Overview of UNCRPD Article 19 In Ireland - Living independently and being included in the community

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# Background to the UNCRPD Article review papers

During 2020 to 2022 the National Disability Authority (NDA) have developed 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 envisages continuing to conduct periodic consultations on specific articles of the UNCRPD and related matters which will seek the lived experience of persons with disabilities individually and through their representative bodies.

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.

The NDA sought to ensure that the information is accurate as of August 2022 but recognises that the changing nature of policies, programmes, services, supports and data will require them to be updated 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 we reviewed 10 articles listed below[[1]](#footnote-1).. 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.

* Article 6, Women with Disabilities
* Article 7, Children with Disabilities
* Article 8, Awareness Raising
* Article 16 Freedom from exploitation, violence and abuse
* Article 19, Living Independently
* Article 24, Education
* Article 25, Health
* Article 27, Work and employment
* Article 28, Adequate Standard of Living and Social Protection
* Article 31, Statistics and Data Collection

It is intended that the NDA will develop further papers, including some papers which will focus on a number of civil and political articles.

# Introduction

The NDA recognises that article 19 is a wide-ranging and intersectional article of the Convention. This paper will focus on many of the core areas identified by the UNCRPD Committee through its General Comment no. 5. These include:

* Concrete action plan for independent living/decongregation
* Non-discrimination in accessing Housing
* Building regulations
* Accessible mainstream services
* Disability-specific services
* Collection of and availability of relevant data
* Funding for inclusive and accessible living services

Some elements essential to the full implementation of article 19 are outlined in detail in other completed UNCRPD papers developed by the NDA. These include:

* Article 25, Health
* Article 27, Work and employment
* Article 28, Adequate Standard of Living and Social Protection
* Article 31, Statistics and Data Collection

Article 19 is, as General Comment numbers 1 and 5 argue, linked to the recognition and exercise of legal personality and legal capacity as enshrined in article 12 of the Convention. Recognition of people’s legal right to make their own decisions is the basis for the realisation of independent living.[[2]](#footnote-2) Therefore, while this paper will discuss Irish policy and legislation relevant to the legal recognition that people with disabilities should be able to choose where and with whom they live, the NDA will (as part of this briefing paper series) separately develop a comprehensive paper on article 12 – Equal recognition before the law. Similarly, as General Comment number 5 states, article 19 is

tied to the obligations of the States parties relating to accessibility article 9 because the general accessibility of all built environment, transport, information, communication and facilities and services open to the public in a respective community is a precondition for living independently in the community[[3]](#footnote-3)

Therefore, while this paper will refer, for example, to the accessibility of housing and communities, these issue will be dealt with more comprehensively in a future NDA briefing paper on article 9.

# Convention text

Article 19 – Living independently and being included in the community

States Parties to this Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

1. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others are not obliged to live in a particular living arrangement
2. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
3. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

# Type of Right

The UNCRPD includes economic, social, cultural and civil and political rights. States which ratify the Convention commit themselves to immediate delivery of civil and political rights for persons with disabilities, and to progressive realisation of social and economic rights. Article 19 is primarily an economic, social and cultural right and is being progressively realised in Ireland.

It should be noted that General Comment no. 5 paragraph 7 states:

Article 19 entails civil and political as well as economic, social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to live independently and be included in the community can only be realized if all economic, civil, social and cultural rights enshrined in this norm are fulfilled.

# General comment No. 5 (2017) on living independently and being included in the community

The UNCRPD Committee issued General Comment no. 5[[4]](#footnote-4) on living independently and being included in the community.

This General Comment aims to assist State parties in their implementation of article 19 and fulfilling their obligations under the Convention. It includes definitions of ‘independent living’, ‘being included in the community’, ‘independent living arrangements’, and ‘personal assistance’ (para. 16).

The General Comment acknowledges that

Article 19 is one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral to the full implementation of the Convention.

The Committee, however, identifies the core elements of article 19 which must be in place to ensure a standardised minimum support level, sufficient to allow the exercise of the rights contained within the article, is carried out by every State party. The Committee states that these core elements of article 19 should always be respected, particularly in times of financial or economic crisis. The core elements are:

* To ensure the right to legal capacity, in line with the Committee’s general comment No. 1, to decide where, with whom and how to live for all persons with disabilities, irrespective of impairment;
* To ensure non-discrimination in accessing housing, including the elements of both income and accessibility, and adopting mandatory building regulations that permit new and renovated housing to become accessible;
* To develop a concrete action plan for independent living for persons with disabilities within the community, including taking steps towards facilitating formal supports for independent living within the community so that informal support by, for example, families is not the only option;
* To develop, implement, monitor and sanction non-compliance with legislation, plans and guidance on accessibility requirements for basic mainstream services to achieve societal equality, including participation by persons with disabilities within social media, and secure adequate competence in information and communications technologies to ensure that such technologies are developed, including on the basis of universal design, and protected;
* To develop a concrete action plan and take steps towards developing and implementing basic, personalized, non-shared and rights-based disability-specific support services and other forms of services;
* To ensure non-retrogression in achieving the content of article 19 unless any such measures have been duly justified and are in accordance with international law;
* To collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions;
* To use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.

# Key data and statistics

## Overview of data availability and gaps

In order to support the measurement of the implementation of article 19, the Office of the High Commissioner for Human Rights (OHCHR) has developed a list of 37 illustrative structural, process and outcome indicators[[5]](#footnote-5) to guide State Parties. The indicators can be used to assess choice of independent living arrangements, disability-specific support services, and the accessibility and responsiveness of mainstream services.

The NDA has identified available data in Ireland related, for example, to:

* Numbers of persons living in congregated settings
* Numbers of people living in other communal settings
* Numbers of persons with disabilities living in designated centres [residential disability services]
* Homeless persons by type of disability

The NDA has identified the need to strengthen data collection in relation, for example, to:

* Unmet need for some community based services such as home support and personal assistance
* Disaggregation of all data by sex, age, and disability
* Outcomes (e.g. Number and proportion of adults with disabilities reporting satisfaction with their level of independence in their living arrangement, disaggregated by sex, age and disability)

## Analysis of available data

There are 643,131 persons with disabilities in Ireland according to the Census 2016 conducted by the Central Statistics Office.

Census 2016 shows that 585,639 individuals with disabilities live in private households. That is, of the 643,131 persons with a disability in Census 2016, 44,531 were living in a communal establishment on census night or 7.07 percent of all persons with a disability. This compares to 2.6 percent for the total population and just 2 percent of persons without a disability (Table 1).

Table 1: People Enumerated in Communal Establishments

|  | Persons with a disability | All others  | Persons with a disability % | All others % |
| --- | --- | --- | --- | --- |
| All types of establishments | 44531 | 81668 | 7.07% | 2.0% |
| Hotel | 3690 | 42834 | 0.6% | 1.0% |
| Guest house, boarding house or B&B | 500 | 6136 | 0.1% | 0.1% |
| Tourist/youth hostel or campsite | 251 | 3757 | 0.0% | 0.1% |
| Educational establishment | 726 | 4747 | 0.1% | 0.1% |
| Religious community | 1548 | 2271 | 0.2% | 0.1% |
| Nursing home/children's home | 25356 | 3668 | 3.9% | 0.1% |
| Hospital | 9515 | 7749 | 1.5% | 0.2% |
| Defence establishment | 25 | 633 | 0.0% | 0.0% |
| Prison | 650 | 3141 | 0.1% | 0.1% |
| Shelter or refuge (including accommodation for homeless persons) | 1920 | 5120 | 0.3% | 0.1% |
| Civilian ships, boats and barges | 7 | 734 | 0.0% | 0.0% |
| Other types of establishments | 343 | 878 | 0.1% | 0.0% |
| Not in a communal establishment on census night  | 598600 | 4037066 | 93.1% | 98.0% |

Source: Census 2016

Not only are persons with a disability more likely to be in a communal establishment than persons without a disability, but also the type of establishment also differs from persons without a disability. For instance, hotels were the most common communal establishment for persons without a disability but for persons with a disability this was nursing homes/children’s homes[[6]](#footnote-6) (Figure 1 below).

Figure 1: Nos. of People Enumerated in Communal Establishments

Source: Census 2016

From the 2016 census we know that there are 1,871 persons with a disability who are homeless. This equates to 27.1 percent of all people who were homeless at that time and would indicate that persons with a disability are disproportionally likely to be homeless. Among persons with a disability who are homeless, two groups stand out as being most common – those with psychological or emotional conditions (44 percent) and other disability, including chronic illness (45 per cent).

Table 2 - Homeless Persons by Type of Disability

| Type of disability | N. | % |
| --- | --- | --- |
| Total persons | 6906 |  |
| Total persons with a disability | 1871 |  |
| Blindness or a serious vision impairment | 158 | 8% |
| Deafness or a serious hearing impairment | 131 | 7% |
| A condition that substantially limits one or more basic physical activities | 581 | 31% |
| An intellectual disability | 213 | 11% |
| Difficulty in learning, remembering or concentrating | 621 | 33% |
| Psychological or emotional condition | 825 | 44% |
| Other disability, including chronic illness | 840 | 45% |
| Difficulty in dressing, bathing or getting around inside the home | 246 | 13% |
| Difficulty in going outside home alone | 362 | 19% |
| Difficulty in working or attending school/college | 619 | 33% |
| Difficulty in participating in other activities | 509 | 27% |

Source: Census 2016

Over 9,000 people with disabilities (n=9,166) received residential accommodation in 1,340[[7]](#footnote-7) designated centres[[8]](#footnote-8) where they avail of disability specific residential or respite services (just over 8,000 people received a residential service in 2021).[[9]](#footnote-9) These facilities are funded by the State and either provided by the Health Service Executive (HSE) or a range of voluntary organisations classified as Section 38 and Section 39 providers according to the Health Act 2004. In 2020 the net current provision for disability services 2020 was €2,056million and it is estimated that residential services account for 64% or approximately €1,245 million of this.[[10]](#footnote-10)

Working Group 1 of Transforming Lives carried out an analysis of anticipated future demand for residential places for persons with an intellectual disability in 2018, looking at the impact of demographic change alone and in combination with addressing under-provision, using three different scenarios:[[11]](#footnote-11)

* Scenario 1 – uses the same age-specific residential care usage ratios as 2015 and allows for demographic change only. It considers that 85% of persons with an intellectual disability being supported to live in disability residential services. This scenario suggests an increase of 400-500 residential places would be required in 2020, and about 700-800 in 2025, because of the growth in, and ageing of, the population of persons with an intellectual disability.
* Scenario 2 – uses the same age-specific 2015 ratios for those under 60 years of age and increases the proportion of people over 60 who are supported to live in disability residential services to 95%. This figure was considered by the working group to be more realistic. This would add an extra 200 or so places to the 2020 requirement, and about 370 to the 2025 requirement.
* Scenario 3 - uses pre-recession rates of residential care usage and includes the increase in over 60s supported to live in disability residential services to 95%. This scenario captures the pent-up demand from the recession years, which has manifested itself in historically high numbers of emergency placements. This would add about 1,200 to demand in 2020.

Informed by the Transforming Lives Working Group 1 report’s projections, the Department of Health carried out further analysis in order to model demand up to 2032. The output of this further analysis (Disability Capacity Review report) estimated that between 1,900 and 3,900 additional residential places would be required by 2032 under the different scenarios which take into account demography, unmet demand and restoring levels of provision to pre-recession levels (where there were a higher proportion of residential places per person with intellectual disability).

The approximate costs of the additional residential places required are estimated below in Table 3.

Table 3 - Summary of additional disability residential places required (over 2017 level) to address demographic and current unmet needs 2017-2032[[12]](#footnote-12)

|  | Demography only | Demography + unmet demand |
| --- | --- | --- |
|  |  | Minimum | Intermediate | Pre-recession |
| 2017  |  | 800 | 1,500 | 2,300 |
| 2022 | 450 | 1,200 | 2,000 | 2,900 |
| 2027 | 800 | 1,600 | 2,500 | 3,400 |
| 2032 | 1,100 | 1.900 | 2,900 | 3,900 |

Source: Department of Health 2021

The annual cost of providing the additional residential places would be between €300m per year by 2032 under the Minimum scenario, and around €550m per year under the Pre-Recession scenario. The Disability Capacity Review notes that providing that level of additional accommodation will not only require very significant financial investment but also be a significant logistical challenge.[[13]](#footnote-13)

Source: Transforming Lives (2018) Working Group 1 Report on Future Needs for Disability Services

# Policy Landscape

The progressive realisation of the rights contained in article 19 require policies and programmes that address

* Independent Living
* Access to specialist support services
* Appropriate access to mainstream services

The text below will present the available data and information under these three broad headings to try to present the information in an accessible way although it is acknowledged that a particular policy or programme could be considered under more than one of these headings.

## Independent Living

### Decongregating disability services

In 2012, government published the Time to Move on from Congregated Settings Report, in which a policy to decongregate persons with disabilities from institutional settings was set out. At the time the policy was published, there were approximately 4,099 individuals living in congregated settings of 10 or more people. A commitment was made to transition all these individuals to the community by 2021. By end 2019, the most recent year for which figures are available, there were approximately 1,950 individuals remaining in congregated settings.

The rate of transition of people leaving congregated settings to live self-directed lives in the community has increased slowly over time. In 2016, 74 individuals transitioned out of congregated settings to live in the community, a figure which represents 2.7 per cent of all individuals in congregated settings. The Health Service Executive now sets annual targets for the number of moves to the community that will be achieved in a year. The 2019 target for example was for 160 people to move, with 116 actually moving (of whom 10 moved to a nursing home and 11 moved to a group home with between five and nine people).**[[14]](#footnote-14)** The HSE is committed to support transitions in a person-centred manner, and this can mean that targets may not be reached in a given year if some individuals chose to delay their move, or if transition plans take longer than expected to implement.

In 2019, 116[[15]](#footnote-15) individuals transitioned which represents 5.4 per cent of all individuals in congregated settings. In 2020[[16]](#footnote-16) and 2021,[[17]](#footnote-17)120 and 144 people respectively transitioned from congregated setting to the community. In 2021 the HSE met its target for transitions, which was 144 individuals. It should also be noted that there have been some admissions to congregated settings. During 2019, for example 23 people were admitted or re-admitted. By the end of 2021, less than 2000 people remained in congregated settings.

Therefore, the original target of 4,099 people being moved out by 2021 was not achieved and based on current targets (a target of moving 143 people in 2022[[18]](#footnote-18)) moving the remaining people out of congregated settings will take a number of years.

There are a range of housing options for those leaving congregated settings. These include houses that are purchased and renovated by service providers for those who use their services, social housing available through a local authority, or private rented accommodation arranged through a tenancy agreement. There are a number of factors leading to the slower than hoped pace of decongregation:

* The Irish housing market in general is constrained, with inadequate supply to meet demand. This was an outcome of the Great Recession of 2008, and home building has only recommenced to an appropriate level in 2018/19 although it has slowed again as a result of restrictions due to the COVID-19 pandemic. Housing supply suitable for individuals moving out of institutions is therefore an issue that impacts on the rate at which transitions can be achieved. The housing stock for sale is also insufficient to meet demand across the population as a whole, leading to high prices for purchase and high rents charged. The Department of Health allocated €100 million over 6 years (2016-2021) to the HSE for the provision of new homes to support people to move from congregated settings into the community, with a focus on accelerating the progress in a number of priority settings. Given the profile of many individuals leaving institutional settings, it is often the case that renovations and adaptations are required to make houses suitable and accessible for those who will be living in them. There is, at present, an insufficient supply of accessible housing in the market.
* Some service provider organisations have found it challenging to support the decongregation process at the same time as achieving compliance with HIQA regulations, within the available resource envelope.
* In the early phases of the process, NDA also notes that some resistance to the process from family members led to delays in decongregation from some sites. A process of communication and engagement has since been rolled out by the HSE. This has been effective in addressing some of the concerns of staff, individuals and families, and therefore in achieving further progress in the process of transition.
* There is no national policy that prohibits ‘recongregation’ and as such, there are a number of admissions to congregated facilities each year – there were 23 admissions in 2019, 33 in 2018, 36 in 2017 and 34 in 2016.[[19]](#footnote-19) In many cases these are ‘emergency placements’ whereby an individual who has previously resided with family caregivers requires a crisis placement due to the death of these caregivers. The State acknowledges that a process to plan for such placements in community rather than congregated settings will need to be advanced. In a smaller number of cases, readmissions to congregated settings occur because a transition to a community placement has not worked. In these instances, efforts are made to support the person in a further move to the community over time, and so readmission is not intended as a permanent situation. The NDA advises, however, that consideration be given to developing a policy to close all admissions to congregated settings for persons with disabilities falling under the Transforming Lives policy be considered to reduce new/re-admissions which can currently arise in crisis situations.

NDA also advises that an acceleration of progress would give older persons with disabilities a chance of community living and a better quality of life for the remainder of their life. In a case study report on deinstitutionalisation in Ireland by the European Union Agency for Fundamental Rights[[20]](#footnote-20) the authors found that despite the drivers for deinstitutionalisation in the 2011 policy ‘Time to Move On’, it took the establishment of HIQA and some damning public reports on life in institutions to provide momentum to the decongregation process.

While COVID-19 may in the short-term impact on efforts to support people to move out to the community, the NDA advises that acceleration of progress should be considered in light of the obvious benefits in terms of infection prevention and control.

The NDA notes that congregated settings for persons with mental health conditions are regulated and inspected by the Mental Health Commission,[[21]](#footnote-21) and that the reporting on numbers within same are separate to those for persons with disabilities in most cases.

The Time to Move On from Congregated Settings report recommended that (where people chose to live with others) that no more than four residents should live together[[22]](#footnote-22). However, the implementation of the policy is focused on those settings with 10 or more residents. The Time to Move On policy does not address those settings where between five and nine individuals are living together. HIQA’s Five Years of Regulation in Designated Centres for People with a Disability report showed that in 2018, 448 designated centres registered with HIQA had between five and eight people living in them (and 339 with nine residents or more).[[23]](#footnote-23)

### Nursing homes

Older persons’ policy will be discussed in more detail below in section on Older Persons with Disabilities (see page 41 below). However, this section deals with nursing homes as the residents of nursing homes constitute a large proportion of people with disabilities living in communal establishments. In 2020 there were 576 registered nursing homes in Ireland, with approximately 32,000 residential places[[24]](#footnote-24) providing support to mostly older persons, the majority of whom have a disabilities. In terms of independent living three main concerns have been raised in relation to the nursing home sector.

#### Nursing homes and the provision of alternative options for independent living

Ireland has a statutory scheme to fund nursing home placements and the state through HIQA regulates the quality of nursing home provision. Long term nursing home care is funded under the Nursing Home Support Scheme which was introduced in 2009 on the basis of the Nursing Homes Support Scheme Act, 2009. Under the Nursing Home Support Scheme, applicants are assessed clinically and financially. The clinical assessment determines whether a person requires nursing home care and financial assessment determines the extent of their financial contribution. Once deemed clinically in need of nursing home care, applicants can choose from a private or public nursing home.

While supports to remain living in one’s own home exist there is currently no statutory scheme to provide such supports and the supports provided are unregulated. This perceived underfunding of home care and the lack of regulation of home care has been criticised by stakeholders as resulting in constrained choice for people who require support to live in the community which may result in them going into residential care due to the lack of an alternative.[[25]](#footnote-25) In 2018 and 2019 the total budgets allocated to Nursing Home Support Scheme were €962 million and €991.4 million respectively while €412 million in 2018 and €446 million in 2019[[26]](#footnote-26) was allocated to home care hours. An increase of €150 million (to fund 5 million additional home care hours) was announced in Budget 2021.[[27]](#footnote-27)

Slaintecare included a recommendation to expand home care. The Slaintecare Implementation Strategy contains a commitment to the development of a statutory home care scheme. A pilot to test a reformed model of service-delivery for home support which will underpin the development of the statutory scheme for the financing and regulation of home support services is underway in 4 areas (West Cork, Galway, Laois-Offaly and Dublin).[[28]](#footnote-28) The Department of Health is currently (as of quarter 1 2022) developing regulations to underpin a new regulatory framework for home support and HIQA is currently (as of quarter 1 2022) developing standards for home care.

### Younger people with disabilities living in nursing homes

A study by researchers in Dublin City University showed that there were over 1,300 younger people (under the age of 65) in nursing homes in 2018. A second phase of this research aims to explore the experiences of younger persons with disabilities and may shed more light on the circumstances in which people decided to go into a nursing home and what alternatives if any were available to them.[[29]](#footnote-29) An Ombudsman report on the issue highlighted the need for a census of those currently in nursing homes, revised procedures around informed consent and ring-fenced funding for those currently inappropriately resident in nursing homes.[[30]](#footnote-30) The HSE is also examining this issue and plans to transition a number of this cohort to community living. This will require significant PA and or Homecare supports and accessible accommodation.

#### Institutionalised care model and proposed Commission on Care

The issues with infection control in nursing homes during the Covid-19 pandemic prompted discussions around the role of nursing homes in the provision of eldercare. Tánaiste Leo Varadkar TD raised the question of whether nursing homes (and public investment in same) should continue to play the same role in supporting older people or whether nursing homes would be looked at as institutional models of care post-pandemic. The Tánaiste called for a review of all care systems for older persons. [[31]](#footnote-31) Gerard Quinn, **now the UN Special Rapporteur on the rights of persons with disabilities** published an article reflecting on the Tánaiste’s comments in which he explicitly framed the discussion on nursing home provision in the context of the UNCRPD and the national policy on decongregating people with disabilities from institutions.[[32]](#footnote-32)

HIQA’s review of the impact of Covid-19 on the nursing home sector concluded that

While we will take the learning from this programme of assessments and continue to monitor nursing homes throughout the course of this pandemic to protect the safety and welfare of residents, wider reform is now necessary. HIQA has previously called for reform of the regulatory framework to allow other forms of care to flourish. The current system predominately directs people into a single model of residential care when other options may be more suitable. Alternative services such as assisted living and homecare would enhance the experience of many older people in the latter stages of their lives.[[33]](#footnote-33)

Commenting on the HIQA review Paul Reid, CEO of the HSE said that the future of elder care support “can’t be in congregated settings” and that “[i]f you look at Denmark, they stopped building nursing homes a few years ago and I think that is lesson number one for Ireland.”[[34]](#footnote-34)

The [Oireachtas] Special Committee on Covid-19 Response – Final Report found that there was a

lack of a coherent policy on the care of older people which, through the provision of tax incentives, has seen the continuation of long-term institutional care in large settings

and

The failure to prioritise empowering older persons to remain at home and develop models including smaller domestic-style units integrated into towns and city community areas[[35]](#footnote-35)

Therefore, the Covid-19 pandemic appears to have influenced the policy considerations around nursing home provision in Ireland among politicians, health service management and regulators. The Programme for Government published in June 2020 committed to the establishment of a Commission on Care to examine “alternatives to meet the diverse needs of our older citizens.”[[36]](#footnote-36)

#### Decision to enter and remain in a nursing home

As noted above the UNCRPD Committee has emphasised that a key element for the progressive realisation of article 19 is the right to legal capacity to decide where, with whom and how to live for all persons with disabilities, irrespective of impairment.[[37]](#footnote-37) Furthermore, the Committee’s view is that the practice of denying the legal capacity of persons with disabilities and detaining them in institutions against their will, either without the free and informed consent of the persons concerned or with the consent of a substitute decision-maker, constitutes arbitrary deprivation of liberty is incompatible article 12 and article 14 UNCRPD requirements.[[38]](#footnote-38)

Court cases, such as the recent AC v CUH & HSE (2018), established that there is no legal basis that allows Irish health and social care providers to detain a person against their will in a health or social care setting (outside of the Mental Health Act 2001, Section 23 and the Health Act, 1947, for infection control purposes). AC v CUH & HSE was appealed to the Supreme Court in 2019 which upheld the view that under Article 40.4 of the Constitution people with impaired mental functioning have the same constitutional guarantee of personal liberty as all other persons. The Supreme Court set out guidance for health and social care providers around how decisions should be made in circumstances where health and social providers believe there is a real risks to the health and welfare or someone who wishes to leave a health and social care setting.

Irish stakeholders have raised concerns about the absence of an appropriate legal framework for decisions around people entering and remaining in long-term care settings such as nursing homes. Sage Advocacy, for example, has criticised the “somewhat casual approach” to contracts being signed between nursing homes and relatives even when residents do not lack capacity or where no functional capacity test has been carried out.[[39]](#footnote-39) Research has suggested that in the majority of cases (53%) there was either “no demonstration of will and preference or it was unclear or not possible to obtain” will and preference in the documentation arranging for a person’s entry into a nursing home.[[40]](#footnote-40)

The full commencement of the Assisted Decision-Making (Capacity) Act 2015 and the establishment of the Decision Support Service in 2022 should go some way to addressing the issue of older persons entering nursing homes based on decisions made by their relatives. The Decision Support Service sought observations on draft Codes of Practice, including a Draft code of practice on supporting decision-making and assessing capacity and a Draft code of practice for healthcare professionals. The HSE has been preparing the health and social care sectors for the impact of the full commencement of the legislation through a programme of conferences and webinars and published documents.[[41]](#footnote-41)

However, in addition to the Assisted Decision-Making (Capacity) Act 2015 there is a legislative gap in relation to legal safeguards around people being deprived of their liberty in residential settings. The Department of Health recognised this legal gap and drafted proposals for deprivation of liberty safeguards for public consultation in 2018 and a draft consultation report was published in 2019.[[42]](#footnote-42) Work on the Protection of Liberty Safeguards was paused in 2020 because of Covid-19. The Department of Health has indicated that work in this area resumed in summer 2022, however, at the time of writing it was not clear when the relevant draft legislation would be published.

### Mental health provision and communal living

Mental health policy and provision will be dealt with in more detail below. However, this section deals specifically with people in receipt of disability services who are living in communal living settings.

A ‘deinstitutionalisation’ programme to move persons with mental health illnesses from large psychiatric institutions to the community took place in Ireland phases from the 1960 to the 1980s. However, people with mental health difficulties are resident in psychiatric hospitals and units and in 24 hour supervised residences for people with mental illness.

There were 1,826 people resident in adult in-patient hospitals and units at the end of December 2020. This figure represents a 91% reduction in in-patient numbers from 19,801 in 1963 to 1,826 in 2020.[[43]](#footnote-43) The average length of stay for all residents in in-patient hospitals and units in 2020 was 1,661.5 days (the median stay was 144 days). “Long-stay” patients, meaning that they had been in the hospital or unit for one year or more, constituted 43% of residents in in-patient hospitals and units. Residents in in-patient hospitals and units with intellectual disability had the longest average length of stay, at 9,528.9 days (median 8,923.0 days), followed by schizophrenia, at 2,097.0 days (median 662.0 days) and alcoholic disorders, at 1,545.4 days (median 26 days). Other drug disorders had the shortest average length of stay, at 35.8 days (median 8 days).[[44]](#footnote-44)

In 2018 there were 118 24 hour supervised residences for people with mental illness, housing approximately 1,200 people (43% of units had more than 10 beds and only 7% had four beds, none had less than four beds). These have been described as mini-institutions and feature many shared bedrooms with little privacy. In addition, 43% of residences did not have single rooms for all residents. The provision of care to this group of vulnerable people is currently unregulated.[[45]](#footnote-45) The Department of Health has committed to these services being regulated[[46]](#footnote-46) (and has undertaken consultation in 2021 on proposals to amend the Mental Health Act, 2001 which included a proposal to regulate community residential houses). Once these settings are subject to regulation the issues identified by the Inspector of Mental Health Services around inappropriate environments, access to supports and privacy will need to be addressed. Sharing the Vision, the Government’s revised mental health strategy, has recommended the expansion of community based mental health services.[[47]](#footnote-47) However, there isn’t an explicit decongregation plan (similar to Time to Move on from Congregated Settings) for 24-Hour Supervised Residences.

### National Housing Strategy for Persons with Disabilities

The Government published the first National Housing Strategy for People with a Disability in 2011. The first National Housing Strategy for People with a Disability was intended to cover the period up to 2016 but was in fact extended to 2021. The first Strategy outlined broad proposals and strategic objectives involved in effectively addressing the housing and related support needs of persons with disabilities. The first Strategy set out an integrated approach to the provision of housing and support services from the local authorities and the HSE, that would enable persons with a disability 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. Under the Strategy local authority-led Housing and Disability Steering Groups were established in each local authority area to support the implementation of the Strategy at local level and to provide an improved basis for planning and service delivery of housing supports to people with disabilities. The timeline for the Strategy was extended to 2021 in order to enable the goals of the Strategy to be met.

The Department of Housing, Local Government and Heritage published the second housing strategy for people with disabilities in early 2022. (The National Housing Strategy for Disabled People 2022 – 2027). The development of the new Strategy involved a review of Irish data sources and international evidence, an evaluation of the Housing and Disability Steering Groups and consultation with people with disabilities. The new Strategy set out actions under six outcome themes -

* Accessible Housing and Communities
* Interagency Collaboration and the Provision of Supports
* Affordability of Housing
* Communication and Access to Information
* Knowledge, Capacity, and Expertise
* Strategy Alignment

The new strategy tasked the Housing Agency with preparing a detailed Implementation Plan. A tri–departmental Working Group comprising the Department of Housing, Local Government and Heritage, the Department of Health and the Department of Children, Equality, Disability, Integration and Youth will approve the Implementation Plan.

The proportion of people whose main need for social housing support is related to their disability has increased from 6.3% in 2016 to 8.2% in 2020 (7.8% in 2019 2017 = 6.7%, 2018 = 7.2%). This increase, although minor, may be due to a number of factors. There has been a move by some residential disability services to put residents on the housing list as part of the decongregation process. The increase in the housing crisis over the past number of years may also have influenced the increase, as people with persons with disabilities are more likely to be poorer and less likely to be working than the rest of the population and therefore may find access to housing more difficult. The 2016 Census found that the proportion of persons with a disability among the homeless population, at 27.1%, was higher than for the general population at 13.5%.

The NDA welcomes the continuing collaborations on housing including the Department of Housing, Local Government and Heritage working in conjunction with the HSE as part of the Implementation Monitoring Group of the National Housing Strategy for People with a Disability. The review of the Housing and Disability Steering Groups conducted as part of the work to inform the new National Housing Strategy for People with a Disability found that members indicated that the benefits of the Steering Groups were

* increased understanding of the needs of disabled people
* better capacity to understand and plan for emerging need
* better relationships with other organisations and increasing
* better access to information

The NDA has advised the Department of Housing, Local Government and Heritage that more needs to be done to address the issues around the availability of accessible homes for people with disabilities. The NDA has advised that while Part M of the building regulations sets out the minimum requirements for housing design, which is that new dwellings are visitable by disabled people. As most housing is built to the minimum requirements, this means that there is a lack of accessible housing, that disabled people can live in, in Ireland.

Part M was last revised in 2010. The NDA has advised that Part M should be reviewed, with priority given to a review of Part M for Dwellings, to ensure that new homes are required to be liveable by all people, including disabled people and older people (to enable ageing in place).

In its recent policy advice the NDA has advised the Department of Housing, Local Government and Heritage of the need to increase the supply of Universally Designed homes. In its advice on the **Housing Options for our Ageing Population: Policy Statement** the NDA advised that 20% homes be built to UD Home level and 10% built to UD Home+ (wheelchair liveable) level. In any review of Part M for dwellings, the base level for all new dwellings should be the UD Home level with 10% built to UD Home+ (wheelchair liveable) level.

# Access to specialist support services

Specialist disability services in Ireland were predominantly delivered by the voluntary sector, and in the past these were primarily charities run by religious orders. In many cases, the charities in question owned the properties in which services were delivered, for example, residential services in congregated settings. As the landscape has evolved, some services are now delivered directly by the Health Service Executive (HSE), while the majority are still delivered by the voluntary sector now made up of religious and non-religious voluntary organisations, with funding provided and administered by the State through the HSE. The HSE is the public body responsible for providing health and social care supports – including residential – to persons with disabilities. This funding has traditionally been delivered through block grants, which has made it challenging to move to individualised funding while continuing to deliver services within existing budgets.[[48]](#footnote-48)

The recommendations of the Value for Money and Policy Review of Disability Services (2012) are being implemented under the leadership of the Department of Health and the HSE, where a transformation of services to be person centred, outcomes focused, and delivered within the community rather than segregated settings is underway. These reforms are being implemented under the broad banner of ‘Transforming Lives’. The programme was devised based on a series of recommendations arising out of a Value For Money and Policy Review of Disability Services published in 2012, and was intended to provide a roadmap to achieving transformation of disability services to a more person-centred and individualised model. This transformation agenda includes a series of national policies to guide progress, each informed by consultation and research. These policies include:

* Time to Move on from Congregated Settings (for residential services)
* New Directions (for adult day services)
* Progressing Children’s Disability Services (for services for 0-18 year olds)

The latter policy regarding Progressing Children’s Disability Services is dealt with in the NDA’s UNCRPD article 7 paper. Clearly access (or lack of access) to appropriate and timely early intervention will have an impact on a person’s capacity to develop skills relevant to independent living. However, as Progressing Children’s Disability Services has crucial links to children’s health, education and early years services it was decided that it would be addressed in the article 7 paper rather than this article 19 paper. The Time to Move on and New Directions policies are discussed below in addition to other work relevant to article 19 that is being advanced through other avenues.

### Regulation of Designated centres for persons with disability

Residential settings are monitored by the Health Information and Quality Authority (HIQA), which has a mandate to conduct regular inspections of facilities, and has the power to grant or withdraw registration should appropriate standards of care be breached. HIQA commits to a minimum of two routine inspections in a three year period for a designated centre registered with the Authority, while additional inspections can be scheduled in instances where follow-up is required or concerns are raised. HIQA currently holds registration for 1,183 residential facilities for disability services. The standards against which HIQA monitors service provision are national standards that cover a number of thematic areas.[[49]](#footnote-49) The HIQA monitoring process has identified a number of facilities where standards are consistently breached, and so has issued ‘closure orders’. (HIQA has issued notice to cancel a centre’s registration on 68 occasions between 2013 and 2018). Where remedial actions have not been carried out to the satisfaction of the Authority, a subsequent ‘closure order’ can be issued. In these instances the HSE takes over management of the site, and several of these have been identified for accelerated decongregation.

A review by the National Disability Authority of the first year of inspection and regulation of residential disability services (which included the views and evidence of the lived experience of residents) found that though regulation had resulted in some improvement it had created challenges too, such as, increased staff time devoted to administration related to regulation.**[[50]](#footnote-50)** In relation to the regulations themselves the review found that because of the definition of ‘designated centre’ and the absence of a definition of what a ’residential service’ is it was unclear how some community living arrangements fit in with the regulations.**[[51]](#footnote-51)** A five year review of regulation of disabilities services later highlighted the same issue of how the various community living arrangements that exist and should exist fit with the current regulations.**[[52]](#footnote-52)**

A review of regulation of residential disability services is an action of the National Disability Inclusion Strategy and HIQA and the NDA have both called for this review to take place.[[53]](#footnote-53)

### Quality improvement initiatives

Since 2012, the NDA has developed a series of frameworks for the HSE for residential and day services aimed at ensuring provision of quality assured services that are person centred and outcomes focused. These included a framework of nine quality of life outcomes;[[54]](#footnote-54) a person-centred planning framework;[[55]](#footnote-55) and a quality framework for outcomes-focused disability services. The HSE is now testing implementation of these frameworks in services in order to guide wider implementation. Work is on-going to consider appropriate means of measuring outcomes for persons with disabilities within services, informed by background research carried out by NDA.[[56]](#footnote-56)

It should be noted that HIQA also regulate 581 designated nursing homes for 31,250 mostly older persons, the majority of whom have a disabilities.[[57]](#footnote-57)

## Day Services

## New Directions

In 2012 the Department of Health and HSE published a policy on New Directions for adult day services.[[58]](#footnote-58) This policy adopted the mainstreaming approach to provision of services for persons with disabilities, and is constructed around 12 supports aimed at facilitating or supporting individuals to access opportunities in social activity, education, training and employment among others, that would lead to a meaningful day.

The implementation of New Directions has been underfunded to date, but there has been a shift away from large centre-based day service activities to smaller community-based hubs. Previous sheltered workshops have also been closed, and the 2,513 individuals in these placements are being supported to transition to appropriate day service placements and/or mainstream education, training and employment situations.[[59]](#footnote-59) Approximately 23,000 people avail of day services.[[60]](#footnote-60)

Demand for adult day services is rising every year due to an inflow of school leavers, and it is set to rise by 4% to 2021 and by 17% to 2026, above its 2016 level (2016 was the base year for projections). 2018 forecasting work carried out by the HSE and the NDA as part of the Transforming Lives Working Group 1 Report on Future Needs for Disability Services estimates that a step increase of around €20m a year for running costs and around €1.5m for premises costs would be needed to address the continual net inflow by 2021.[[61]](#footnote-61) These figures would rise gradually to €24m a year for running costs and €2m a year for premises costs by 2026. It is also possible that the increase in autism being seen in schools could partially translate into an increased rate of future demand for day service places for school leavers, which may increase the annual increment of spending required.

### Regulation of Day Service Provision

It is intended that over time HIQA will have a role to regulate the standards that would apply to day services in addition to its existing responsibility for regulating residential services. Until this time, the HSE has implemented a series of interim standards for the monitoring of New Directions services.[[62]](#footnote-62) Assessment against these standards is provided through a process of self-evaluation and continuous quality improvement.

## Personalised Budgets

In 2016, the Minister for State with special responsibility for Disabilities established a Taskforce to examine the issue of personalised budgets for persons with disabilities, following a commitment in the Programme for a Partnership Government of that year. The intention was to achieve maximum choice and control for persons with disabilities in how they selected and paid for their social care services and supports. The traditional funding model for disability services had been through provision of a block grant for service providers from HSE under Section 38 and 39 of the Health Act. The Taskforce explored a series of models and considerations regarding how a personalised budget could be used by individuals to purchase these services and supports. The report of the Taskforce was published in July 2018,[[63]](#footnote-63) and recommended that a series of demonstration projects be advanced to test the provision of personalised budgets across a range of variables including: model of payment, geographic area, type and level of disability, gender, age and level of governance.

The demonstration projects got underway in late 2019, with the aim of securing 180 participants over two phases of activity: Phase 1 testing direct payments and budgets co-managed with service providers; and Phase 2 testing brokerage scheduled for roll-out in Q2 2020. The Demonstration Projects were paused March 2020 until quarter 4 2020 due to COVID-19. Though the project was recommenced in quarter 4 2020 Covid-19, staff recruitment, procurement and issues has meant that the project is significantly behind schedule. At the end of Q 1 2022 there were fewer than 20 participants who had progressed to taking up a personalised budget. As a consequence the Demonstration Projects have been rolled out over a greater length of time than originally planned. An independent evaluation of the demonstration phase has been commissioned and is being overseen by the National Disability Authority. Delays in the recruitment of Demonstration Projects participants mean that the final evaluation report has not yet commenced and is unlikely to be completed until mid-2024. The findings of the evaluation phase will inform government decisions about a national mainstreamed programme of personalised budgets.

## Personal Assistant services

Individuals living within the community can access personal assistant (PA) or home care supports through the HSE. There is currently no national policy governing eligibility for, or allocation of, these supports. In 2019, the HSE National Service Plan committed to providing PA and home support hours to more than 10,000 persons with disabilities. In 2018, the HSE provided 1,636,883 hours of PA supports and 3,138,939 of homecare support hours.[[64]](#footnote-64) By June 2019, 824,467 PA hours were delivered, 12,607 more than the same period the previous year. Regarding Home Support Hours 1,538,169 hours were delivered to June 2019, 23,137 hours less than the same period the previous year.[[65]](#footnote-65) HSE performance indicators reveal that the number of people receiving PA services varies across CHO areas. For example CHO6 reports only nine people in receipt of PA hours whereas CHO4 reports 449 people (Table 4).

Table 4 - Target Activity 2019: No. of adults with a physical and/or sensory disability in receipt of a PA Service by CHO area

| CHO area | Number of people |
| --- | --- |
| CHO1 | 254 |
| CHO2 | 431 |
| CHO3 | 427 |
| CHO4 | 449 |
| CHO5 | 406 |
| CHO6 | 9 |
| CHO7 | 52 |
| CHO8 | 281 |
| CHO9 | 226 |
| Total | 2,535 |

Source: HSE Disability Services – Key Performance Indicator Metadata 2019

From its work to understand the perspectives of disability organisations and their members on implementation of article 19, NDA notes that stakeholders feel strongly that PA provision is at present insufficient to meet demand, and yet is a critical enabler of independent living. A number have called for personal assistance to be set on a statutory footing, while others have indicated the need for, at minimum, a national policy for same.

In addition to the availability of PA supports varying from region to region, the number of hours received also varies greatly (Table 5). Over 1,000 people receive between one and five hours per week which likely makes it challenging for these individuals to have their daily care needs met, even before considering supports for wider participation in society.

Table 5 - Target Activity 2019: No. of adults with a physical and/or sensory disability in receipt of PA hours per week

| Number of hours | Number of people |
| --- | --- |
| 1-5 hours | 1,051 |
| 6-10 hours | 627 |
| 11-20 hours | 460 |
| 21-40 hours | 259 |
| 41-60 hours | 72 |
| 60+ hours | 67 |
| Total | 2,536 |

Source: HSE Disability Services – Key Performance Indicator Metadata 2019

2018 forecasting work carried out by the NDA as part of the Transforming Lives Working Group 1 Report on Future Needs for Disability Services estimates, on the basis of best available evidence, that an additional €17m may be required by 2021 for personal assistant and home support services. Furthermore, an additional €6m a year would be required by 2026 for further population change.[[66]](#footnote-66)

The NDA has agreed a joint research programme with the Economic and Social Research Institute (ESRI) on the experiences of persons with disabilities across key policy areas. One element of the joint research programme examines the provision of specialist community living and PA supports in Ireland, and in particular the extent of need and supply for these specialist services. It also includes the experiences of personal assistance service users in Ireland captured through a survey and interviews.

Outputs from the study note that there is currently no standardised tool for assessing needs in Ireland, and that needs assessment procedures thus vary between CHOs. The first output from this work programme notes that the data sources available in Ireland mean that for many disability service areas (and in particular services used primarily by persons with physical and sensory disabilities, such as home support and PA services) it is not possible to reliably estimate unmet demand.[[67]](#footnote-67) The study also considers proposals to document unmet need, which is not currently captured.

## Slaintecare

In 2018, a cross-party committee within the Oireachtas developed a 10-year strategy for delivery of healthcare services that would be based closer to the communities in which people lived. This shifted an emphasis to provision of health services towards primary and social care in our community, and also developed a funding model for same. The Slaintecare strategy is to be delivered through a series of annual action plans, with the first such being published and implemented in 2019. Planned activities that would have relevance to persons with disabilities included:

* Review current framework and develop a policy proposal and roadmap for universal eligibility
* Progress design of a statutory scheme for homecare
* Commence a staged pilot of personalised budgets for persons with a disability over a two-year period
* Develop a plan for the design of a system of population-based funding
* Advance community-based costing focusing initially on residential placements and home help services
* Develop a Social Care Strategy
* Establish future needs for persons with disabilities

For persons with disabilities, the Slaintecare Strategy commits to provision of necessary services and supports within the community, moving away from traditional wrap-around services in institutional settings.

It is noted that the Slaintecare Strategy did not conduct a comprehensive review of the costs associated with funding services specific to disability – e.g. residential or day service supports. The Strategy indicates €290 million over ten years as being earmarked for additional services for disability, but it is not made clear how this relates to the current HSE disability budget of over €2bn. The 2019 action plan also commits to the development of a dedicated social care strategy, recognising the differing needs of persons with disabilities, older people, and those with mental health difficulties. At time of writing, the Department of Health which is responsible for implementation of the Strategy and associated action plans, is currently considering how previous strategies relevant to disability, e.g. Time to Move on (from Congregated Settings), New Directions and Progressing Children’s Disability Services, might be incorporated within a social care strategy, recognising how the landscape has further developed since their first publication.

The Slaintecare Strategy is also committed to further advancing the shift towards individualised models of funding, and away from block provision of services, with the personalised budgets demonstration projects described above forming one step in this process.

## Moving In Study

**Moving In, Moving On: An evaluation of the outcomes and costs of congregated and community models of service in the disability sector** was published in 2021. This study sought to provide an evidence base regarding the delivery of service models which are aligned with Irish government policies. [[68]](#footnote-68)Relevant policies include:

* Time to Move on from Congregated Settings
* New Directions
* National Housing Strategy for People with a Disability 2011-2016

The study was commissioned by the HSE and was undertaken by the NDA. The study aims to evaluate the costs and benefits of ‘new’ models of service, or models of service congruent with government policy and compare these costs and benefits to those associated with models of service not in accordance with government policy. The study set out to evaluate the outcomes and cost of new or emerging models of service in order to assess the effectiveness and financial sustainability of the changes emerging and envisioned in the disability sector. Additionally, the study provides a means of identifying good practice that would inform and promote change in the sector.

In the first phase of the study, participants were recruited from 11 priority sites for decongregation. It was anticipated that Phase 1 participants would transition from congregated settings to homes in the community - thus facilitating a ‘before and after’ evaluation of costs and outcomes. Of 149 individuals interviewed in the before stage 91 transitioned to the community and were interviewed in the after stage. In general, Phase 1 participants had high levels of support need, little family contact and very constrained lives. Following decongregation the 91 participants were found to have met or partially met more of the nine quality of life outcomes [[69]](#footnote-69) than before decongregation and to have improved wellbeing and improved behaviours. They also went out in the community a lot more.

In Phase 2 of the study 280 persons with disabilities across 48 settings with varying levels of support needs and a variety of living arrangements were interviewed. Among this group positive outcomes are more likely to be achieved where supports are delivered in a tailored and person-centred way, which is not generally compatible with institutional or congregated living. Lower quality of life scores captured with the ASCOT tool were more likely among those in the Phase 2 sample who were living in congregated residential settings. As the quote below demonstrates choice emerged from Phase 2 of the study as a key variable.

Disliking the people an individual lives with, or living in a congregated setting was also detrimental. The variable about liking or disliking the people lived with may seem to be beyond public policy but as the cluster analysis demonstrated, it is associated with other variables such as picking staff, having family support and having the key to the door. Where service providers work to ensure that the individual has choices and actually likes the people they live with (or don’t actively dislike them) the negative effect of being in a residential setting can be offset. It is, therefore, wrong to focus on a single variable – such as the key to the door, or picking staff. Rather, what seems to be important is working with residents to give them as much choice over as many variables as possible regarding the life they want to lead.[[70]](#footnote-70)

The Moving In, Moving On study contained a service delivery unit cost comparative analysis which looked at the costs arising from the transfer of individuals from congregated settings to community housing. The cost analysis indicated a cost uplift of 60% for providing services in the community rather than congregated settings for those yet to transition from congregated settings. The key driver of costs was the level of support required by residents, with higher support needs incurring higher costs - mainly due to the need for additional frontline staff.

## Assistive Technology

Assistive technology (AT) provision for independent living involves a combination of HSE and NGO services. The HSE directly provides ‘aids and appliances’ services as well as working closely with, and funding, NGOs (usually Section 38 and 39 organisations) that provide assistive technology services. In general, HSE ‘outsourcing’ to NGOs is funded at regional level. Funding to NGOs is generally allocated as a block grant and funding for AT is not ring-fenced within this. At local level, the relationship between the HSE and NGOs in relation to AT can take a variety of forms and varies across organisations and areas. There is relatively little documentation or published data available on HSE aids and appliances services. Additionally, separate provision systems exist for supporting people who need AT in education, Early Learning and Care settings and employment.

The provision of HSE-funded aids and appliances is based on Medical Card eligibility. The **Health Act 1970** made provisions for (the former) Health Boards to supply "medical or surgical appliances" to eligible persons, as well as provisions for ophthalmic and aural appliances and for "equipment, materials or similar articles for a disabled adult person where neither the person nor the person's spouse (if any) is able to provide for his maintenance".

Research commissioned on behalf of the NDA examined the approaches to provision of assistive technology in Ireland and a number of other jurisdictions with relatively well-developed systems. The scope of the study covered provision of assistive technology to meet the needs of persons with disabilities and older people across three core settings – employment, education and independent living. Overall, the study found that Ireland has an underdeveloped assistive technology infrastructure in comparison with other countries such as Norway, Denmark, the Netherlands, and Germany.

In 2015, the NDA commissioned a study which provided a detailed profile of levels and patterns of usage and unmet need for various types of assistive technology among persons with disabilities in Ireland. This involved an in-depth analysis of data from the 2006 National Disability Survey. The results of the study showed that large numbers of persons with disabilities use assistive technology in their daily lives. However, the study also highlighted substantial levels of need and unmet demand for assistive technology across all disability groups.

Just over two thirds (3,870, 68.4%) of people registered on the National Physical and Sensory Disability Database (NPSDD)[[71]](#footnote-71) in 2017 used assistive products, and the most commonly used product groups were:

* Special furniture and other aids to personal care (4,641, 35.7% of the 12,994 assistive products used)
* Aids to mobility (4,151, 31.9% of all products)

Just over 10% of service users (599, 10.6%) required one or more assistive products (854 total aids and appliances required).[[72]](#footnote-72)

A discussion paper by the Disability Federation of Ireland and Enable Ireland has recommended, amongst other things, the introduction of an Assistive Technology Passport that would act as a record of AT use and funding, and would support AT users to access the training and supports they need.

The Citizens Information Board hosted the Assist Ireland website (assistireland.ie) which provided information about aids, appliances and assistive technology. The Citizens Information Board decided discontinue the website in December 2019 following analysis which showed that substantial resources were required to maintain the website and that there was significant reduction in the demand for website.

An inter-departmental working group has been established to consider national policy in terms of how Assistive Technology (arising from an action in the National Disability Inclusion Strategy). The work of the group has been interrupted by Covid-19. However, in 2021 there was a re-commencement of the working group’s meetings and their work. The NDA has developed discussion papers and arranged a speaker to inform the deliberations of the working group.

In relation to AT in health and social care services the HSE established task group on Digital and Assistive Technology as part of National Clinical Programme for People with Disability (which was established by the HSE in 2020). The task group will map existing Digital and Assistive Technology (DAT) use and the needs and gaps in provision and use of DAT and develop stepped framework for access to and support of DAT within health and social care services.

## Local Area Coordination

In 2015 the National Disability Authority published a Local Area Coordination Briefing paper. This followed a number of National Disability Authority hosted seminars and conference presentations on Local Area Coordination. The 2015 Briefing paper described Local Area Coordination as a system of community-based support for persons with disabilities whereby a locally-based co-ordinator engages with individuals with disabilities, their families and the wider community. The co-ordinators

* Provide individuals and families with support and practical assistance to clarify their goals, strengths and needs
* Work to build inclusive communities via partnership and collaboration with individuals and families, local organisations, and the broader community
* Assist individuals and families utilise personal and local community networks to develop practical solutions to meet their goals and needs
* Assist individuals and families to access the supports and services they need to pursue their identified goals and needs
* Use discretionary funding to purchase required supports

In 2016 a series of pilot projects were implemented to test Local Area Coordination with specific relevance to supporting persons with disabilities. The individual pilot projects were evaluated. There have been discussions with officials about where Local Area Coordination may sit within an Irish context but to date there has been no commitment to further roll out Local Area Coordination.

Further research conducted by the NDA looked at a number of community development approaches including Local Area Coordination. It found that new structures and groups in Ireland such as Local Development Committees and Disabled Persons Organisations had changed the landscape and it was unclear whether Local Area Coordination was the best methods of increasing social inclusion and participation.[[73]](#footnote-73)

# Older Persons with Disabilities, Long Term Residential and Community Care

HIQA regulates 585 designated nursing homes with the capacity to accommodate 31,969 residents. Nursing home residents are mostly older persons, the majority of whom have a disability and many of whom will have acquired that disability in their older years. Private providers operate the vast majority of nursing homes (76% or 443 of 581 nursing homes).[[74]](#footnote-74)

Legislation governing nursing homes in Ireland does not refer to the number of beds allowed in a nursing home. The average capacity of a nursing home is 55 beds (ranging from 9-184 beds) (Table 6).[[75]](#footnote-75) In 2018, HIQA noted an ongoing trend whereby smaller nursing homes, which often epitomise a person-centred ethos and are generally located near the person’s community, are closing, and larger occupancy centres opening.[[76]](#footnote-76) According to HIQA, this trend may reflect a change in the ethos of care being provided to residents.

Table 6 - Profile of nursing homes in Ireland by the number of residential places at the end of 2018 and 2019

| Centre size (in bed-number bands) | Number of centre - 2018 | Number of centre - 2019 |
| --- | --- | --- |
| Less than or equal to 20 | 38 | 35 |
| Between 21 and 40 | 179 | 177 |
| Between 41 and 99 | 313 | 319 |
| Greater than or equal to 100 | 51 | 54 |
| Total number of registered centres | **581** | **585** |

Source: HIQA (2020) Overview report on the regulation of designated centres for older persons – 2019

All nursing homes are subject to inspection by HIQA. HIQA undertook 547 inspections in 457 centres. In 2019 - including 102 dementia thematic inspections and 42 restrictive practices thematic inspections.[[77]](#footnote-77)

In 2019, 21.5% of all centres inspected by HIQA, were found to be fully compliant with relevant regulations. Some of the areas where nursing homes were most often non-compliant related to staff training and development, infection control, fire safety and records. The findings of the dementia thematic inspections indicated that while the majority of centres are providing good quality care to residents with dementia, more work could be done to improve the service provided to this group of residents.

Established under the Nursing Homes Support Scheme Act 2009, the Nursing Home Support Scheme, also known as Fair Deal, is a scheme under which the HSE provides financial support to people who need long-term nursing home care. Residents are required to make a contribution towards the care costs, depending on their means, with the HSE contributing the balance. The scheme covers approved private nursing homes, voluntary nursing homes and public nursing homes. In 2018, the HSE provided financial support in respect of just over 23,300 individuals, amounting to €969 million.[[78]](#footnote-78)

Long-term residential care is currently the only service available to older persons which has a clear legislative basis for assessment of need and eligibility (under the Nursing Homes Support Scheme Act 2009). Home care and community care services are provided on the basis of need and availability of resources. A 2015 review of the Fair Deal Scheme by the Department of Health determined that a range of initiatives and actions should be progressed to ensure the sustainability of services for older people and to facilitate the re-balancing of funding between long-term residential care and community based services. Recommendations included providing sufficient home help and home care packages, and reviewing, simplifying and standardising procedures for assessing, approving and procuring home supports across the system.[[79]](#footnote-79)

## Alternatives to Long Term Residential Care / Nursing Home Care

A Thematic Report on Challenges in long-term care in Ireland, published by the European Social Policy Network, identified the following as the main issues facing the long-term care system in Ireland:

* The better sharing of costs between the recipient and the state - the contribution of recipients accounts for about a quarter of the cost of residential care
* The absence of plans to improve the conditions, labour market situation and possibilities for a work-life balance for both formal and informal carers
* Adequacy of supply of residential but especially home-care services – there are significant waiting lists for both home care and residential nursing home care and funding increases to cope are stop-gap rather than planned[[80]](#footnote-80)

### Statutory Home Care

In 2019, 51,345 older persons accessed 17.5 million hours of home support services from the HSE, while 188 persons received an intensive homecare package totalling 376,665 hours. Personal assistance services are not available to those over the age of 65 (those already in receipt of personal assistance hours can keep them beyond the age of 65).

According to the HSE’s 2019 Annual Report, demand for home support services continues to exceed levels of funding. The HSE states that

waiting lists for home support have become a feature of the service as resources have not kept pace with population growth or with the increasing dependency of the growing numbers of people aged over 80 years, within the over 65 years’ cohort.”[[81]](#footnote-81)

The increasing numbers of persons living with dementia in the community also places demand on such supports. In addition, the NDA is aware from its engagement with persons with disabilities, and their families and carers, of concerns about and the impact of unmet need in this area.

The Programme for Government commits to introducing

a statutory scheme to support people to live in their own homes which will provide equitable access to high quality, regulated home care.

The Department of Health has progressed some work on a statutory home care scheme, including a public consultation on home care services and a 2017 evidence review by the Health Research Board on **Approaches to the regulation and financing of home care services in four European countries[[82]](#footnote-82)**.

The evidence review concluded that there are several principles included in regulated home care in other countries (Scotland, Germany, The Netherlands and Sweden), such as standards, transparency, consultation, choice, equity and sustainability. These principles are implemented through legislation, policy, strategy, service planning and financing. The study also found that these countries could reportedly meet the demand for homecare needs, but that they had taken steps to reduce the need, such as encouraging informal caregiving, and tightening the access criteria for services.

As noted above a pilot to test a reformed model of service-delivery for home support which will underpin the development of the statutory scheme for the financing and regulation of home support services is underway in 4 areas.[[83]](#footnote-83) The Department of Health has developed draft regulations to underpin a new regulatory framework for home support and HIQA is currently developing standards for home care.

**Community-based housing options**

The NDA advises that meaningful consideration is afforded to providing more community-based living options for older people, including small, community-based residential centres or supported living in self-contained housing units. The NDA also recommends that appropriate models of sheltered housing could be explored further for those who might choose same, an option examined by the Irish Council for Social Housing in their publication **An Overlooked Option in Caring for the Elderly: A report on sheltered and group housing provided by housing associations in Ireland.[[84]](#footnote-84)**

The NDA is commissioning research on good practice in ageing in place for those with intellectual disabilities and complex health conditions, which will help inform policy considerations in this space. This is particularly important in light of the planned legislation being advanced by the Department of Health to address deprivation of liberty (as discussed above on pages 23 - 24).

## Age-Friendly Ireland

The national Age Friendly Ireland Programme supports cities, counties and towns across Ireland to prepare for the rapid ageing of the population by paying increased attention to the environmental, economic and social factors that influence the health and well-being of older adults. Age-friendly programmes work to provide walkable streets, housing and transportation options, access to key services and opportunities for older people to participate in community activities. The national Age Friendly Programme office brings together, supports and provides technical guidance to the 31 local authority led, multi-agency Age Friendly Programmes.

## Nursing Homes and COVID-19

The impact of COVID-19 on those living in nursing homes was disproportionate by comparison with the impact on the general population.[[85]](#footnote-85) People in nursing homes and equivalent centres were disproportionately likely to contract Covid-19 compared to those in their peer age-group living in the community. The mortality rates seen in nursing homes were also higher than those seen in the general population for most age groups. The very infectious nature of the COVID-19 virus made it difficult to prevent and control in residential care settings such as nursing homes. Restrictions were placed on visits to residential care settings and on residents’ freedom to access the community at different points during the Covid-19 pandemic.

Data published on 14 July 2020on all deaths showed that, of the 1,748 Covid-19-related deaths notified, 985 (56%) related to people in nursing homes.

Formed in May 2020, the COVID-19 Nursing Homes Expert Panel published a report in August 2020 examining emerging best practice and recommendations to ensure that all protective COVID-19 public health and other measures to safeguard nursing home residents are planned and in place to respond to the ongoing impact of the COVID-19 pandemic over the next 6-18 months. The report made a number of recommendations, including that:

* access to home support should be expanded and prioritised
* incentives, including financial, be explored to help provide a wider range of service and ownership models for both care in the home and in smaller congregated units/ settings
* policy and legislation be reviewed and developed, as necessary, with the objective of introducing a single integrated system of long-term support and care, spanning all care situations with a single source of funding

In October 2020, the Special Oireachtas Committee on Covid-19 Response published its final report.[[86]](#footnote-86) On the topic of nursing homes, the Committee made a number of recommendations, including that:

* A public inquiry be established to investigate and report on all circumstances relating to each individual death from Covid-19 in nursing homes
* A review be undertaken into the impact of privatisation of Ireland’s nursing homes

The Committee also referred for consideration the need to explore in more detail issues concerning the future model of care for older people in Ireland to the Joint Oireachtas Committee on Health.

In 2022 the NDA launched a (NDA commissioned) research report by TrinityHaus in collaboration with Tallaght University Hospital on COVID-19 on the design of residential care settings for older people which focused on how the layout, design, and physical environment of these settings could impact both on residents’ outcomes and on the management of infectious diseases as such as COVID-19.

# Mental Health Services

### Deinstitutionalisation

Ireland, like many other Western European countries, significantly expanded the provision of ‘mental hospital’ places in the 19th century and the first half of the 20th century. The 1966 report of the **Commission of Inquiry on Mental Illness** found that in 1958 there were over 21,000 inpatient beds in Ireland. It reported that there were,

approximately 7.3 psychiatric beds were provided in 1961 per 1,000 of the population; this rate appears to be the highest in the world and compared with 4.5 in Northern Ireland, 4.6 in England and Wales, 4.3 in Scotland, 2.1 in France and 4.3 in U.S.A. At any given time, about one in every seventy of our people above the age of 24 years is in a mental hospital.[[87]](#footnote-87)

The **Commission of Inquiry on Mental Illness** was very critical of the conditions of people residing in ‘mental hospitals’ and recommended a move away from a model of provision of mental health services based on ‘mental hospitals’ being the primary location of delivering many mental health services towards more provision in the community. While the numbers of inpatients declined from the 1960s to the 1980s they did not decline at the rate anticipated by the Commission report. In 1984 there were 12,000 in ‘mental hospitals’, 9,000 of whom were considered ‘long stay’.[[88]](#footnote-88)

In 1984, the **Planning for the Future** report reiterated many of the Commission of Inquiry report’s criticisms of how mental health services were delivered in Ireland. It recommended the mental health services should be predominantly based in the community and recommended the establishment of multi-disciplinary teams to use

different approaches to treatment, and the participation of people from a number of professional disciplines are required to cater adequately for the needs of the mentally ill.[[89]](#footnote-89)

A further gradual move away from a predominantly inpatient model took place in the late 1980s and 1990s and by 2001 there were 4,321 in inpatient units, including 1,104 patients in 86 high support community residences (staffed mostly by nurses on a 24-hour basis).[[90]](#footnote-90)

**A Vision for Change,** published in 2006, recommended that the remaining psychiatric hospitals be closed. **A Vision for Change** called for,

A plan to bring about the closure of all mental hospitals should be drawn up and implemented. The resources release by these closures should be protected for re-investment in the mental health service.[[91]](#footnote-91)

Numbers in psychiatric units continued to decline and there were 2,198 patients resident in adult units in 2019. This represents an 89% reduction since 1963.[[92]](#footnote-92) Therefore,

with the exception of one 19th century public psychiatric hospital containing a small number of rehabilitation/ continuing care patients, one public catchment service with beds in an independent/ private psychiatric hospital, the Central Mental Hospital and the specialised St Joseph’s Unit for intellectually disabled no patients remained in 19th century psychiatric hospitals.[[93]](#footnote-93)

Despite the significant progress made since the 1960s in moving away from the 19th century ‘mental hospital’ model of service provision, the establishment of appropriate services in the community to support good outcomes for those experiencing mental health difficulties has proved challenging. **Planning for the Future**, **A Vision for Change** recommended that Community Mental Health Teams be established per 50, 000 of the population with additional teams for particular target groups, such as, persons with severe and enduring mental health difficulties, children and adolescents, older persons, persons with intellectual disabilities, people experiencing homelessness, people with a substance misuse problem, etc.

However, in the early years after the publication of **A Vision for Change** Ireland went into a recession which resulted in a decline in public service employee numbers in many areas. Mental health services actually lost approximately 1,000 staff in the early years of implementing **A Vision for Change** and progress on establishing community based teams was slow. A stock-take report of progress on **A Vision for Change** noted that there had been some progress in establishing and staffing a number of these teams. However, it rated progress in this area as poor and noted that even where these teams had been established there was a dearth of information on how those teams actually operate.[[94]](#footnote-94)

In 2020 the Government published **Sharing the Vision**. The Oversight Group that developed **Sharing the Vision** acknowledged that there had only been ‘partial’ implementation of **A Vision for Change.**[[95]](#footnote-95) However, the new policy document seeks to align mental health policy with Ireland’s mainstream health reform policy (Sláintecare). **Sharing the Vision** has more emphasis on outcomes and on early intervention, prevention and mental health promotion based on a whole of population-based planning approach. It also has more emphasis on social inclusion and states that supporting those with mental health difficulties is the responsibility of all Departments and state agencies rather than the responsibility of the Department of Health and Health Service Executive. **Sharing the Vision** positions mental health as a whole of government policy issue.

### 24-Hour Staffed Houses for Persons with Mental Health Difficulties

As part of the deinstitutionalisation process described above where people moved out of psychiatric hospital and units Ireland developed a model of supported houses in the community, from the mid-1980s onwards. Some of these houses are staffed 24 hours a day. The policy intent at the time was that as mental health supports in the community improved the need for these 24 hour staffed houses would decrease.

However, the Inspector of Mental Health Services pointed out in her **2018 Inspection of 24-Hour Supervised Residences for Persons with Mental Illness** that,

In 2005 there were 127 24-hour supervised residences. In 2018, 13 years later, 118 of these residences remained. The policy of housing people with mental illness in such facilities has continued, with the number of people residing in them remaining relatively stable over many years, currently just over 1,200….. in 2019, this is not considered in line with best practice. The HSE’s own report – **Time to Move on from Congregated Settings A Strategy for Community Inclusion Report of the Working Group on Congregated Settings** (June 2011) – states that community houses for people with disabilities should have no more than four residents with their own rooms. However, many larger mental health community residences have multi-bed rooms, often with no privacy between beds.[[96]](#footnote-96)

Some of those living in 24-hour supervised residences have insufficient access to rehabilitation teams that may enable them to move to more independent living arrangements and therefore are likely to remaining living in what the Inspector of Mental Health Services calls “mini-institutions”.[[97]](#footnote-97)

### Review of the Mental Health Act, 2001

The legal basis for involuntary admissions of adults and children to inpatient mental health services is provided for in the Mental Health Act, 2001. The Act provides for a system of review (through Mental Health Tribunals) for all involuntary admissions. The Act was reviewed by an expert group (the review process included a public consultation which included meetings with mental health service user groups). The Expert Group report acknowledged that the Act didn’t reflect Irish mental health policy (**A Vision for Change**) and that there were implications for the legislation from the UN Convention on the Rights of Persons with Disabilities.[[98]](#footnote-98) The Expert Group report recommended 165 changes to the 2001 Act. Progress on the legislation has been slow. The heads of the draft legislation were sent to the Mental Health Commission in mid-2019. There was consultation on the Mental Health Act, 2001 in 2021 and the heads of the draft legislation were approved by Government. Pre-legislative scrutiny is ongoing as of April 2022.

# Accessibility

As noted in the introduction, the Committee on the Rights of Persons with Disabilities has argued that article 19 is

tied to the obligations of the States parties relating to accessibility article 9 because the general accessibility of all built environment, transport, information, communication and facilities and services open to the public in a respective community is a precondition for living independently in the community.[[99]](#footnote-99)

It is beyond the scope of this paper to present an in-depth overview of what is in place in Ireland to ensure that environment and services are accessible. A future NDA paper on article 9 will address these issues.

## Accessibility of public services

The Disability Act, 2005 requires all public bodies to ensure that public services - public buildings, services and information - are accessible to people with disabilities. The Act requires all public bodies to appoint Access Officers to co-ordinate the provision of assistance and guidance to people with disabilities in accessing their services. The Act also requires public bodies to ensure that the services it procure are accessible.

The Act provided for the establishment of the Centre for Universal Design (CEUD) on a statutory basis. The CEUD, which is part of the NDA, was established 2007 and promotes Universal Design through the development of standards, education and professional development and through promotion and awareness raising of Universal Design issues.

The NDA developed a statutory Code of Practice on Accessibility of Public Services and Information provided by Public Bodies[[100]](#footnote-100) which guides public bodies on meeting their obligations under the Disability Act. The NDA in keeping with its statutory function to monitor the implementation of standards and Codes is developing indicators and a monitoring mechanism to report on public bodies’ conformance with the Code of Practice. This will involve collecting feedback from people with disabilities on their experience of the service as well as evidence from public bodies.

The NDA has published a ‘toolkit’ to support public bodies to make their services, buildings, information, and websites more accessible to customers with disabilities.[[101]](#footnote-101) In 2019 the Department of Public expenditure and reform and the NDA jointly published a revised Customer Communications Toolkit for the Public Service - A Universal Design Approach.

## Accessibility of private services

The Equal Status Acts require that people are treated equally when they access goods and services (including services provided by private companies or organisations). Under the Equal Status Acts discrimination on the grounds of disability includes a refusal or failure by a service provider (company or organisation) to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities, if without such facilities it would be impossible or unduly difficult for the person to avail himself or herself of the service.[[102]](#footnote-102) However, a service provider (company or organisation) is not obliged to provide special facilities or treatment when this would cost more than a ‘nominal cost’. What constitutes a ‘nominal cost’ will depend on the circumstances such as the size and resources of the body involved. In late 2021 the Government commenced a review of the Equality Acts, including s public consultation on the legislation.

## Accessibility of the built environment

Part M (Access and Use) of the Building Regulations (which came into force in 1992) sets out the minimum statutory requirements for the accessibility of a building, its facilities and surroundings.

The regulations require commercial buildings and apartment blocks to have a Disability Access Certificate which confirms a building’s compliance with Part M requirements.

Advocates have argued that the Part M regulations are insufficient as the regulations require buildings to be ‘wheelchair visitable’ rather than ‘wheelchair liveable’ and that as a result there is an insufficient supply of accessible homes.[[103]](#footnote-103) There is work underway under Action 97 of the National Disability Inclusion Strategy 2017-2021 in relation to increasing the supply of accessible homes. The Action states that

We will prepare policy advice on ways of achieving universal design solutions for new housing so that new homes can be accessed and used by all persons, irrespective of size, age, ability or disability. We will advise on any implications of same for stakeholders including designers, builders, homeowners and tenants.

In progressing this action the NDA’s Centre for Excellence in Universal Design produced a policy advice paper, **Action 97: Policy Advice Paper on Achieving Universal Design in new housing**, in 2019 and has been collaborating with the Society of Chartered Surveyors Institute in to develop a paper on the costs of delivering Universal Design homes. This cost assessment will inform a cost benefit analysis of Universal Design homes scheduled for completion in 2022.

A number of stakeholders, including a dedicated campaign group,[[104]](#footnote-104) have highlighted how the very low numbers of changing place toilets in Ireland has been an obstacle to some people with disabilities participating in community life. The Department of Housing, Local Government and Heritage has a proposal to amend Part M of the Building Regulations) which would require certain new build and refurbishment projects to include a changing place toilet). This is currently out for consultation (closing in May 2022). During 2021 NDA published a paper estimating the number of disabled people who may benefit from a changing places toilets in Ireland.[[105]](#footnote-105) The NDA is now working on guidelines regarding building a changing places toilet.

The Centre for Excellence in Universal Design in the NDA has developed a 'Building for Everyone, A Universal Design Approach' which provides design guidance on how to design, build and manage buildings and spaces so that they can be readily accessed and used by everyone, regardless of age, size ability or disability[[106]](#footnote-106).

# Community inclusion, participation, and attitudes

The right to be included in the community encompasses a wide range of elements. General Comment no. 5 (paragraph 16.b) states that being included in the community

includes living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them to be fully included and participate in all spheres of social life.[[107]](#footnote-107)

The UNCRPD Committee highlights the importance of inclusion in relation to housing, transport, shopping, education, employment, recreational activities and all other facilities and services offered to the public, including social media in this regard.

The policy of the State is one of mainstreaming, i.e. empowering persons with disabilities to live ordinary lives in ordinary places, and access services on an equal basis with others. This will mean that individuals who may previously have had wrap-around services and supports provided in a congregate setting should now be facilitated to access mainstream services within the community, e.g. banking, GP care, social welfare services, education, training, employment supports etc.

This will mean that communities will need to ensure that their services are inclusive and accessible to all. There is a commitment under Part 3 of the Disability Act 2005 that public services should be accessible. The National Disability Authority has a role to monitor compliance with same. The NDA are also reviewing the community supports available to or potentially available to persons with disabilities.

It is noted that there have been some challenges in the transition to this model, including issues around ensuring that health facilities or other public services are physically accessible (e.g. GP surgeries, primary healthcare centres, further education settings, Intreo offices etc.). Further work is also required to ensure information regarding public services is provided in ways that can be accessed and understood by all. As noted above the Department of Public Expenditure and Reform together with the Centre for Excellence in Universal Design at the NDA has published a Customer Engagement Toolkit, which sets out a Universally Designed approach to engaging with users of public services, whether in in person, in writing or digitally.[[108]](#footnote-108) This Toolkit has been rolled out across the public service, and public sector bodies are expected to implement its recommendations in their provision of services to the public. This toolkit was updated to take into consideration the transition to the virtual environment for meetings and other activities as a result of COVID-19.

## Data on attitudes and inclusion

There are some data available on inclusive communities and the extent to which persons with disabilities engage in common social activities.

One possible indicator of how inclusive communities are could be public attitudes towards persons with disabilities. Public attitudes to persons with disabilities are broadly positive in Ireland. A Public Attitudes to Disability Survey was conducted in 2017. People were asked to score out of 10 how comfortable they would be with having a person with a disability as their neighbour where 10 was very comfortable and 1 was very uncomfortable. The scores ranged from 8.8 to 9.3 with the variance based on type of disability. Having someone with a mental health difficulty scored the lowest at 8.8.[[109]](#footnote-109). Comfort levels in relation to persons with disabilities accessing mainstream education with their own child and being a work colleague are also relatively positive (7.7- 8.6 out of 10 and 8.2 - 8.9 out of 10 respectively). While these are high scores, they could be improved, particularly for persons with mental health difficulties.

This survey also used the Lubben Social Network Scale-6 to measure the size of the social network in terms of respondent contact with friends and relatives. It found that 32% of persons with a disability are at risk of being socially isolated compared to 22% of persons without a disability. With regard to having a hobby or pastime there was a statistically significant difference between the two groups with 67% of persons with a disability having a hobby or pastime compared with 82% of persons without a disability.[[110]](#footnote-110).

The 2018 Positive Ageing Indicators report finds that96% of persons with an intellectual disability (aged 48+) compared to 52% of persons without an intellectual disability (aged 56+) engage in at least one social leisure activity on a weekly basis. We know that the intellectual disability sector organises many social events for their clients some of which are within the service rather than in the mainstream community. As the Positive Ageing Indicators report does not differentiate it is therefore difficult to know whether this indicator is showing more social isolation among persons without an intellectual disability. The report also includes an indicator on loneliness with 8.2% of persons with an intellectual disability (aged 50+) reporting being lonely compared with 5.4% of persons without a disability (aged 50+).[[111]](#footnote-111)

In 2022 the NDA commissioned IPSOS MRBI to conduct a national survey on wellbeing and social inclusion.[[112]](#footnote-112). The survey is open to all adults but it is hoped that the data collected will help identify the specific groups that are feeling left out of Irish society, and who are finding life tough.

## Natural Community Supports

The NDA developed a research programme around the concept of “natural community supports”. In 2011 the NDA published a literate review which sought to examine the evidence in relation to the question of “what is the role of natural supports in facilitating independent living on the part of people with disabilities?”[[113]](#footnote-113) A follow up commissioned research project surveyed service providers on what programmes/initiatives they had in place to link people with disabilities to natural supports within their communities. The survey asked providers about approaches, such as

* Circles of Support and similar models (such as MicroBoards) which draw principally on existing natural supports such as family and friends, but involve these in a more formalised way in supporting the person with disability.
* Peer-based approaches including peer advocacy groups and interventions using self-authored spaces.
* Programmes which seek to promote social inclusion through developing social skills and social competence amongst people with disabilities and/or implement individual goal setting in relation to social participation.
* Programmes which seek to develop social capital through implementing befriending strategies and strategies to build inclusive communities.[[114]](#footnote-114)

A third element of the NDA research stream on natural community supports was a report on the experiences of people with disabilities on the support that they received from their community. This report was based on interviews with people with disabilities who received little or no formal supports from disability services providers.[[115]](#footnote-115) The report outlines factors that act as barriers and enablers to people using natural community supports to maintain their independence. Barriers included inaccessible environments, poor public transport, poorly trained staff in mainstream services, ill-health and financial constraints. Factors that enabled people to rely on natural community supports to sustain their independence included having a secure home, supportive family and friends, having social outlets and involvement in productive activities such as work, study or advocacy and having an adequate income.[[116]](#footnote-116)

## Formal mainstream community supports

There are a range of formal support structures within communities to enhance the provision of supports and services to groups who might be considered disadvantaged, e.g. racial or ethnic minorities, socio-economically disadvantaged persons, or persons with disabilities. Some examples in relation to people with disabilities are discussed below.

### Sport

An initiative in 2019 saw the launch of a Sports Inclusion Disability Charter. Hundreds of sports organisations have signed up to this Charter and are provided support by the Cara Centre.[[117]](#footnote-117) This initiative is supported by Sport Ireland.

### Health and Education

Work is ongoing to build capacity within public services to meet the requirements of individuals moving to the community from institutional settings, whether residential or day services. In the health space, this is facilitated through the Slaintecare implementation exercise, noting that further work may be required to build knowledge and capacity within primary care teams to meet the needs of persons with disabilities who may have a range of needs and complexity.

Support to access and participate in further and higher education and training is available to persons with disabilities as follows:

* The Disability Access Route to Education scheme and the Fund for Students with Disabilities[[118]](#footnote-118)
* Access Officers, personal assistant supports, various access routes etc.[[119]](#footnote-119)
* Disability awareness training of case managers in the public employment service began in 2016, and at least one member of staff in each regional office (over 60 staff members) of the service have been trained to be disability competent.[[120]](#footnote-120) The Department facilitated training for these disability Case Officers, with speakers from the National Disability Authority and some disability organisations. Further tailored instructor-led training nationally in Employment Supports for People with Disabilities was also provided. This training is now incorporated as standard into an accredited programme for all Case Officers, the Level 8 Certificate in Professional Practice in Employability Services (which is delivered in conjunction with the National College of Ireland).

### SICAP

The Social Inclusion and Community Activation Programme (SICAP) 2018 – 2022 provides funding to tackle poverty and social exclusion through local engagement and partnerships between disadvantaged individuals, community organisations and public sector agencies. It falls under the remit of the Department of Community and Rural Development.

SICAP addresses high and persistent levels of deprivation through targeted and innovative, locally-led approaches. It supports disadvantaged communities and individuals including unemployed people, people living in deprived areas, persons with disabilities, single parent families, people on a low income, members of the Traveller and Roma community and other disadvantaged groups. The programme is managed at a local level by 33 Local Community Development Committees (LCDCs), with support from local authorities, and actions are delivered by Programme Implementers (PIs). PIs work with marginalised communities and service providers using a community development approach to improve people’s lives. Since 2018 the SICAP programme has supported over 3,500 community groups and 55,000 individuals. The programme has supported 4,521 persons with a disability (which equates to 8% of the total caseload). The programme also supported 203 (8% of total) Local Community Groups that primarily targeted persons with a disability and Local Development Companies participated in 31 collaborations that addressed the needs of persons with a disability.[[121]](#footnote-121)

An example of what this work with Local Community Groups looks like in practice is the work by County Kildare LEADER Partnership - a designated

Programme Implementer for SICAP in Co. Kildare which used SICAP funding to enhance the inclusion of persons with disability in sport and recreation. This project involved facilitating collaborations with partners on development plans, getting service agreements in place with sports groups and activity providers, development of a county wide data base and the provision of disability inclusion training courses in order to develop an interagency approach to including children and adults with disabilities in mainstream sports and recreation activities.[[122]](#footnote-122) Other types of activities supported with SICAP funding include, for example, disability awareness training for local community groups and support and capacity building for local disability groups and networks.[[123]](#footnote-123)

### Public Participation Networks

A Public Participation Network (PPN) is a network that allows local authorities to connect with community groups around the country. Community groups register to join the Public Participation Network in their local authority area. Public Participation Networks give citizens a greater say in local government decisions which affect their own communities. These networks also fall under the remit of the Department of Community and Rural Development.

The Networks allow diverse views and interests to be considered as part of the decision making process of local government. The three main types of community group are:

* Voluntary groups working in our communities, like sports clubs, cultural societies, Meals on Wheels or TidyTowns
* National organisations with local branches formed to protect the environment, like An Taisce or Bird Watch Ireland
* Groups representing people who are socially excluded and whose voices are not heard in our society, such as persons with disabilities, migrants or Travellers

PPNs can form Thematic Groups to work on cross-cutting issues such as disability. Some PPN’s Thematic Groups have coordinated submissions on issues of local or national importance, collaborated in organising disability training and networking events and facilitated consultation.[[124]](#footnote-124)

# Summary and conclusions

Ireland has a plan and process in place to decongregate the people living in its remaining disability institutions. However, progress in moving people into the community has met with a number of challenges and has been slow. The publication of the NDA’s Moving In, Moving On report has provided evidence around a number of key issues in relation to decongregation including evidence around costs and outcomes for people who do move to the community. The COVID-19 crisis has exposed a new set of challenges for congregated living arrangements. In order to meet its obligations under article 19 it is important that the evidence base in the Moving In, Moving On study is leveraged to encourage a faster pace of decongregation.

Where there are available data, it suggests that supports that help to maintain people to live in their community are experiencing demographic and other pressures and will require investment in the years ahead. The absence of data on unmet needs for some vital areas of support for independent living, such as Personal Assistance services, is problematic. It is hoped that the (National Disability Authority funded) ESRI research in this area will result in some evidenced based proposals to address this challenge. However, at the time of writing it appears that better data (particularly on need), a national Personal Assistance policy and further investment are likely to be required.

The availability of housing suitable for people with disabilities remains an issue. The regulatory framework in place ensures an adequate supply of homes which are visitable by people with disabilities there is a need to ensure that sufficient numbers of homes are required to be liveable by all people, including disabled people and older people.

In relation to adequacy of the protections to ensure that people with disabilities can make decisions on key independent living issues, such as, where and with whom they live progress has been made in terms of the enactment of the Assisted Decision-Making (Capacity) Act 2015 and the establishment of the Decision Support Service. However, the 2015 Act is not yet commenced. Work on Protection of Liberty Safeguards was paused in 2020 due to Covid-19 and while work in the area resumed in summer 2022 it is unclear when the draft legislation will be published.

Personalised budgets are a means by which some people who use disability services could gain control over decisions about how their support is provided. Therefore, it is important that the challenges that the current Demonstration are rolled out, evaluated and mainstreamed.

It is important that the model of regulation of disability support services does not restrict the development of innovative supported living arrangements in the community. It is therefore required that regulations are reviewed regularly to ensure that they are appropriate for the range of supported living arrangement models that facilitate persons with disabilities living in the circumstances of their choosing.

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