



Submission on the new Housing Strategy for People with a Disability

1.0 Introduction

Approximately 70% of disability support services in Ireland are provided on behalf of the State by Section 38 and Section 39-funded organisationsⁱ. The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability is the national umbrella organisation of not-for-profit agencies providing direct supports and services to people with intellectual disability in Irelandⁱⁱ. Across almost 60 organisations, our members support more than 26,000 children and adults with intellectual disabilities and their families, providing services and supports throughout the lifespan. National Federation member organisations have community presence and connection across large urban centres and small villages throughout Ireland.

The National Federation warmly welcomes this opportunity to participate in consultation on the new ***Housing Strategy for People with a Disability***¹. In order to prepare this submission, we brought together our members in a consultation workshop; and members also provided written feedback. Since implementation of the United Nations Convention on the Rights of Persons with Disability (UNCPRD) is so central to the vision of how services and supports for people with disabilities should be delivered into the future, we have also built into this submission relevant sections of recent work the National Federation undertook in response to the consultation process on the ***State's Initial Report under the United Nations Convention on the Rights of Persons with Disabilities***. That work, which we submitted in April 2021, was also based on a significant consultation process with members and included much of relevance to the new housing strategy.

We outline in this submission areas of positive progress; key areas in which the rights of people with intellectual disabilities are not currently being realised in relation to housing and associated supports;

¹ The National Federation represents service providers who support people with intellectual disabilities. We are conscious of and respect that DPOs in Ireland have indicated the need for the use of the term 'disabled people' rather than 'people with disabilities' in a social model approach. People with intellectual disability have expressed a preference for person-first language (i.e., people with intellectual disabilities) and therefore that is the form of language that is used within this submission. This is done with full acknowledgement and respect for the preference for the term 'disabled people' that is more commonly adopted with reference to the wider disabled community.

areas in which there is a need for change to effect progress; and recommendations to support positive progress in the new Housing Strategy. As the largest umbrella body of service providers supporting people with intellectual disability in Ireland, we believe that this submission presents a broad insight into views on the new Housing Strategy from the not-for-profit intellectual disability service provider perspective.

The key recommendations for the new Housing Strategy contained in this submission are:

- 1) The vision of the new Housing Strategy should be underpinned by the UNCRPD, and in particular Articles 19 and 12; and should take account of the recommendations contained in the General Comment on Article 19ⁱⁱⁱ;
- 2) The Strategy should build an integrated approach to the provision of housing and supports for people with disabilities;
- 3) The Strategy should recommend increased joint/interdepartmental working at three levels:
 - a. Between Government Departments;
 - b. At Housing Agency and HSE national operations level;
 - c. At Local Authority/CHO level.

Structures should be put in place to resolve any gaps in responsibility between Departments/agencies in a timely manner;

- 4) Sufficient, multi-annual investment in housing and supports should be put in place to meet the housing and associated support needs of people with disabilities, in line with the population of people requiring support identified through the *Disability Capacity Review to 2032* (July 2021);
- 5) Our members have identified three groups of people with intellectual disabilities, for whom housing with supports are urgently required. It is our recommendation that the housing and support needs of these three cohorts should be a key priority in the new Strategy:
 - a. Supporting people who remain living in congregated settings to move to community living should be prioritised and addressed as a matter of urgency, as there is evidence of significantly worse quality of life outcomes and rights restrictions for those living in congregated settings^{iv}. The pace of change over the past decade has not been sufficient to ensure access to community living for all citizens as envisaged by the *Time to Move on from Congregated Settings (2011)*^v policy. Within the vision of the new Strategy should be included measures to ensure that those citizens with disabilities who have the highest levels of need, many of whom are living in congregated settings, should be enabled to live their lives in the community, with access to appropriate housing and supports.
 - b. There are approximately 1250 people aged 70 years and over, more than 400 of whom are over the age of 80, who remain the primary carers for their adult son or daughter with an intellectual disability^{vi}. Currently there is no avenue for the citizen with a disability in this situation to apply for housing together with support, unless the family carer becomes seriously ill or dies. This leaves the person with an intellectual disability and their family members in extremely distressing circumstances, without future planning available to offer reassurance.
 - c. People with intellectual disabilities experience many health inequalities (as outlined in the findings of the IDS TILDA studies to date^{vii}) when compared with the general

population. In particular, a higher level of dementia is present in this population, along with challenges in bone health, obesity levels, and significantly less favourable mental health outcomes than the general population.² As a result, many individuals with intellectual disabilities experience changing needs that require adaptations and/or additional supports. The Strategy should factor in changing needs as a requirement of planning, delivery and resourcing of housing and supports;

- 6) It is important that the models of support and accommodation provided through the Strategy avoid over-reliance on standardised approaches that cater for specific numbers of individuals living together in a group home. The Strategy should provide for models that are diverse and individualised (for example offering choice for individuals to live alone, or with others who have/do not have a disability) and that are based directly on the housing and support needs of the person;
- 7) Whilst ensuring that individualised approaches are implemented for each person seeking housing support, it would be useful at a national level to gather shared learning through the Strategy on a range of built environment models that enable and facilitate supported independent living;
- 8) Input from disability service providers should be sought at an early stage of housing planning and development to ensure that at a minimum, a proportion of housing in each development is accessible and wheelchair livable, and to avoid necessity of retrofitting for adaptation at a later stage;
- 9) Shared data gathering should be established to ensure the extent of housing and support need is understood and addressed through clear KPI's on an ongoing basis;
- 10) All funding streams should be examined to ensure fit for purpose (for instance, members provided feedback that use of the CAS funding has become less practical on the ground in more recent years, in part due to the absence of associated revenue funding for the individual and due to the timeframes for approvals);
- 11) The Housing Strategy should include a process to develop clear guidance nationally on the support needs of individuals who have a particular requirement to access additional space – for instance to accommodate additional equipment, staff sleepovers, or for a small number of people with particularly complex needs, the requirement for lone living along with staff accommodation due to behavioural support needs;
- 12) The Strategy should seek to foster inclusive communities (more accessible for people with disabilities, more accessible for all citizens including older people; parents of young children, etc.);

² The rates of diagnosis of dementia are significantly higher in people with intellectual disabilities, and in particular for people with Down syndrome, for whom there is a genetic predisposition to the disease. In the IDS Tilda findings indicate there was an overall incident rate of 9.1% in participants between Wave 3, and within Waves 2 and 3 an incidence rate of 22.5% was found for participants with Down syndrome. The average age of diagnosis of dementia for those with Down syndrome was 52.3 years compared to 65.5 years for those with intellectual disability from other aetiologies.

- 13) At local and national levels, the Strategy should encourage the use of accessible and alternative methods of communication; and sufficient time and support where required for people with intellectual disabilities to understand and respond/participate.
- 14) The Strategy should recommend that all legislation and regulation affecting the housing and support requirements for people with disabilities should undergo an impact assessment. The intersection of regulatory requirements from different Departments should be factored together and appropriate resourcing provided to allow regulation to be implemented effectively. The impact of regulation on people's lives should be examined, to ensure that proposed new measures do not become a barrier to living an ordinary life.
- 15) The Strategy should seek to identify mechanisms to support the engagement of mainstream AHB's and should examine challenges present for AHB's that are linked with disability service providers in order to maximise the ability of AHB to support the delivery of housing to people with disabilities.
- 16) A clear set of measurable deliverables should form the cornerstone of the Government's overarching approach to meeting its housing and support obligations under the Convention, through the new Housing Strategy; with clear monitoring and oversight processes put in place.

2.0 Context in which the Housing Strategy will be implemented

In preparing this submission a number of cross-cutting themes became evident. It is important that the housing-related themes identified in this submission are viewed alongside important factors in the wider context of how the new Strategy will intersect with other key areas of the policy, legislation and the operational landscape in which it will be implemented. These are outlined below and form an important overarching aspect of our feedback.

2.1 Positive framework of policy and legislation

The past decade has seen the development in Ireland of a highly positive framework of policy, legislation and practice programmes across the lifespan for people with disabilities. In relation to housing for people with a disability, these include the previous *Housing Strategy for People with a Disability* (2011-2016, extended to 2020); the *Time to Move on from Congregated Settings Report* (2011); and the *National Disability Inclusion Strategy*. The recent establishment of the Oireachtas Joint Committee on Disability Matters is a positive step in terms of confirming parliamentary priority and oversight of the Government's progress in terms of realising the rights of people with disabilities. The *Assistive Decision-Making (Capacity) Act* (2015) will bring an important legislative underpinning in terms of a focus on rights and on the person's will and preference, when fully commenced, and this will be relevant in responding to the housing needs of the individual. The National Federation welcomes these developments and participates in many of the steering committees and national groups set up to progress their implementation.

The most important development of the past decade in terms of the State’s response to people with disabilities, however, came with the ratification by Ireland in March 2018 of the *United Nations Convention on the Rights of Persons with Disabilities*, a defining moment in the journey towards the realisation of the rights of people with disabilities in Ireland. The Convention provides the blueprint for State parties to uphold the rights of individuals with disabilities as equal citizens and sets out in its Articles the responsibilities of State parties in order to achieve this – including in relation to a range of areas relevant to the Housing Strategy the most important of which in this context are Articles 19 and Article 12, which are discussed below. **The National Federation is of the view that the new Strategy should be underpinned by the UNCRPD, and in particular Article 19 and Article 12, and should be informed by the General Comment on Article 19.**

2.2 Implementation challenges

Unfortunately, the establishment of the positive framework of policy and legislation outlined above and underpinned by the ratification of the UNCRPD, has not been matched over the past decade with all of the necessary requirements, including sufficient investment and legislative commencement, to implement the vision held within these progressive policies, laws and programmes for many people with disabilities. According to HIQA^{viii}, close to 3,000 people remain living in congregated settings a decade after the publication of the *Time to Move On From Congregated Settings* report. Many more live together with people that they have not chosen to live with. Sadly, more than 500 people have passed away living in congregated settings since 2012, without having had the opportunity to share in ordinary community life and experiences.

A particular challenge has been experienced by people with disabilities when responsibilities cross between Departments. Issues that arise through co-ordination gaps have left citizens without an adequate State response to accessing rights and needs; for instance, where housing has been provided but supports are not in place, or vice versa; or where vital assistive technology cannot be purchased due to a lack of clarity of the correct resourcing stream. These issues have impacted, unfortunately, on the achievement of supported independent living with access to housing for people with disabilities. In addition to the personal cost to the individual, this leaves significant challenges to the State’s compliance with the requirements of the United Nations Convention on the Rights of Persons with Disabilities. These deficits will require focused attention on behalf of the State and all relevant stakeholders, to ensure that progress is achieved.

Issues of supply are also of concern. The provision of housing for people with a disability over the lifetime of the previous Strategy, has been impacted by the same challenges that are being experienced across all groups over the past ten or so years. Supply of housing relative to demand in general is exacerbated by the paucity of supply of accessible and wheelchair-livable housing.

However, there are signs of hope. The establishment of the Housing and Disability Steering Committees in each Local Authority under the previous Housing Strategy provides a national architecture to support

strategic planning for the housing needs of people with disabilities. Much positive work has taken place under the previous Housing Strategy and this has provided a platform for further progress under the new Strategy. The most recent national budget has brought about significant investment into disability services and supports. Whilst not sufficient to address the magnitude of the difficulties facing people with disabilities, nonetheless this investment is at a scale not seen for over a decade. The publication in July 2021 of the *Disability Capacity Review to 2032* provides an evidence-based insight into the scale of the need for supports to enable people to live as independently as possible in the community. The recent investment will need to be continued over a number of years to achieve sufficient progress to address challenges outlined in this submission and in other sources ^{ix}.

The HSE's Corporate Plan 2021-2024 includes as one of its six key priorities, the objective to *“Work to reimagine disability services, to be the most responsive, person-centred model achievable with greater flexibility and choice for the service user”*^x. This plan also commits for the first time to the multi-annual funding of disability supports, which will be essential to making a lasting impact on the ability of citizens to access housing where they also require support. The establishment of the Decision Support Service and Oireachtas Disability Matters Committee similarly offer hope in relation to the implementation of key reforms. These welcome steps must be continued over the coming years to have a sustained effect.

2.3 Progressive realisation of the UNCRPD and measurable targets

The Irish Government's *Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities* indicates that the *National Disability Inclusion Strategy 2017-2021* (NDIS) addresses broader equality and inclusion issues such as the need for joined up public services to meet the needs of people with disabilities. Unfortunately, the implementation of NDIS has not yet succeeded in securing change at a sufficient pace to ensure that many people with disabilities are enabled to live lives of their choosing. In fact, the mid-term review of the NDIS concluded that:

“for most indicators there are no targets in the current strategy against which to measure any incremental changes. There were also some indicators for which there were little or no data available”.

April 2020, P. 72

It is our view that a clear set of measurable targets should form the cornerstone of the Government's overarching approach to meeting its housing and support obligations under the Convention, including the new Housing Strategy; and that a new approach will be required to ensure greater momentum. This will be particularly important in the approach to implementation of Article 19, which should form the cornerstone of the Strategy. There is therefore a need to consider how a more coordinated approach to housing can be achieved at Departmental; national operations; and local levels; and how the architecture and structures required can be aligned to ensure and support cross-Government and inter-Departmental cooperation in developing and implementing legislation and policy arising from the CRPD.

2.4 Inclusive Communities

A key theme that emerged from the consultation with National Federation members is that our shared focus together with Government and key stakeholders, should be building the capacity of communities to be **fully inclusive of all groups and individuals**. Accessibility in the physical environment; Government systems; communications; and services **benefits all citizens**. A focus on disability rights in the new Housing Strategy can be understood as having intersectional benefits for society as a whole. It is important for the new Strategy to be particularly cognisant, also, of people with disabilities who experience additional challenges, including as those currently experiencing homelessness^{xi}; children living in temporary/emergency accommodation; and those for whom English is not a first language.

In building supportive communities, it is important that the inclusion of people with disabilities is factored into mainstream policy and legislative developments from the outset. **The National Federation calls for communities to be supported and capacity built on the assumption that the needs and aspirations of people with disabilities are considered from the outset and form part of coherent policy which is inclusive of all citizens. To assist in planning, the Government should be guided by the steps outlined in the ‘General Comments’ issued by the UN Committee on the Rights of Persons with Disabilities regarding ‘Implementation at the national level’^{xii}.**

2.5 Listening to the Voice of People with Disabilities

All processes of consultation and practice relevant to people with disabilities should proactively seek to include the voice of people with lived experience of disability. At an individual level, communications from Local Authorities, Approved Housing Bodies, service providers and any other agencies interacting with the person should ensure that the person has sufficient time to allow them to understand (with support if required) letters, forms, tenancy agreements and any other documentation of importance. Where required, alternative formats should be made available to support the person in understanding key information. It is essential that independent advocacy is made available to all people with disability who require it, especially at times when the person is considering important issues in their lives including their housing needs. The principles of ‘will and preference’ that underpin the Assisted Decision Making (Capacity) Act must be the guiding framework for listening and responding to the voice of the individual with a disability.

At the broader national level, to ensure the lived experience of people with intellectual disabilities in particular is fully included, consultation processes must allow sufficient time to allow for people with intellectual disabilities to be supported to understand documentation, deliberate on the information they would like to put forward, and formulate and submit their responses. This means that all national consultation processes should include a substantial time frame for response and materials seeking submissions should be provided in accessible formats. **The consultation for the next *Housing Strategy for People with a Disability* is a positive example of a highly inclusive process that should be seen as a model for future national consultation processes.** We warmly welcome the approach that has included the

materials for consultation being made available in plain English, Easy to Read format and presented in a video format. This helps people for whom written communication is challenging.

As with all universal design processes, the provision of these kind of accessible options for participation in consultation processes benefits many more individuals than just those with disabilities, and there are many citizens for whom accessible communication is welcome and essential. Individuals with disabilities have indicated that video summaries of key content with Irish Sign Language (ISL), as well as Easy-to-Read and Plain English formats are helpful. As the Strategy itself rolls out, it will be welcome and important to maintain this accessible and inclusive approach to communication, and it would be useful to share learning between Local Authorities, HSE, service providers and all key stakeholders in relation to this process, so that key positive aspects can be widely adopted.

3.0 Positive progress and challenges to date

3.1 Article 19 – Independent Living & Inclusion in Community

During our consultation for this submission, the central importance of two articles of the UNCRPD were evident, namely Articles 19 and 12. The Committee on the Rights of Persons with Disabilities; the body of independent experts which monitors implementation of the Convention by the States Parties, has described Article 19 in its General Comment No. 5 (2017), as:

“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”.

Without the progression of implementation of this Article, the aims of many of the other Articles cannot be achieved.

Positive progress

The development of the first *National Housing Strategy for People with a Disability* and the consultation currently taking place for its successor, is a positive, cross-Departmental response to the importance of access to housing and the required supports for people with disabilities to live in the community. One of the key positive achievements of the Strategy has been the introduction of the Assessment of Housing Need process – which explicitly underpins the State’s approach that a person *‘shall not be deemed adequately housed’*^{xiii} when they live in a congregated setting, group home, or in the family home if they no longer wish to do so. In this way the Assessment process recognises individual choice in a very tangible manner. The *National Housing Strategy for People with a Disability* has also overseen the setting up of Housing and Disability Steering Committees in each Local Authority, with the aim of putting in place strategic planning for the housing process for individuals with disabilities. For those individuals who have been supported to move from institutional settings to homes of their choice in the community; with the appropriate supports, it has been a transformative process^{xiv}.

Issues of concern

Whilst recognising these successes **it is also essential to acknowledge the very significant deficits in relation to the States’ implementation of Article 19 that persist**, a summary of which will be set out

below. The target set out for completion of the work under the State's own policy *Time to Move on from Congregated Settings* (2011) was 2019, and yet according to HIQA, in 2019 there were close to 3,000 people remain living in these settings. Action is also required to ensure that the transition to community living avoids creating smaller mini-institutions; and a pathway to planned living supports outside of emergency provision is created.

The CRPD states, in Article 19, that people with disabilities must:

“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”.

However, there is ample evidence, in numerous reports, of these needs not being currently met due to a lack of investment of the required resources. For instance:

- The *Annual Overview Report* on the inspection and regulation of disability services published by HIQA in September 2020 identifies that 2914 people with disabilities remain living in congregated settings^{xv}. The impact for people living in these settings is considerable: the report references the fact that quality of life outcomes for people living in these settings is poorer and safeguarding issues significantly more prevalent than for those living in appropriate settings;
- 1300 younger people with disabilities under the age of 65 are inappropriately accommodated in nursing homes^{xvi}
- The National Federation's own research has indicated that more than 1250 people are supported in the family home by a primary carer who is over the age of 70, at least 400 of whom are over the age of 80^{xvii};
- At this time resources are so scarce that for adults living in the family home there is no pathway to apply to access supports to live apart from their family of origin in the community, other than through an emergency.

Although funding has been provided over the past decade to support a proportion of the cohort of people living in congregated settings to move to the community, the pace has fundamentally been too slow, leaving many people remaining in these settings. This is having a significant impact on individuals' lived experience^{xviii}, and breaches their basic human rights on a daily basis. The report presents evidence of individuals living in over-crowded living environments; lack of privacy as individuals are sharing bedrooms; and individuals being exposed to peer-to-peer assaults due to living in living environments where people sharing are not compatible and never choose to live with each other. In many cases, individuals are living in environments very removed from the life of the community, as they are situated in very rural areas with little or no public transport infrastructure – which exacerbates ongoing isolation and segregation;

“Providers of congregated settings were challenged in their ability to provide a dependable service that promoted and protected the rights, safety and quality of life of residents”

[HIQA Annual overview report on the inspection and regulation of disability services in 2019, p.9]

Over the past decade there has been a lack of funding for *new planned residential supports*, leading to significant built-up unmet need^{xix}. Funding cuts over the past ten years^{xx} and the lack of new funding to

meet demographic need means that those residential supports that have been put in place have often been met on an emergency basis ^[xxi] ^[xxii]. This means that many citizens living in the community continue to live in situations that are not of their choosing or where families are experiencing significant unsustainable care responsibilities ^[xxiii].

Simultaneously, the (appropriate) closure of those congregated settings or places which have been discontinued, means that previously available residential support options are no longer available as new need comes on-stream. Congregated settings have not been replaced with a sufficient pipeline of new, funded community-based supports for those coming into adulthood, or whose needs (or those of their carers) change and who now require residential support. In the period 2009-2014 there was a net reduction in the number of residential places provided ^[xxiv] contributing to a continually growing and urgent level of unmet need. For many people living in the family home or in unsuitable or overcrowded situations, their level of need has increased due to their frustration and distress. This has contributed to very high support costs for some citizens when their needs are met, often in emergency circumstances.

While mainstream housing options have been made increasingly accessible to people with disabilities via the *Housing Strategy for People with a Disability* ^[xxv], ^[xxvi], these options cannot be accessed without corresponding health and social care supports. With a lack of new support packages, the potential benefits of mainstream housing allocation have not yet been fully realised for people with intellectual disabilities in terms of the numbers of allocations, in spite of the success and considerable quality of life benefits for those individuals who have been able to secure tenancy ^[xxvii]. In addition to the stress of having the transition to living outside the family home met in an emergency rather than in a planned and individually chosen way, meeting residential support need in an emergency model is more expensive than planning and maintaining vital natural supports which can then be supported with the required level of paid resources needed for an individual.

Given that the pace of movement from congregated settings to community settings remains gravely behind schedule ^[xxviii], and together with the lack of new planned residential supports, this leaves many people with intellectual disabilities living in unsuitable settings with people that they have not chosen to live with.

In summary:

- It is still fundamentally the case that contrary to Article 19 of the UNCPRD, adults with intellectual disabilities **do not have a pathway to planned residential support**. Instead, it is the experience of our members that most individuals with intellectual disability who begin accessing residential supports currently do so under distressing emergency circumstances, often when an elderly parent who has been providing primary support passes away or when significantly complex needs are not possible to meet within a family's circumstance and this leads to an urgent requirement for residential placement.
- This has consequences not only for the person themselves but often for their family too. Older family members are trapped in unsustainable caring roles in the community as a consequence of a

decade in which there has been a lack of investment in planned supports. Many parents are currently providing significant support as primary carers into their 70's, 80's and beyond, with no visibility or security in terms of planning for the future of their loved one. The impact of Covid-19 has in particular further tested the resilience of these individuals and their families.

- Ten years on from the publication of the *Time to Move On from Congregated Settings* report, there remains a substantial number of people living in congregated settings, with significant impact on individual lives as outlined above.
- Due to the lack of availability of planned residential supports as outlined above, many individuals and their families have an urgent need for respite based on their underlying unmet needs. For many services, the reality presenting now is that a significant proportion of their capacity for planned short breaks/respite is taken up with providing full-time support to individuals and their families who are in crisis, when family arrangements break down or acute emergencies present; thus reducing service providers' capacity to support the wider range of individuals and families who need to access this service.
- Covid-19 has pushed the resilience of many people with disabilities and their families to breaking point, as the quantum of service usually provided has been reduced for social distancing and in line with HSPC guidance.
- Planned residential supports that respond to the individual's choice, and support independence can be provided in a wide range of models including supported independent living; PA and home support; and full-time residential support. Currently there is an over-reliance on the group home model as an alternative to congregated living arrangements. There is a need for planned access to the full range of potential residential supports.
- To facilitate the needed change, substantial multi-annual, planned funding will be required, and agencies must be supported in unbundling funding from group arrangements/bridging funding and provided with particular support at transition times to ensure that the individual can plan their access to a living arrangement that is in line with their will and preference.
- Measurable targets for the development of housing using Universal Design are essential to ensuring meaningful implementation so that the future stock of housing includes a pipeline of accessible and wheelchair-livable homes for individuals with disabilities.
- In order for the individual to secure their rights under Article 19, there is a complex interaction required between State provision of housing, disability supports and other mainstream supports such as access to Primary Care, transport and community facilities. **To navigate this complex landscape and achieve real progress in the implementation of Article 19, the new Strategy will need to be a cross-Governmental plan on progressing the rights of persons with disabilities to independent living, will need strong implementation targets and should be informed by the Committee on the Rights of Persons with Disabilities' General Comment No. 5 (2017).**

3.2 Article 12- Supporting capacity and decision-making

The second Article that holds the most significant potential change for citizens with disabilities in Ireland is Article 12. The Committee on the Rights of Persons with Disabilities speaks to this importance also, and its interdependence with Article 19:

“Legal personality and legal agency are the bases for the realization of independent living within the community for persons with disabilities. Article 19 is, therefore, linked to the recognition and exercise of legal personality and legal capacity as enshrined in article 12 of the Convention”. [General Comment No. 5, 2017]

The full commencement and implementation of the Assisted Decision Making (Capacity) Act (2015) and the inclusion of its principles in all policy and legislation that will impact on people with a disability, are fundamental to the programme of work required to progress implementation of the CRPD in Ireland, including through the new Housing Strategy for People with Disabilities.

Article 12, similarly to Article 19; is an article with enormous intersectional implications, the implementation of which affects the rights accessed throughout the rest of the UNCRPD. There is a sense of frustration that the roll-out of this Act has been very slow and for instance, that the existing Ward of Court system continues to be highly restrictive to those subject to it. Indeed, in the absence of an alternative, individuals continue to be brought into this process. **The National Federation stresses as a priority the urgency removing any remaining impediments to commencement of the Assisted Decision Making (Capacity) Act, in order to support implementation of Article 12.**

The Enactment of the Assisted Decision Making (Capacity) Act in 2015 (ADM) was a significant, positive milestone in the State’s progress towards ensuring the individuals with disabilities enjoy equal legal capacity in all aspects of life as envisaged in Article 12 of the CPRD. The incorporation of the principles of the Act in more recent policy and legislative proposals is also becoming evident e.g., in the HSE’s *National Consent Policy*. The establishment of the Decision Support Service is very welcome. It will be essential that sufficient resources are provided by Government to ensure that this service can fully implement its responsibilities as set out under the Act. As the choice of where and with whom we live is such a fundamental life decision, it is essential that the ADM is fully commenced in order to provide a legislative underpinning for the legal capacity of individuals in the context of the work to be undertaken under the new the Housing Strategy.

3.3 Article 9 – Accessibility

The Disability Act (2005) provides a statutory basis for making public services fully accessible, placing obligations on public bodies to make public buildings, services, and information accessible to persons with disabilities. There is a need to ensure that the new Housing Strategy considers accessibility in relation to transport requirements; information and communications; and access to Assistive Technology as well as the built environment. Where there are significant developments being considered, the provision of accessible public facilities should be included. The development of accessible housing to Universal Design

and wheelchair-livable standards, will require engagement at an earlier stage in the planning and development process, of support services for people with disabilities, to ensure sufficient suitable supply and avoid expensive retrofitting.

National Federation members would welcome, through the Housing and Disability Steering Groups, further opportunities to work collaboratively on the planning of housing with an outlook of 5 years; identifying future need in a partnership model between Local Authorities, HSE and the disability service providers with engagement from people with lived experience; and supporting the achievement of specific targets in relation to accessible housing stock. It would be useful for work to take place to clarify the kinds of housing options, range, size, equipment, adaptations for people of different levels of need that are required, costing them to inform discussions between Local Authorities, HSE and AHBs. It will be important that the work of the Housing Strategy includes clear guidance nationally on the needs of individuals who have a particular requirement to access additional space – for instance to accommodate additional equipment, staff sleepovers, or for a small number of people who have particularly complex needs, the requirement for lone living along with staff accommodation due to behavioural support needs.

Members have identified that some HDSGs are working very well but that there is a need for further work to ensure effective engagement and consistency nationally. It would be very useful for the representation structures to be reviewed to ensure the needs and views of all stakeholders across a Local Authority are fully represented. In the case of disability service providers there is a need to review this representation structure and the National Federation would be delighted to participate in this work.

To ensure the availability of suitable housing, it is important that the various funding streams available are reviewed and their current fit for purpose assessed. Member organisations have identified particular challenges in the use of the CAS funding on the ground in more recent years, in part due to the absence of associated revenue funding for the individual and due to the timeframes for approvals leading to a lack of ability to compete for purchase of housing on the private market.

There are also issues arising in relation to the use of CAS funding and applications for Rent Supplement, with individuals and service providers experiencing gaps between the eligibility criteria for both supports causing difficulty in accessing the supports.

There is also a need to examine the particular challenges that are being experienced by Approved Housing Bodies associated with disability service providers, alongside the Approved Housing Bodies Regulatory Authority, to ensure that the needs of people with disabilities can be met through mainstream or specific disability-related AHB's.

3.4 Additional Articles

In addition to Articles 9, 12 and 19, it is important for the new Housing Strategy to examine the UNCRPD in its entirety to ensure its alignment with the Preamble and Articles. For instance, Article 22 – Respect for privacy - focuses on the protection of personal, health and rehabilitation information of persons with

disabilities on an equal basis with others. The National Federation welcomes the assertion in the *Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities* that the State will defend and vindicate the personal rights of all citizens, including persons with a disability and that the provisions of the Data Protection Act 2018 and the EU General Data Protection Regulation (GDPR) apply equally to all persons in Ireland. In this regard whilst building shared information systems that allow for integrated planning across housing and supports through the new Housing Strategy, it will be important that all information gathered/retained by organisations / state bodies relating to persons with a disability meet relevant legal requirements.

Article 23 (Respect for home and family) supports the right to family and home life for people with a disability. There is a particular need, as outlined above, for comprehensive planning in relation to the changing needs of older adults with disabilities. There is a need for a statutory entitlement to homecare with the aim of supporting people to live in dignity and independence in their own homes/communities for as long as possible; without this, the will and preference of the person will not be enabled.

Article 26 – (Habilitation and Rehabilitation) focuses on States’ responsibilities in taking:

‘effective and appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life’.

Article 26 details that *‘state parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services’*. There is a need to focus on the continual development of staff skills, competencies and abilities across the stakeholders responsible for delivering the outcomes of the Housing Strategy, with shared learning on achieving positive outcomes for people with a disability.

Article 26 also focuses on the need for state parties to promote the availability, knowledge and use of assistive devices, designed for person with disabilities, as they relate to habilitation and rehabilitation’. There a need for significant investment in this area with Services / individuals with a disability being funded to avail of aids, appliances, and assistive technologies to support everyday living. This work needs to be adequately resourced and supported.

There is a strong correlation between disability and poverty; the 2019 CSO *Survey on Income and Living Conditions* found that those most at risk of poverty were people who were not at work due to illness or disability. Poverty rates for people with disabilities in Ireland are 10% higher than the EU average^{xxix}. The data indicates a need to address levels of income for people with disabilities through the social welfare system and access to employment. Article 28 (Adequate standard of living) points to the need to examine the array of income support measures in place for people with disability in relation to accessing housing, to ensure the accessibility of same. During this consultation, members have highlighted particular challenges in supporting people to access Rent Supplement. Research currently underway on the Cost of Disability is welcome and requires action, as is the commitment to reduce the percentage of those *At Risk of Poverty* from 36.9% to 28.7% by 2025 and to 22.7% by 2030. Members have also highlighted difficulties in bridging the gap between the Housing Assistance Payment and the rent charged by private landlords –

particularly given the correlation between poverty and disability, and the high levels of unemployment experienced by people with disabilities currently.

Article 31 (Statistics and Data Collection) outlines the obligation on state parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give full effect to the requirements of the Convention. This also includes a provision to;

‘..assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others’.

There is also an onus on states to;

‘..identify and address the barriers faced by persons with disabilities in exercising their rights’.

We welcome that following public consultation and pilot testing, the 2021 Census will include enhanced questions on disability and plans to conduct a post-Census National Disability Study (NDS) post the Census scheduled for 2026.

The disability database for those receiving specialist disability services, the National Ability Supports System, is a key tool in gathering robust accurate data relating to those receiving services and those requiring services into the future. It would be useful if the data systems available through the Local Authorities and the NASS were examined to develop methods of shared planning and resourcing.

The introduction of a legislative requirement to collect and publish data disaggregated by disability, including complaints regarding discrimination across all sectors could support monitoring of progress in the field of equality and non-discrimination (OCO Report, 2021).

The work of groups run directly by people with a disability or that represent people with a disability e.g. the recently established Disability & Participation Network are vitally important in hearing directly from people with a disability about their lived experiences. The research undertaken by groups such as the [Inclusive Research Network](#) is a valuable source of evidence and information that should be consulted.

The National Federation welcomes the publication of the *Disability Capacity Review to 2032* to provide an evidence base to underpin the response to the substantial unmet needs requiring investment.

5.0 Conclusion

The National Federation appreciates this opportunity to participate in the consultation process for the new *Housing Strategy for People with a Disability*. We welcome the progress to date under the previous Strategy and believe that this new Strategy represents an opportunity for increased integrated, cross-Departmental approaches that focus on the rights and needs of the citizen in relation to both their housing and support needs. We believe that the consultation process for the development of the new Strategy has been a model of inclusive consultation.

It is our view that the new Housing Strategy for People with a Disability will be an important driver in achieving the rights required under the State's responsibilities following ratification of the UNCRPD, and in particular in meeting its responsibilities under Article 19 to support people with disabilities to live independently, in inclusive communities.

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