

# Ireland Initial Report (Draft) under the Convention on the Rights of Persons with Disabilities

## *Submission by the Citizens Information Board*

### Introduction

The Citizens Information Board (CIB) welcomes the opportunity to respond to this consultation on Ireland's Initial Report (Draft) under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This Report is highly important as it sets out where Ireland is at in the process of implementing the UNCRPD.

CIB is the statutory agency responsible for supporting the provision of information, advice and advocacy services to the public and, particularly, in relation to people disabilities.<sup>1</sup> It is the agency responsible for the National Advocacy Service for People with Disabilities (NAS). The Citizens Information Act 2007 includes a requirement for the Board *"...to support the provision of or, where the Board considers it appropriate, to provide directly, advocacy services to individuals, in particular those with a disability, that would assist them in identifying and understanding their needs and options and in securing their entitlements to social services"*.

NAS operates in accordance with the principles that people with disabilities:

- Make decisions about their lives
- Are listened to and consulted by their families and those who provide their services
- Access the supports they need to enable them to live their life and enjoy meaningful participation in family, work and leisure
- Enjoy the benefits of participation in and contribution to their local communities

The services provided by NAS are centrally relevant to UNCRPD implementation.

CIB also funds and supports the Sign Language Interpreting Service which works to ensure that Deaf people have easy access to public and social services and can exercise their rights and entitlements under Equal Status and Disability legislation.

It is noted that in compiling the Draft Report, the Department of Children, Equality, Disability, Integration and Youth consulted with other government departments and agencies and that there was input from the National Disability Authority. Reference is also made to a new Disability Participation and Consultation Network which has been established to ensure that persons with disabilities and their representative groups have input into the formation of policy and legislation in Ireland. This Network is very important in identifying the very significant issues faced by people with disabilities on a daily basis and the major barriers which militate against people with disabilities

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<sup>1</sup> CIB supports the national network of Citizens information Services which provide information, advice and advocacy services to the public, including people with disabilities. The Board also supports the Money Advice and Budgeting Service (MABS).

asserting their rights under UNCRPD. The Consultation Network is also important in ensuring that the voice of people with disabilities is heard fully.

The Draft Report references a number of strategies and initiatives relevant to UNCRPD that have been put in place in recent years, including, in particular, the *National Disability Inclusion Strategy 2017 – 2021* (NDIS), the *Comprehensive Employment Strategy for People with Disabilities 2015-2024* and the *National Housing Strategy for People with a Disability*. CIB has made submissions on these strategies.

While the Draft Report makes frequent reference to the range of initiatives that have been taken that can be directly or indirectly linked to the implementation of each article of the UNCRPD, the underlying theme is that the Assisted Decision-Making (Capacity) Act 2015 (ADMC Act) is central to UNCRPD compliance.

### Observations relating to the Draft Report and selected UNCRPD Articles

This Submission makes observations on the Draft Report in relation to selected UNCRPD articles and related points based primarily on the experience of CIB delivery services (NAS, CISs and MABS).

#### Article 5: Equality and non-discrimination

The statement in the Draft Report (Paragraph 8) that the *“Irish Government is committed to the principles of the Convention and to its purpose to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”* is important. However, until the ADCM Act is implemented, Ireland’s legislation for people whose decision-making capacity is in question continues to be the totally outdated *Lunacy Regulation (Ireland) Act 1871*.

The Mid-Term Review of Progress under the NDIS (published in 2020)<sup>2</sup> found that progress had been slow, particularly in relation to the move from congregated settings. As stated in the Draft Report (Paragraph 12), Government departments and agencies will be requested to develop their own implementation plans linked to the national plan. This process should commence immediately.

The commitment to the strengthening of rights, to developing a UNCRPD implementation plan and a commitment to commence the *Assisted Decision-Making (Capacity) Act 2015* in the period 2020-2021 are central and it is very important that this timeline is met if Ireland is to be UNCRPD compliant. CIB very much welcomes the establishment within the HSE of the National Office for Human Rights and Equality Policy which should ensure that equality and non-discrimination matters are kept to the fore in policy and practice.

#### Article 6: Women with disabilities

The Draft Report notes (Paragraph 36) that the majority (51.6%) of people with a disability in Ireland are females. It lists a number of policies, laws and protocols such as the National Strategy for Women and Girls 2017-2020. (it is noted that this strategy is now past its end date), Ireland’s

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<sup>2</sup> Mid-term Review of Progress: The National Disability Inclusion Strategy and Indicators, <http://nda.ie/Publications/Justice-and-Safeguarding/National-Disability-Inclusion-Strategy/Mid-term-Review-of-Progress-under-the-National-Disability-Inclusion-Strategy-Indicators1.pdf>

ratification of the Council of Europe Istanbul Convention and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW).

Reference is made (Paragraph 40) to Tusla's statutory responsibility for the care and protection of victims of domestic, sexual, or gender based violence. An issue that has been identified by CIB services is that Tusla does not provide social worker support to parent/grandparents in child access/custody court cases. This is a particular issue for parents in such cases with an intellectual disability and/or experiencing mental health difficulties cases (many of whom are women).

#### Article 9: Accessibility

CIB has carried out research<sup>3</sup> on the experiences of the Deaf Community in accessing public and social services and related information on rights and entitlements in Ireland. Members of the Deaf Community have faced severe difficulties in accessing public information in their preferred language which impacts on the realisation of their rights. The CIB Report considered the current provisions by public agencies for meeting the needs of the Deaf Community and identifies the main issues in developing more accessible services. The Irish Sign Language Act 2017 which conferred official language status on Irish Sign Language and came into force in 2020 is highly important for the Deaf community. (As already stated, CIB funds and supports the Sign Language Interpreting Service).<sup>4</sup>

Section 42 of the Irish Human Rights and Equality Act 2014 established a positive duty on public sector bodies to eliminate discrimination, promote equality of opportunity and treatment and protect human rights. This requires that all public bodies have responsibility to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans. There are, however, questions about how well some public services are meeting their legal obligations. For example, a 2019 CSO Report<sup>5</sup> has found that almost 12% of people reported that they had experienced discrimination when accessing services. While data on access to public services by people with a disability was not provided separately, it is important that compliance by public services in respect of people with disabilities is kept under ongoing review.

The Draft Report outlines an extensive list of initiatives and policies relating to accessibility. It states the commitment of the Irish Government to ensuring that persons with disabilities can access information, services and buildings and implements this commitment through anti-discrimination law, specific legislative requirements and through the National Disability Inclusion Strategy (NDIS). There is also reference to the principle of universal access and universal design as referenced in the Disability Act 2005. It is noted in the Draft Report (Paragraph 89) that Ireland's policy for accessible

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<sup>3</sup> Information provision and access to public and social services for the Deaf Community [https://www.citizensinformationboard.ie/downloads/social\\_policy/Deaf\\_Community\\_Research\\_Report\\_Feb2018.pdf](https://www.citizensinformationboard.ie/downloads/social_policy/Deaf_Community_Research_Report_Feb2018.pdf)

<sup>4</sup> With funding from the NDIS, SLIS has increased interpreters numbers and extended opening hours to support the provision of extended remote Irish sign language interpreting services to the Deaf community; the service has also developed a pilot on-demand interpreting App platform and has established a professional register for ISL Interpreters.

<sup>5</sup> CSO, Equality and Discrimination, <https://www.cso.ie/en/releasesandpublications/er/ed/equalityanddiscrimination2019/>

public transport is embodied in the concept of ‘Transport Access for All’ and is based on the principle of universal access to public transport.

Issues relating to accessibility are regularly reported by CIB services, including lack of accessible transport<sup>6</sup>, accessible housing/accommodation, information/communication and financial services.

CIB is particularly interested in accessible information and in ensuring that information provided via all CIB platforms and channels is fully accessible to all people with disabilities. We very much welcome the commitment by Government (Paragraph 117 Draft Report) to design public sector websites in accordance with universal design principles.

#### Article 10: Right to Life

As stated in the Draft Report (Paragraphs 123 and 124), the right to life is well protected in Ireland. The Covid-19 pandemic has presented significant challenges for the whole of society but has particularly affected nursing home residents. At the beginning of February of this year, there had been 1,500 deaths from Covid-19 in nursing homes.<sup>7</sup> An important question that needs to be asked is whether or not the lives of some were put at greater risk by virtue of the fact that they were living in a nursing homes when this was not necessary. The statutory Nursing Homes Support Scheme (‘Fair Deal’), combined with the absence of a statutory provision for home care, results in a situation where older people with complex health and social care needs are left with no choice but to live in a nursing home. It is noted that the Special Oireachtas Committee on Covid-19 expressed the view (p.14) that *“future moves to support the older people at home must have, as a priority, a publicly funded and publicly provided model of care that is underpinned by community intervention teams from the HSE”*.<sup>8</sup>

#### Article 12: Equal recognition before the law

Paragraph 141 of the Draft Report states that Ireland is putting in place the required legislation that will give full effect to its obligations under Article 12. The Report outlines a number of the provisions in the ADMC Act that will give effect to promoting and supporting decision-making for those people who require decision making support. The Act needs to be fully implemented to give people with reduced capacity adequate and equal protection under the law.

The Draft Report (Paragraph 158) states that the Legal Aid Board (LAB) in Ireland provides Civil and Criminal Legal Aid to eligible persons in Ireland, that persons with disabilities have equal access to legal aid and that the LAB has appointed an Access Officer in accordance with the Disability Act

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<sup>6</sup> CIB has previously published a Social Policy Report, *Getting There: Transport and Access to Social Services* which highlighted transport difficulties encountered by people with disabilities in accessing health and social care services as well as social amenities.

[https://www.citizensinformationboard.ie/downloads/social\\_policy/Getting\\_There\\_Report\\_2010.pdf](https://www.citizensinformationboard.ie/downloads/social_policy/Getting_There_Report_2010.pdf)

<sup>7</sup> Oireachtas Joint Committee on Health 2<sup>nd</sup> February 2021,

[https://data.oireachtas.ie/ie/oireachtas/debateRecord/joint\\_committee\\_on\\_health/2021-02-02/debate/mul@/main.pdf](https://data.oireachtas.ie/ie/oireachtas/debateRecord/joint_committee_on_health/2021-02-02/debate/mul@/main.pdf)

<sup>8</sup> Special Committee on Covid-19 Response. Houses of the Oireachtas. 2020,

[https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special\\_committee\\_on\\_covid\\_19\\_response/reports/2020/2020-10-09\\_final-report-of-the-special-committee-on-covid-19-response-sccr004\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-10-09_final-report-of-the-special-committee-on-covid-19-response-sccr004_en.pdf)

2005. However, it is sometimes the case that LAB solicitors do not have the time or the skills to help people with reduced decision-making capacity to understand what is involved in court processes and how it impinges on their lives, for example, parents with an intellectual disability and/or experiencing mental health difficulties engaged with court child care proceedings. Also, as confirmed by the Supreme Court,<sup>9</sup> Legal Aid is not currently available to a person who is the subject of wardship.

#### Article 13: Access to justice

Access to justice for people whose decision-making capacity is in question would be greatly enhanced by the full commencement of the ADMC Act. The Act is underpinned by a number of fundamental principles (Section 8) aimed at promoting and protecting the legally binding decision-making rights of people, including, in particular,

- Supported decision-making
- Presumption of capacity
- Right to privacy
- Provision for necessary intervention only
- Right to make unwise decisions
- Least restrictive interventions
- Interventions giving effect to the individual's will and preferences
- Consideration of other views
- Likelihood of recovery and urgency of the issue

Underpinning these principles, CIB believes, is the right to information and the right to independent advocacy to enable people to fully understand and be empowered to use that information.

Article 13 of the UNCRPD refers to “the provision of procedural and age-appropriate accommodations, in all legal proceedings ... including at investigative and other preliminary stages” as well as the appropriate training for those working in the administration of justice. Paragraph 165 of the Draft Report states that ‘*draft rules of court to facilitate the operation of the new capacity regime have been prepared by the Courts Service*’. However, the Draft Report does not give any details of the programme of training for those involved in the administration of justice.

CIB notes that Paragraphs 159-164 of the Draft Report refer to access for people with physical/sensory disabilities only. While access to legal professionals willing to represent them or accessible court premises and communication systems is clearly important for people with disabilities, access to justice is much wider. There are significant information, social and attitudinal barriers that need to be addressed.

#### Article 14: Liberty and security of person

Article 40.4.1 of Bunreacht na hÉireann provides that ‘*No citizen shall be deprived of his personal liberty save in accordance with law*’. In a Submission to the Department of Health in 2018 on

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<sup>9</sup> See *AC and Others V Cork University Hospital and Others*, <https://www.lawsociety.ie/gazette/top-stories/supreme-court-judgment-on-lawfulness-of-ward-of-court-procedures/>

Deprivation of Liberty: Safeguard Proposals<sup>10</sup>, CIB noted that in all cases, deprivation of liberty should occur in accordance with due process of law, and subject to regular review and lawful challenge. People with disabilities, including, in particular, older people with complex care and support needs, may be deprived of their liberty due to a lack of appropriate accommodation and supports to enable them to live independently.

While Draft Heads of a Deprivation of Liberty Bill were published by the Department of Health as part of a consultation process in 2017, legislation has not yet been enacted to meet the UNCRPD requirement that people are not arbitrarily or unlawfully deprived of their liberty.

In relation to younger people with disabilities, while it is clear Government policy is to move people out of congregated settings, there have been delays in the process due to sourcing additional funding schemes and the increasing costs of properties (Paragraph 229 Draft Report). While some progress has been made in accommodating people with disabilities in community settings, a total of 1,953 people remained in congregated settings at the end of 2019<sup>11</sup>. Of these, 65% are aged between 18 and 59 years of age with many having spent a very considerable period of their lives in congregated settings. There is a clear need to expedite the move from congregated settings for people with disabilities.

The Draft Report (Paragraph 147) confirms that Part 6 of the ADMC Act provides for the abolition of wardship and for the phased transition from adult wardship to the new decision-making support arrangements. CIB notes that questions about the wardship system have been raised by both the Supreme Court and the Court of Appeal. Safeguarding Ireland research<sup>12</sup> highlights the shortcomings of the current wardship system in Ireland, including, in particular, the following:

- The Voice of the Ward is not heard during an application for wardship, or subsequent to the individual being made a Ward;
- There is no automatic system of providing respondents (prospective Wards in an application for wardship) with independent legal or non-legal advocacy.
- More frequently than not, a respondent has no representation independent from the person making the application to have them made a Ward

#### Article 16: Freedom from exploitation, violence and abuse

UNCRPD Article 16. 1 states that *'States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects'*.

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<sup>10</sup> CIB Submission on Deprivation of Liberty: Safeguard Proposals, [https://www.citizensinformationboard.ie/downloads/social\\_policy/submissions2018/CIB\\_submission\\_Deprivation\\_of\\_Liberty\\_Dept\\_Health.pdf](https://www.citizensinformationboard.ie/downloads/social_policy/submissions2018/CIB_submission_Deprivation_of_Liberty_Dept_Health.pdf)

<sup>11</sup>Time to Move on from Congregated Settings: Annual Progress Report 2019 <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-annual-progress-report-2019.pdf>

<sup>12</sup> Safeguarding Ireland Report on Wardship <https://63273-593977-raikfcquaxqncofqm.stackpathdns.com/wp-content/uploads/2018/10/Wardship-Review-2017.pdf>

In this regard, the publication by the Mental Health Commission and HIQA in 2019 of the National Standards for Adult Safeguarding<sup>13</sup> was an important initiative. It outlined a number of principles to help promote people's rights and safeguard them from abuse, neglect and exploitation – empowerment, a rights-based approach, proportionality and partnership.

However, these Standards cover health and social care settings only. Safeguarding is obviously required in many other contexts. In 2019, the HSE National Safeguarding Office was notified of 11,929 safeguarding concerns<sup>14</sup>, the vast majority of which related to people with a disability. Of the 3,990 concerns alleging abuse by persons other than other service users, almost two-thirds (63%) were allegedly perpetrated by a relative or friend/neighbour. Physical abuse, psychological abuse and financial abuse were the three main abuse types reported.

As acknowledged in Paragraph 156 of the Draft Report, the Banking and Payments Federation Ireland and Safeguarding Ireland have highlighted the need for greater awareness of financial abuse and the need for people to plan ahead to safeguard their finances. While the Central Bank's Consumer Protection Code offers some financial safeguards for people, more is required to strengthen safeguards against financial abuse. These include meaningful alternatives to remote banking for people with under-developed digital literacy skills in order to offset some of the effects of the closure of many bank and post office branches.<sup>15</sup> There is also a need for greater oversight of agency arrangements for social welfare payments

It is clear that Standards on their own will not be sufficient and need to be followed by effective adult safeguarding legislation in order to ensure that they are adhered to and enforced. The findings in a recent Red C Poll commissioned by Safeguarding Ireland found that 91% of respondents support stronger laws to safeguard people from abuse or neglect, particularly those who are vulnerable<sup>16</sup>. It is almost certain that without such legislation, full compliance with Article 16 will not be achieved. The 2019 HSE National Safeguarding Office Annual Report refers to the importance of safeguarding legislation – *“there remains an urgent need to progress on a statutory basis for adult safeguarding as reflected by the information in this and previous NSO annual reports. Also, adult safeguarding should be seen as an issue beyond health care.....there is a need for a broader cross societal responsibility<sup>17”</sup>.*

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<sup>13</sup> National Standards for Adult Safeguarding. HIQA and MHC (2019), <https://www.hiqa.ie/sites/default/files/2019-12/National-Standards-for-Adult-Safeguarding.pdf> .

<sup>14</sup> National Safeguarding Office. Annual Report. 2019, <https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/national-safeguarding-office-annual-report-2019.pdf>

<sup>15</sup> CIB has made a Submission on the Digital Strategy [https://www.citizensinformationboard.ie/downloads/social\\_policy/submissions2018/Digital\\_Strategy\\_CIB\\_Submission.pdf](https://www.citizensinformationboard.ie/downloads/social_policy/submissions2018/Digital_Strategy_CIB_Submission.pdf) and on the National Adult Literacy, Numeracy and Digital Literacy Strategic Development

<sup>16</sup> Safeguarding Ireland Incidence of Adult Abuse in Ireland RedC October 2020 <https://63273-593977-raikfcquaxqncofqfm.stackpathdns.com/wp-content/uploads/2020/10/Incidence-of-Adult-Abuse-in-Ireland-during-COVID-19-5.10.20-FINAL.pdf>

<sup>17</sup> National Safeguarding Office. Annual Report. 2019, <https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/national-safeguarding-office-annual-report-2019.pdf>



There is also a need for a stronger regulatory framework for people in long term residential care. In that context, CIB strongly supports the recommendations contained in the Covid-19 Nursing Homes Expert Panel's report that "*the current regulations need to be modernised and enhanced with additional powers and requirements*<sup>18</sup>". Furthermore, there is currently no regulation of home care. This places all people with disabilities, regardless of their age, who need care in the home at risk of abuse, exploitation and neglect. There is an urgent need to introduce statutory regulation for all home care services and the current Programme for Government has committed to introducing a statutory scheme to support people to live in their own homes, which is envisaged as providing equitable access to high-quality, regulated home care.

While the Domestic Violence Act 2018 introduced a new offence of "coercive control", it limited the offence to where the perpetrator and victim are related to one another as spouses or partners only. The legislation does not cover situations where the coercive control is by an adult child or sibling. This needs to be rectified so that the offence of coercive control is extended to all relationships.

#### Article 19: Living independently and being included in the community

CIB notes that there have been some important advances in encouraging independent living and community participation for people with disabilities. The continued move away from congregated settings, both for people with disabilities and those with mental health challenges, notwithstanding the slow pace of implementation, is a welcome and positive development. However, despite the fact that the National Housing Strategy for People with a Disability was put in place in 2011, there continue to be considerable shortcomings in the way people with disabilities are accommodated. CIB very much welcomes the Review of the National Housing Strategy for People with a Disability currently being undertaken by the Housing Agency. In this regard, a CIB Social Policy Report, *Meeting the Accommodation Needs of People with Disabilities*, is being prepared (jointly with Disability Federation of Ireland) which is intended to inform the review.

Paragraph 34 of the Draft Report states that "*persons with disabilities make their own choices and decisions, are treated with dignity and respect and are free from all forms of abuse*". In relation to accommodation, the reality is somewhat different with some people with disabilities having little or no choice in terms of their living accommodation. For example, approximately 1,500 younger people (under 65 years of age) with disabilities are currently residing in nursing homes in Ireland<sup>19</sup>, mainly because of insufficient community supports and/or a lack of accommodation appropriate to their needs. It has long been acknowledged that nursing home accommodation, which is primarily designed and provided for older people, is not suitable for younger people with disabilities.

The current policy emphasis on accommodating people with disabilities to live independently in the community is not working as envisaged. For example, some of the work of NAS involves helping people to assert their right to independent living and to find appropriate accommodation accordingly. Continuing the trend from previous years, the most significant issues worked on by NAS advocates in 2019 were housing and accommodation, accounting for 50% of representative advocacy cases.<sup>20</sup> The cases included those experiencing homelessness or those at risk of

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<sup>18</sup> Covid-19 Nursing Homes Expert Panel. Examination of Measures to 2021. Report to the Minister for Health, <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>.

<sup>19</sup> [https://www.disability-federation.ie/assets/files/pdf/dfi\\_rr\\_2018\\_web.pdf](https://www.disability-federation.ie/assets/files/pdf/dfi_rr_2018_web.pdf)

<sup>20</sup> NAS Annual Report 2019 <https://advocacy.ie/app/uploads/2020/12/NAS-AR-2019-FINAL-WEB.pdf>



homelessness, those in inappropriate residential placements<sup>21</sup>, and people in the process of moving out from large residential centres to live in the community. Rent arrears and social housing waiting list issues also featured regularly in NAS casework.

There are some 90,000 queries on housing annually to CISs. These include people with disabilities seeking appropriate accommodation or looking for assistance with getting house adaptations to help them manage in their own homes following an acquired disability. Families requiring house adaptations because they have a child with a disability is also a recurring theme.

A key objective of Government policy in recent years has been to explore the concept of personalised budgets for people with disabilities to empower them to live independent lives.<sup>22</sup>The Draft Report (Paragraph 246) discusses the supports needed to live independently and references the Task Force on Personalised Budgets. This Task Force was established in 2016 and reported in June 2018. The Draft Report states that a pilot programme was initiated in 2019 and will run up to the end of 2021. The Government commitment to build on the experience of the pilot study is important. However, while the report states that the National Disability Authority is evaluating the project, there is no timeline given for this review

Given the central importance of independent living and the need for supports commensurate with this, CIB is of the view that the Draft Report does not give sufficient cognisance to what is required to enable more people with a disability to live independently. Indeed, the UNCRPD Committee, in its General Comment on Article 19, stated that barriers to living independently also include the denial of legal capacity, negative attitudes, stigma and stereotypes and the lack of available services such as transport.<sup>23</sup>

UNCRPD Article 19 makes specific reference to Personal Assistance (PA). The National Disability Inclusion Strategy 2017-2021 refers to 'achieving maximum independence' for disabled people in Ireland. The inadequate availability of PA is an important factor in limiting options for independent living. There are significant constraints on the current PA service. There is no standardised application procedure and those in receipt of this support do not have any security regarding the continuation or extent of their service due to a lack of legislative protection. The practice of assigning home help hours to disabled people instead of a PA service prevails. Furthermore, individuals are also at risk of being removed from waiting lists for PA services when they accept home help hours instead. The practice of assigning home help hours to disabled people instead of a PA service should be discontinued.

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<sup>21</sup>Inappropriate residential placements refer to situations where a person is living in a type of accommodation that is not suitable for their needs or wishes and does not allow them to participate in their communities.

<sup>22</sup> CIB Submission on Personalised Budgets,

[https://www.citizensinformationboard.ie/downloads/social\\_policy/submissions2017/Personalised\\_Budgets\\_CI\\_B\\_Subm\\_Oct2017.pdf](https://www.citizensinformationboard.ie/downloads/social_policy/submissions2017/Personalised_Budgets_CI_B_Subm_Oct2017.pdf)

<sup>23</sup> Committee on the Rights of Persons with Disabilities, General comment No. 5 (2017) on living independently and being included in the community, <https://bettercarenetwork.org/sites/default/files/CRPD.C.18.R.1-ENG.pdf>

## Article 25: Health

CIB takes the view that health as it relates to people with disabilities must be understood as including social care. Social care access issues are identified by CIB services on an ongoing basis and include:

- Lack of statutory right to home care
- Significant regional disparities in the supports available in the community
- Adults aged under 65 with diagnosed disabilities or illness resident in congregated nursing home settings because their care and accommodation needs could not be met in the community
- Long-term residential care the only option offered on discharge of older people from hospital
- People being placed in a nursing home setting for rehabilitative or respite care and being effectively abandoned there because of lack of proactive engagement in getting an appropriate Home Care Package
- Lack of person-centred support and planning for adults with an intellectual disability – evidenced in inadequate supports to enable family carers to continue in the caring role
- Funding streams for support for those under 65 with a diagnosed disability from disability services and funding for all adults over 65 from older persons' services – the latter often results in a reduction of support to people with a disability
- Integrated and standardised needs assessment (e.g., in relation to supported housing) not always carried out
- Therapies (Occupational Therapy and Physiotherapy) not available in private nursing homes as they are in the community and in public nursing homes

The Draft Report (Paragraph 176) notes that a comprehensive review of the Mental Health Act 2001 is underway and that Draft Heads of Bill have been prepared, taking into account the recommendations of the Expert Group Review of the Act, the views of the Mental Health Commission (MHC) and Ireland's obligations under the UNCRPD. The introduction of new mental health legislation is long overdue and should be progressed in order to address issues relating to, *inter alia*, involuntary detention and supported decision-making and to ensure compliance with both UNCRPD and the ADMC Act.<sup>24</sup>

## Article 28 – Adequate standard of living and social protection

There have been significant developments in income supports for people with disabilities in recent years, particularly in relation to people with disabilities taking up employment or training. These are important from a social inclusion perspective.

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<sup>24</sup> NAS has made a submission in response to the recent consultation on mental health legislation.

CIB has over the years frequently called for a cost of disability payment to help to address the additional difficulties and challenges faced by people with disabilities in being able to live their lives on an equal basis to the rest of society.<sup>25</sup> This is a complex area where a multi-faceted response is required built around a twin approach: (a) enabling more people with disabilities to be fully socially included and (b) social protection and supports targeted at mitigating the costs of living with a disability.

Addressing the issue of the cost of disability is linked intrinsically with equality of access. It is also the case that the Nursing Home Support Scheme leaves people whose only income is the Non-contributory State Pension with inadequate personal income to cover personal living expenditure and leaves them without money for cultural/social and recreational activities.

#### Article 30 – Participation in cultural life, recreation, leisure and sport

While there are opportunities for participation by people with disabilities in social, cultural and recreational activities in the community, CIB is of the view that many people residing in nursing homes are often deprived of cultural life and leisure activities of their choosing. The main obstacles to participation in social and cultural life are identified as follows:

- Some people require wheelchair accessible transport, which can be difficult to access in some parts of the country.
- The costs associated with attending social and cultural events (transport, tickets, accompanying support personnel) cannot be met.
- Some people with a disability have their funds managed by their families, who might not see any value in the person attending social and cultural events.
- The requirement by nursing homes that someone accompany a resident on trips outside the nursing home affects those without external social networks.

#### Article 33 – National implementation and monitoring

As referenced in the Draft Report, there are many important and developmental strategies in place which are having an impact on people with disabilities. These strategies are crucially important in implementing UNCRPD provisions. However, stronger and more active implementation frameworks are required across all relevant strategies and more focused cross-Departmental working.

#### Key points

CIB identifies the following as areas requiring further attention by Government in the context of moving towards full UNCRPD compliance:

- Full and immediate commencement of the Assisted Decision Making (Capacity) Act 2015

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<sup>25</sup> It is noted that research on this issue has been commissioned by the Department of Social Protection and is currently well advanced.

- Ongoing and targeted implementation of the Comprehensive Employment Strategy for People with Disabilities
- Development and implementation of a comprehensive framework of adult safeguarding legislation which includes, but is not limited to, health and social care services
- Provision for statutory entitlement to independent advocacy
- Enactment of Deprivation of Liberty legislation and statutory safeguards
- Amendment of the Domestic Violence Act 2018 to expand the offence of coercive control wider sets of relationships
- Updating and strengthening the regulation of health and social care services to include regulation of home care
- Provision of statutory entitlement to home care.
- Tighter timelines for implementing *Time to Move On*
- Provision of a wider range of accommodation options, including more supported housing to support ageing in place
- Better regulation of financial institutions to ensure provision is made to assist people who may be challenged by on-line banking

Independent advocacy is particularly important for people with reduced decision-making capacity who are vulnerable because of their place of residence or a lack of trusted relatives or networks. There is no current effective mechanism to compel service providers to support people with disabilities to exercise their autonomy or to assess an independent advocate even though this is a requirement under HIQA standards. It is the CIB view that legal recognition for the practice of independent advocacy is central to UNCRPD compliance. NAS has already sought legislation to give NAS statutory powers of access.

Access to information is vital in enabling people with disabilities to assert their rights under UNCRPD. All service providing agencies and professionals should be required to ensure that each person with a disability is enabled and supported to understand and process information to the fullest extent possible and to make decisions accordingly. This is at the very core of a rights-based approach and should happen without waiting for the ADMC Act 2015 to be commenced.

Finally, CIB believes that it would be very important for Ireland to sign the UNCRPD Optional Protocol. This provides for the Committee on the Rights of Persons with Disabilities to receive and consider communications from or on behalf of individual or groups.