **LGBTI+ National Youth Strategy 2018-2020**, Dublin: DCYA.

for LGBTI+ young people and ascertain how these positive factors can be replicated.

The Gay and Lesbian Equality Network (GLEN), in conjunction with the Mental Health Commission, published guidance for staff working in mental health services to assist them in their day to day interactions with lesbian, gay, bisexual and transgender (LGBT) people availing of services.¹⁸¹

Impact of Covid-19 on People with Disabilities

The impact of Covid-19 on people with disabilities could be discussed with reference to a range of UNCRPD Articles. Covid-19 had a disproportionate impact on people with disabilities because people with disabilities are more reliant on certain public services (such as social care) which were disrupted, more likely to be at risk of getting seriously ill from Covid-19 and therefore had to restrict their normal activities and social encounters more and are more likely to be resident in congregated settings such as nursing homes, residential disability or mental health settings.

In terms of health, the data from the earlier phases of the pandemic show that people with underlying health conditions¹⁸² - who are likely to be people classified as having a disability (in the Census definition for example) – represented 92% of those who died from Covid-19¹⁸³.

Mainstream health services were significantly disrupted during the Covid-19 pandemic and particularly during the lockdowns. Certain groups of people with disabilities require ongoing engagement with medical professionals in the mainstream health services to stay healthy and independent. Many of these services were disrupted for periods during 2020 and 2021. For example, a report of a nationwide survey carried out by the Neurological Alliance of Ireland examined the impact of COVID-19 on persons with neurological conditions and family carers showed that 25% of respondents had significant issues in accessing

¹⁸¹ GLEN and Mental Health Commission (2013) **Lesbian, Gay, Bisexual and Transgender Service Users Guidance for Staff Working in Mental Health Services**, Dublin: GLEN and MHC.

¹⁸² The five most commonly reported underlying health conditions were chronic heart disease, chronic respiratory disease, diabetes, chronic neurological disease, and cancer/malignancy.

¹⁸³ Figure as of 22nd of June 2020. <https://covid-19.geohive.ie/>

services/treatment for their condition (during the 2020 lockdown). Respondents reported a range of challenges in accessing services and treatment including:

- Cancellation of outpatient appointments with neurology services
- Cancellation of infusion/injection treatments
- Delays in commencing new treatments, changes in medication postponed
- Postponement of routine MRI scans and delays in getting results from MRI
- Challenges in getting prescriptions renewed
- Cancellation of physiotherapy and other allied health services

The pandemic has contributed to increasing already significant treatment waiting lists. At the end of July 2021 there were 567, 584 people on hospital out patient waiting lists¹⁸⁴ and 69, 597 on hospital inpatient / Day case waiting lists¹⁸⁵. These waiting list figures are not disaggregated by disability.

However, there are a number of allied health / therapy services which are more likely to be specifically relevant to persons with disabilities and these services too have long waiting lists, some of which were impacted by Covid-19. The waiting lists for these services as of September 2020 stood at¹⁸⁶:

- 1, 894 on the CAMHS waiting list nationally
- 38, 630 on the Physiotherapy assessment waiting list
- 32,526 on the Occupational Therapy assessment waiting list including 9,296 waiting more than 52 weeks
- 15,358 on the Speech and Language Therapy waiting list and 7,586 on the Speech and Language Therapy treatment waiting list
- 8,836 on the Psychology treatment waiting list

¹⁸⁴ National Treatment Purchase Fund, 2021a, Outpatient by Hospital as at 29/07/2021
<https://www.ntpf.ie/home/pdf//2021/07/nationalnumbers/out-patient/National01.pdf>

¹⁸⁵ National Treatment Purchase Fund , 2021b, Inpatient/Day Case as at 29/07/2021
<https://www.ntpf.ie/home/pdf//2021/07/nationalnumbers/in-patient/National01.pdf>

¹⁸⁶ HSE, 2020a, **Health Services Performance Profile July - September 2020**
<https://www.hse.ie/eng/services/publications/performance-reports/performance-profile-july-september-2020.pdf>

The Covid-19 pandemic and responses to the Pandemic also forced innovation in many areas of the Irish health system. Various forms of remote care and support were introduced or scaled up in response to the challenges posed by the pandemic. Some of these innovations may be beneficial to people with disabilities in the post-pandemic context. The NDA and the HSE have undertaken reviews of some of these innovations¹⁸⁷.

Summary & Conclusion

The present paper underscores that while in recent years the specific needs of persons with disabilities are afforded greater consideration in mainstream strategies across the spectrum of healthcare, people with disabilities continue to have poorer health outcomes than the general population and continue to experience certain challenges accessing mainstream healthcare services.

The NDA notes that recent positive measures in the healthcare domain for persons with a disability include changes to the medical card earnings disregard for persons in receipt of Disability Allowance, tailored disability training for health and social care professionals and detailed commitments in the new oral health strategy designed to improve oral health outcomes for persons with disabilities. The NDA also notes data illustrating that persons with intellectual disabilities have either higher or similar levels of access to health screening than those without a disability, and welcomes action and progress towards the realisation of Sláintecare, which aims to achieve a universal healthcare system.

The NDA also notes that a number of areas require further development in light of UNCRPD ratification, in particular mental health. The NDA and other stakeholders are clear that the Mental Health Act 2001 needs to be amended to align with the provisions of the Convention, and the NDA advises that the recommendations of the 2012 Expert Group are instructive in that regard. The NDA welcomes the recent publication of the refreshed national mental health policy and underlines the importance of adequate funding for its realisation.

In addition, the NDA notes that greater levels of funding are required for disability services, in line with the forecasting work carried out by Working

¹⁸⁷ NDA, 2021, **Lockdowns Unlock Innovations Report**.

<https://nda.ie/publications/others/research-publications/lockdowns-unlock-innovations-report.html>; HSE, 2020b, **Digital and Assistive Technology use in Disability Services during Covid-19: A Report on the Experiences of 120 service providers**

<https://www.hse.ie/eng/about/who/cspd/ncps/disability/programme-publications/digital-and-assistive-technology-use-in-disability-services-during-covid19-report.pdf>

Group I under the Transforming Lives programme and the more recent Department of Health Disability Capacity Review. Enhanced funding should result in better and more efficient access to healthcare services for persons with a disability. The NDA also notes calls from stakeholders about funding restrictions imposed on certain disability services.

Finally, the NDA notes that more data and research is required in a number of areas, including particular areas within the health service where persons with a disability experience discrimination, the needs and experiences of minority groups accessing and requiring access to disability and mental health services and the high levels of polypharmacy amongst adults with an intellectual disability over the age of 40.