



**Submission on Ireland Initial Report under
the Convention on the Rights of Persons
with Disabilities**

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Introduction

Sage Advocacy welcomes the opportunity to make a submission in response to Ireland's Initial Report (draft) under the Convention on the Rights of Persons with Disabilities (referred to hereafter as the Draft Report). The Submission draws mainly on the casework experience of Sage Advocacy in delivering independent advocacy to vulnerable adults over the past five years, including, in particular, vulnerable adults with a disability. In 2020, there were 1,248 referrals for advocacy support to Sage Advocacy and 1,670 calls seeking information and support.

The Submission comments and makes observations on the United Nations Convention on the Rights of Persons with a Disability (UNCRPD) Articles most relevant to the role of Sage Advocacy, viz., to promote, protect and defend the rights and dignity of vulnerable adults, older people and healthcare patients through the provision of independent advocacy and support. It provides observations and commentary on current lived realities for many people with a disability and adults who may be otherwise vulnerable based primarily on Sage Advocacy casework.

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. Sage Advocacy is a member of this Network and looks forward to working purposefully with the other groups involved 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 asserting their rights under the UNCRPD.

While there is a strong emphasis on meaningful consultation in the preparation of the Ireland Draft Report, it must be noted that there is a crucial and important difference between consultation and participation. Those who are consulted make comments and observations within pre-defined frameworks while those who participate engage organically in identifying the questions to be addressed based on their own lived experiences. This participatory model is at the very heart of a rights-based approach and is particularly important for people with disabilities who are frequently on the margins of society. Sage Advocacy believes that much more is required in order to fully reflect the authentic voice of people with a disability.

The Submission responds to the overall thrust of the Ireland Draft Report which has outlined the wide range of policy initiatives introduced by the Irish Government in recent years relating to people with disabilities. Many of these are laudable and have some innovative elements which reflect the provisions of the UNCRPD, for example, income support and targeted employment initiatives. However, the Ireland Draft Report in its current draft fails to engage in any meaningful way with the daily lived realities of many people with disabilities. Much of what has been put in place at policy and strategic level is

not reflected in the daily encounters that people with disabilities have with the health and social care infrastructure or in the shared spaces in which we all live. In effect, this Sage Advocacy's Submission describes current lived realities for many people with disabilities in the expectation and hope that these will be reflected in the next iteration of the Ireland Draft Report.

Sage Advocacy's Submission does not for the most part make recommendations as to how the issues highlighted might be addressed based on the premise that there must first be an honest acknowledgement by the Government of the issues. Rather, the Submission focuses on exposing the current situation for many people with disabilities as it actually is as distinct from how it is said to be in the Ireland Draft Report. It is hoped that this exposure of lived realities will assist the Government to better formulate the current situation for people with disabilities in addition to outlining and listing the initiatives that have been taken.

Six key messages underpinning the Sage Advocacy Submission

- 1) There is a significant gap between Irish Government aspirations in relation to the rights of people with disabilities (aspirations that are very laudable in themselves) and the lived reality for many people with disabilities. One of the main themes of our Submission is to point out that the actions necessary to close this gap need far higher priority than they currently enjoy.
- 2) Until the Assisted Decision-making (Capacity) Act 2015 (ADM Act) is fully commenced, including the replacement of the wardship jurisdiction, Ireland will continue to fall short in implementing the UNCRPD.
- 3) In pressing the case for recognition and practical implementation of the rights of people with disabilities (e.g. in relation to self-determination), Sage Advocacy is conscious that, in many cases, it will be necessary also to take account of the competing rights and concerns of other parties (often close family members). However, it is critically important that these latter concerns do not become the dominant factor to the point where, as is frequently the case, the wishes of the person with a disability remain unheard or are simply ignored.
- 4) There is little evidence as to whether disability related strategies and initiatives (including joined up thinking by Government) have resulted in broader equality and inclusion for people with disabilities and there is insufficient focus on what the actual outcomes of these initiatives are for people with disabilities.
- 5) It is critically important that the current fragmentation of policies for people with disabilities and older persons does not result in the rights of older people with acquired disabilities as they age being ignored or their disabilities not being categorised as such – this is hugely important in the context of adherence to UNCRPD provisions.
- 6) The fact that Ireland has not signed the UNCRPD Optional Protocol, which provides for the Committee on the Rights of Persons with Disabilities to receive and consider communications from or on behalf of individual or groups, is a matter of some concern in that it means that this important avenue for redress remains unavailable.

Section Two

Comments by Sage Advocacy on Ireland Draft Report

General

The Ireland Draft Report describes the wide range of initiatives that have been taken that can be directly or indirectly linked to the implementation of each article of the UNCRPD. Also included are a number of statements of intent and the identification of steps to be taken in the future to meet Ireland's obligations under the Convention. The Government has established the Disability Participation and Consultation Network to feed into the reporting process. This is important in order to ensure that the voice of all people with disabilities is heard.

While the Ireland Draft Report states that Government policy on advancing the rights and inclusion of people with disabilities is co-ordinated through a number of whole-of-government strategies, including the Comprehensive Employment Strategy for People with Disabilities 2015-2024 and the National Disability Inclusion Strategy 2017-2021, there is little or no reference to whether or not and how these strategies are working. This is a significant omission in the Ireland Draft Report.

While consultation with disability stakeholder groups and wider civil society is a component of strategic development and monitoring mechanisms, there is little evidence of the perspectives of these stakeholders having been reflected in the Ireland Draft Report. It is not at all clear that the voice of disabled people is being heard with regard to the basic requirements for social inclusion and participation, for example, access to the environment and public spaces and access to decision-making supports. Also, there is no legislative provision for the right of a person with a disability to access independent advocacy in order to enable them to assert their voice on matters concerning them. Also relevant is the fact that neither Safeguarding of Vulnerable Adults legislation¹ or Protection of Liberty legislation² has been introduced despite commitments to do so by successive Governments. The Legislative Programme for Spring 2021 includes a Health (Adult Safeguarding) Bill. However, this is narrow in scope and only refers to health matters. The Ireland Draft Report does state that Heads of a Bill on Protection of Liberty Safeguards are being progressed.

The Ireland Draft Report also describes recent legal changes to protect the rights of people with disabilities with particular reference to the Assisted Decision-Making (Capacity) Act 2015 (ADM 2015). However, the Report fails to state the fact that this legislation has not to date been fully commenced or, indeed, to provide any specific timeframe as to when it will be commenced. The ongoing absence of regulatory provision for supported decision-

¹ A Private Members *Adult Safeguarding Bill 2017* lapsed on the change of Government in 2020.

² The Department of Health published a *Deprivation of Liberty: Safeguard Proposals Consultation Paper* in 2018 and the Government's proposed approach to deprivation of liberty provisions was included in the General Scheme of the Equality/Disability (Miscellaneous Provisions) Bill, which was published as the Disability (Miscellaneous Provisions) Bill 2016.

making mechanisms as provided for in the ADM 2015 Act undermines in a fundamental way the rights provided for under the UNCRPD. The Irish Sign Language Act 2017 which conferred official language status on Irish Sign Language is a welcome development as is the requirement since 2014 for all public authorities in Ireland to be bound by a positive legal duty to protect human rights, promote equality and eliminate discrimination against certain protected groups which includes people with disabilities. There are, however, serious questions about how well some public services are meeting their legal obligations in this regard as indicated by Sage Advocacy casework referenced throughout this Submission.

The failure to fully commence the ADM Act means that frequently decisions continue to be made about people's lives without access to support and advocacy to enable people to articulate their will and preferences. This issue is compounded by inconsistency among health professionals regarding how decision-making capacity is interpreted. In Sage Advocacy's work, we have observed the often unnecessary and inappropriate use of Wardship³ on a regular basis which fundamentally undermines the UNCRPD.

This continuing reliance on Wardship, in the absence of an appropriate alternative system, is a matter of major concern and is referenced throughout the Submission in comments under specific Articles. Safeguarding Ireland research⁴ 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 him or her made a Ward (this is in stark contrast to the position in many jurisdictions, particularly for example in the UK, where a person who is the subject of capacity proceedings is automatically appointed an advocate to help them to articulate his or her wishes and preferences.
- The court procedures, to have someone made a Ward of Court, do not take account of the vulnerability of the Respondent: procedures which may be fair in a standard application may not be fair where the Respondent is vulnerable.

Although it may be the State's intention to evolve away from the 1871 Act, in view of the significant impact of Wardship on the lives of people with disabilities and on those with perceived reduction of their decision-making capacity, Sage Advocacy strongly believes that

³ Per the Lunacy Regulation (Ireland Act) 1871

⁴ <https://63273-593977-raikfcquaxqncofqfm.stackpathdns.com/wp-content/uploads/2018/10/Wardship-Review-2017.pdf>

the necessity to commence the replacement system and replace the Wardship system should have been referenced and commented upon in the Ireland Draft Report.

Specific UNCRPD Articles

This section of the Submission deals with a number of specific UNCRPD Articles. The Articles included for commentary are those where Sage Advocacy has direct experience of breaches or failure to fully implement the Article. Sage Advocacy casework is recorded on a Salesforce Database and is retrievable for purposes of both updating and analysis. It should be noted that, while there are many instances where there have been breaches of multiple Articles, the Submission references the most relevant Article in a particular case.

The Articles are commented on sequentially rather than in order of priority in relation to the actual breaches identified and the impact of these on people's lives.

Article 5 - Equality and non-discrimination

Synthesis of relevant points on Article 5 in Ireland Draft Report

The Ireland Draft Report correctly cites, *inter alia*, the non-discrimination legislation that has been put in place, the recognition in law of the Public Sector and Human Rights Duty. Paragraph 38 states that equality and choice for people with disabilities are major themes embedded in the State's legislation and in other specific measures designed to ensure that persons with disabilities are recognised and treated equally before the law and that, *inter alia*, they have the same rights and responsibilities as other citizens, that they can make their own choices and decisions, are treated with dignity and respect and are free from all forms of abuse.

Issues relating to Implementation of Article 5: The Sage Advocacy experience

The Sage Advocacy experience is that, while such provisions are in place, there continues to be many instances where current legal and regulatory provisions either fall short or are not implemented in practice. Sage Advocacy case evidence shows clearly how far the ideal promulgated by the State falls short for vulnerable adults. For example, some interventions continue to be based on what are perceived to be in the 'best interests' of a person rather than on the person's will and preferences, including the right to make what might be considered to be an unwise decision.

Public sector duty

The vast majority of Sage Advocacy cases stem from the denial in one way or another of an adult's human rights associated with discrimination against them on account of their vulnerabilities/disabilities, be that due to age or state of health, whether mental or physical or having a disability.

Ireland's health service is subject to the Public Service Duty. Through its work, Sage Advocacy has highlighted the bias towards nursing home residential care for people with significant care and support needs. Wardship continues to be utilised frequently and is often seen as the only option where there is any question about a person's decision-making capacity.

Sage Advocacy is aware that in some instances public bodies do not adhere to their Public Service Duty to protect the rights of vulnerable individuals despite the fact that legislation is in place for this purpose. This is a matter that goes completely unmentioned in the Ireland Draft Report. This may be related to the fact that Ireland has not signed up to the UNCRPD Optional Protocol under which this kind of discrimination can be reported directly to the UNCRPD Committee.

It should be noted that the issue of people being “placed” in unsuitable nursing home accommodation because of a support need is widespread. Information acquired under FOI shows that 1,350 people under the age of 65 are being cared for in Ireland’s nursing homes.⁵ It is noted that the Office of the Ombudsman is in the course of preparing a report on this matter.

Article 6 – Women with disabilities

Synthesis of relevant points on Article 6 in Ireland Draft Report

The Ireland Draft Report notes that the majority (51.6%) of people with a disability in Ireland are women or girls.

The Ireland Draft Report 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) and Ireland’s 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 to the Child and Family Agency Act, 2013, Tusla (Child and Family Agency) in terms of its statutory responsibility for the care and protection of victims of domestic, sexual, or gender-based violence. However, Sage Advocacy’s experience of Tusla is that it lacks the resources to assist parents/grandparents in child access/custody cases.

Issues relating to Implementation of Article 6: The Sage Advocacy experience

More than half (56%) of Sage Advocacy clients are women. Through its casework, Sage Advocacy has become aware of: (i) a lack of sexual and relationship education for young adults in some disability care settings; and (ii) allegations of women in residential care settings being sexually abused.

In the latter instance, the failure to share information between community/Gardaí/residential facility/nursing homes to better inform safeguarding plans and risk management was a significant factor. Safeguarding legislation and a clearer policy re. data sharing in respect of sexual offenders in nursing homes would have helped prevent this abuse.

Another issue identified by Sage Advocacy affecting women in particular is relatives collecting people’s social welfare payments and retaining the money for their own use. In one case, a Sage Advocacy client reported being left without adequate food. In some such instances, a relative is also in receipt of a Carer’s Allowance but does not provide the care

⁵ <https://www.newstalk.com/news/number-of-younger-people-living-in-irelands-nursing-homes-very-concerning-1167169>

required. This leaves the vulnerable adult at risk because there may understandably be a presumption that care is being provided.

Sage Advocacy regularly provides support for women where coercive control and neglect are a factor.

Article 9- Accessibility

Synthesis of relevant points on Article 9 in Ireland Draft Report

The Ireland 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 (Paragraph 89) that Ireland's policy for accessible 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 Implementation of Article 9: The Sage Advocacy experience

The Sage Advocacy response under Article 9 also considers issues associated with part of Article 21 referring to access to information.

Despite the extensive list of developments and initiatives relating to accessibility outlined in the Ireland Draft Report, the reality is that many people with disabilities continue to live with access barriers relating to transport, public and shared spaces, houses and buildings, services (health, social and financial) as well as difficulties in accessing information by those who communicate differently.

While there are many positive developments in relation to improved accessibility, the lived experience is still very different and this is not reflected in the Ireland Draft Report. Universal access is far from normative and universal design in terms of access for all falls far short of what is required. There is insufficient attention given in practice to monitoring the implementation of various regulatory and legal provisions relating to accessibility and this matter is totally overlooked in the Ireland Draft Report. While, as stated above, there is an emphasis on consultation with stakeholders, the lived realities of disabled people in terms of accessibility have not been given due cognisance. This is the case in respect of both identifying the barriers and formulating solutions.

Lack of accessible and appropriate housing/accommodation and supports.

Sage Advocacy casework shows that frequently people with a disability, including younger adults, are being forced to move to nursing homes because of lack of accessible accommodation and supports. This can have a negative impact on an individual's mental health, well-being, self-esteem and self-confidence as a result, of, for example, not being facilitated or supported to engage in social activities outside of the nursing home.

Issues identified from Sage's case work relating to access to appropriate accommodation include:

- Lack of 'choice' for people with a disability and/or mental health difficulty in relation to the area in which housing is located with particular reference to safety and security matters.
- Local authorities not delivering on their obligation to provide social housing for people with a disability as provided for in the National Housing Strategy for People with a Disability.
- Part M of building regulations relating to accessibility only applicable to new houses.
- Inadequate suitable accommodation for people with mental health difficulties.

Transport

The lack of accessible transport significantly impacts on people's day to day lives. Sage Advocacy casework has identified the following issues:

- People unable to attend medical or other appointments because of lack of accessible transport or being compelled to use expensive taxis.
- Social isolation and non-participation in social and community activities.
- Self-exclusion from employment opportunities because of not having transport to get to where a potential job is.

Other transport accessibility barriers identified are:

- Bus stop design impacting on people with reduced vision (e.g. colour of bus stops and cycle lanes between stop and bus).
- Lack of assistance at DART stations and the requirement for wheelchair users to give four hours-notice before travelling coupled with the frequent lack of functioning lifts.
- Audio announcements are not working on transport services or provide inaccurate information.
- Some buses in circulation that have unusable or unsuitable ramps and safe secure clamps for wheelchairs.
- Space on buses for only one wheelchair and wheelchair users being left behind and/or having to cancel a journey.
- No reduced/subsidised taxi fares for persons with disabilities even though very often there is no alternative accessible transport.

Environment and living spaces

- Safe space on footpaths not always provided, e.g. barriers created by street furniture and outside dining facilities.
- Traffic lights and signals not universally user-friendly for people with disabilities.
- Lack of taxi access to hotels and public entertainment centres in pedestrianised car-free zones.

Information and communications

Despite some important developments in information and communication systems for people with sensory disabilities, for some people with a disability, access to information continues to present a huge difficulty.

- Easy to read materials not always available.
- Sign Language is not always available, in spite of the Irish Sign Language Act 2017 which conferred official language status on Irish Sign Language.
- Assistive technology remains expensive and waiting lists can be long depending on where an individual lives.

Money/banking

- Lack of standardisation of chip and pin machines (screen-based keypads) makes them inaccessible to some.
- A lack of audio, privacy and standards can make some ATM machines inaccessible.
- The closure of bank branches and post offices and the inaccessibility of on-line services for many people with disabilities or and/or those with underdeveloped digital skills is a significant factor in financial exclusion.

Accessibility issues in residential care settings

- Under-developed use of audio and vision technology.
- Lack of due care and attention to residents' hearing aids or low vision aids requirements.
- Hearing aid "sharing" with use by more than one resident.

Article 10: Right to life

As stated in the Ireland Draft Report (Paragraphs 123 and 124), the right to life is well protected in Ireland. However, questions arise relating to the significant impact of Covid-19 on residents of long-term care facilities, in particular nursing home residents. At the beginning of February of this year, there had been 1,500 deaths from Covid-19 in nursing homes.⁶ 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.

Sage Advocacy has previously⁷ highlighted the implications of the lack of policy integration between home care and residential care. In effect, the current statutory right to only

⁶ Oireachtas Joint Committee on Health 2nd February 2021, https://data.oireachtas.ie/ie/oireachtas/debateRecord/joint_committee_on_health/2021-02-02/debate/mul@/main.pdf

⁷ *Choice Matters*, <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf>

nursing home care can result in a situation where people live in a nursing home earlier than needed due to their inability to access adequate home care support.

Clearly, some nursing home residents (at increased risk of exposure to the virus) would not have been in that situation if there had been realistic care and support options available to them in their own homes. Nursing home residents have been identified by the World Health Organisation (WHO) to be at a higher risk of being susceptible to infection from Covid-19 and for subsequent adverse outcomes⁸. The Covid-19 experience brought to a head this reality and points to the need for a fundamental review of the current system. The impact on the pandemic in nursing homes should reinforce the point that more people should and could be cared for and supported in either their own homes or in local-based small-scale sheltered/supported housing complexes thereby reducing the risk of infection from Covid-19 (and any other similar pandemic). 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”*.⁹

Article 12 - Equal recognition before the law and Article 13 – Access to justice

Since there are clear linkages between Article 12 (equal recognition before the law) and Article 13 (access to justice), the two Articles are grouped here in setting out the issues identified by Sage Advocacy. Many Sage Advocacy cases have involved supporting people whose rights under Article 12 were breached and who also experienced a breach of their Article 13 rights. Article 12 provides for a paradigm shift in thinking on legal capacity, reducing the situations in which guardianship or substituted decision-making is imposed and increasing the emphasis on supported decision-making.”¹⁰

Synthesis of relevant points on Article 12 and Article 13 in Ireland Draft Report

The Ireland Draft Report (Paragraph 141) confirms that equal recognition before the law is contained in Ireland’s Constitution (Article 40.1) since 1937. The Report further states that Ireland is putting in place the required legislation that will give full effect to its obligations under Article 12. The Draft Report (Paragraph 157) states that the Irish Government is

⁸ WHO (2020), Infection Prevention and Control Guidance for Long-Term Care Facilities in the context of COVID-19 Interim guidance (21st March 2020)

https://apps.who.int/iris/bitstream/handle/10665/331508/WHO-2019-nCoV-IPC_long_term_care-2020.1-eng.pdf?sequence=1&isAllowed=y

⁹ 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

¹⁰ Centre for Disability Law & Policy NUI Galway Submission on Legal Capacity the Oireachtas Committee on Justice, Defence & Equality

[https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-\(August,-2011\).pdf](https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/archive/Submission-on-Legal-Capacity-to-the-Oireachtas-Committee-on-Justice,-Defence-&-Equality-(August,-2011).pdf)

working to ensure the right of persons with disabilities to have effective access to justice on an equal basis to others, without being excluded from legal proceedings.

Issues relating to Implementation of Article 12 and Article 13

Sage Advocacy casework strongly indicates that frequently there is no more than ‘lip service’ given to the right of all citizens to be equal before the law. While the passing of the ADM Act 2015 was a significant landmark, the fact that most provisions remain to be commenced to this date means that Ireland continues to fall significantly short in meeting its obligations under Article 12 of the UNCRPD. The full commencement of the Act must now be made an absolute priority by Government—otherwise adherence to Article 12 will remain no more than tokenistic and aspirational.

Since the enactment of the ADM Act, the Government has repeatedly stated that the ADM Act will be fully brought into force “next year” and the Ireland Draft Report is the latest example of this¹¹. Most recently, the Minister for Children, Equality, Disability, Integration and Youth, has stated that his Department “anticipates the commencement of Decision Support Service (DSS) services in mid-2022”¹² The “anticipation” of the commencement of a service which is pivotal to Ireland’s compliance with a critical article of the UNCRPD is not sufficient to ensure the protection of the rights of people with disabilities to equal recognition before the law.

The truth is, and the reality for those whom Sage Advocacy supports, is that Ireland still enforces a Victorian-era and archaic law dating from 1871. Similar legislation from other jurisdictions has been long-repealed¹³. Commenting on the use of guardianship and conservatorship systems such as Ireland’s ward of court system, the UN Committee on the Rights of Persons with Disabilities has previously stated that “historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner”¹⁴

The Ireland 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 2005. However, the experience of Sage Advocacy is that the civil legal aid provided, and the skill base of the lawyers employed by the LAB, is largely limited to family law. Sage Advocacy has previously engaged with the LAB to seek provision of legal assistance for vulnerable adults in matters such as the preparation of Enduring Powers of Attorney and Advance Healthcare Directives, the defence of Wardship proceedings, initiating proceedings for the return of property from relatives or others who have unduly influenced a vulnerable adult to part with their property (all matters with which Sage Advocacy is supporting clients). Sage Advocacy has previously offered to provide the

¹¹ Paragraph 144

¹² <https://www.kildarestreet.com/wrans/?id=2020-11-26a.771>

¹³ Such as the Lunacy Act 1890 in England & Wales

¹⁴ UN Committee on the Rights of Persons with Disabilities General comment No. 1 (2014) Article 12: Equal recognition before the law, https://digitallibrary.un.org/record/779679/files/CRPD_C_11_4-EN.pdf p.3.

necessary legal training and support in these areas. To date, these arrangements have not been put in place.

It is noted that Paragraphs 159-164 refer to accommodation for people with physical/sensory disabilities only. It has been the experience of Sage Advocacy that access to justice for people with disabilities is much wider than merely finding lawyers willing to represent them or accessible court premises and communication systems.

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.

A 2018 Human Rights Council Report¹⁵ re-iterated the point that “effective access to justice for persons with disabilities on an equal basis with others [requires] the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings”. This is essential for the effective enjoyment and exercise of all rights. Failure to provide a procedural accommodation therefore constitutes a form of discrimination on the basis of disability in connection with the right of access to justice.

This point is particularly applicable to Ireland since no such procedural accommodations exist in the Irish Courts system thereby denying vulnerable adults the right to partake or participate in court proceedings concerning them. It is the experience of Sage Advocacy that a major procedural accommodation required is the provision of a “support person” for litigants. This was described by the former UN Special Rapporteur as support persons or facilitators who support the person with the disability to understand and make informed decisions.¹⁶ Such support persons do not speak for the person with the disability but are neutral enablers for that person to participate in the legal process. She clarified that it is then up to the support person to insist that the pace of court is slowed sufficiently and adjourned as necessary to enable the person with the disability to “catch up” with their support person, and with their lawyers if necessary, on what is happening.

Increasingly, Sage Advocacy has been asked to provide such support for LAB clients in family law matters but only after the court has requested an advocate or a Guardian ad Litem for a client whom the Judge observes is not following or partaking properly in the proceedings. It would be reasonable to expect that lawyers for such people would identify the client’s need for this from the beginning and not just after the case has been before the court. It would appear that frequently LAB lawyers do not have the training or skills to do so and it is not part of any legal training.

¹⁵https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/Issues/Disability/A_HRC_37_25.docx&action=default&DefaultItemOpen=1 p.5.

¹⁶ Contemporaneous notes taken by Sage Advocacy during Presentation by Catalina Devandas-Aguilar, Former UN Special Rapporteur on the rights of persons with disabilities to National Disability Authority Conference (Virtual) held on 21st October 2020.

Sage Advocacy is firmly of the view that, until such time as the ADM 2015 Act is fully brought into force, it will be impossible for Ireland to state that it complies with Articles 12 and 13 and the evidence included in the Ireland Draft Report are mere semantics. As already stated, the faults with Ireland's 1871 Wardship and its denial of basic human rights have been set out extensively elsewhere.¹⁷

At a minimum, Sage Advocacy believes that the bringing into force of Sections 3 and 8 of the ADM Act (which would introduce the functional approach to capacity and Guiding Principles) would, even without the Decision Support Service, improve the present position of vulnerable adults in accessing justice in Ireland. Sage Advocacy casework illustrates clearly how vulnerable adults continue to be denied their Article 12 rights by having to endure the effects of the 1871 law which remains in force as well as the non-recognition of and, therefore, the non-enforcement of Article 13 rights by the Courts.

Article 14 (Liberty and security of person), Article 18 (Liberty of movement and nationality) and Article 20 (personal mobility)

Synthesis of relevant points on Articles 14, 18 and 20 in Ireland Draft Report

Since there are clear linkages between Article 14 (liberty and security of the person), Article 18 (liberty of movement and nationality) and Article 20 (personal mobility), the three Articles are grouped in setting out the issues identified by Sage Advocacy.

Under Article 14 (Liberty and security of the person), the Ireland Draft Report (Par. 173) states as follows:

To strengthen Ireland's laws on liberty and security of the person, as they relate to persons with a disability, and to ensure that Ireland fully complies with Article 14, the Government has been working towards enacting specific legislation.

The Ireland Draft Report states that Heads of a Bill on Protection of Liberty Safeguards are being progressed which will provide procedural safeguards to ensure that people are not unlawfully deprived of their liberty in relevant facilities. However, there is no reference to this in the current Programme for Government.

Issues identified by Sage Advocacy relating to Implementation of Articles 14, 18 and 20

Sage Advocacy casework demonstrates clearly that the absence of specific deprivation of liberty legislation results in the liberty of many vulnerable people being curtailed, particularly those in nursing homes and other residential care facilities. One such example is a person with reduced decision-making capacity who had been made a Ward of Court and admitted to long-term care. Subsequently, the person's condition improved and they were released from Wardship. However, they had not been afforded the opportunity to consider the

¹⁷ <https://63273-593977-raikfcquaxqncofqfm.stackpathdns.com/wp-content/uploads/2018/10/Wardship-Review-2017.pdf>

option of leaving the nursing home to return home despite improvement in their overall functioning and wellbeing.

Deprivation of liberty in residential care facilities

It has been Sage Advocacy's experience that a number of residential care facilities are using pin codes on doors for entering/exiting place of residence and secure gates are kept locked on grounds of some residential settings. There is also some evidence of use of incontinence wear to discourage requests by persons for assistance with toileting, hoists being used to support persons getting in and out of bed, chair or shower, rather than encouraging and facilitating people to maintain mobility where possible. There is evidence in some instances of mobility aids not being left beside residents in order to discourage free movement around the place of residence. Such practices are clearly a breach of personal liberty.

Other breaches of UNCRPD provisions relating to mobility and liberty of movement that have emerged through Sage advocacy casework include:

- People with disabilities in younger age-groups being required to reside in nursing homes contrary to their will and preferences.
- Staff intervention in preventing persons from leaving a facility, calling of the Gardaí to prevent a person from leaving hospital.
- Some evidence of people in nursing homes being overmedicated to manage behaviours or agitation.
- People who did not have dementia inappropriately placed in a secure Dementia Unit.

Deprivation of liberty linked to inadequate services in the community

An actual or potential infringement of liberty frequently arises due to insufficient services in the community to enable and support a person to remain living in their own home. Sage Advocacy casework suggests that some people require relatively little assistance but, due to the lack of appropriate services in the community, they may have no alternative but to go into a nursing home which is completely inappropriate for people under 65 with a disability or persons over 65 with relatively low care needs. Instances very regularly come to light where because the basic support required for daily living is lacking, people had to move into a nursing home. For example, a Sage Advocacy client needed night time support which could not be provided and was left with no option but to move into a nursing home.

Another case refers to a person with a visual disability who had access to a Personal Assistant under the HSE Disability Services programme but who had this support withdrawn when they reached 65. This person cannot now leave their home without support from relatives or friends.

A further Sage Advocacy case referred to a situation where a person was brought to a nursing home by relatives under a false pretence (being brought out for lunch) and left there without any explanation or any discussion on the matter.

A key underlying issue is that there is grossly inadequate home care support provision in some areas and, to compound the matter, nursing home residents tend not to be prioritised

for home support which means their liberty continues to be compromised by the fact that they must remain in a nursing home setting against their wishes.

Another issue emerging from Sage Advocacy casework is that frequently neither the hospital or community care services used a Quality of Life Indicators¹⁸ approach in order to establish the supports required to enable the person to remain at home. This omission effectively results in a deprivation of liberty.

Fear of risk-taking

Some of the issues relating to deprivation of liberty arise because of fear of risk-taking embedded throughout the health and social care system. Health care professionals may look at the potential risks involved in a particular case and believe that it is their duty and right to make decisions on the person's behalf which minimise risk-taking and does not allow for a person to self-determine in respect of the risks involved. In some cases, a requirement for 24/7 supervision is identified which is impossible to achieve in a community setting within the resources available. This leaves residential care as the only the option which is essentially a deprivation of liberty arising from absence of meaningful choice.

A number of Sage Advocacy cases clearly illustrate both the need for Adult Safeguarding legislation and the extension of the offence of coercive control (see below). For example, there are cases where relatives exert significant control by insisting that a person should not be allowed to return home 'for their own safety'.

Article 16 - Freedom from exploitation, violence and abuse

The Ireland Draft Report lists policies in place, guidelines published and studies carried out or about to be carried out. The publication by the Mental Health Commission and HIQA in 2019 of the National Standards for Adult Safeguarding¹⁹ was an important initiative which outlined a number of principles to help promote people's rights and safeguard them from abuse, neglect and exploitation. However, these Standards cover health and social care settings only.

The HSE National Safeguarding Office was notified of 11,929 safeguarding concerns in 2019²⁰, 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. These are very important issues which require much more attention by the Irish Government.

¹⁸ <https://www.oecd.org/statistics/measuring-well-being-and-progress.htm>

¹⁹ National Standards for Adult Safeguarding. HIQA and MHC (2019), <https://www.hiqa.ie/sites/default/files/2019-12/National-Standards-for-Adult-Safeguarding.pdf> .

²⁰ National Safeguarding Office. Annual Report. 2019, <https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/national-safeguarding-office-annual-report-2019.pdf>

As acknowledged in Paragraph 156 of the Ireland 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. 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 of 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 vulnerable²¹. 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”²².

There is also a need for a stronger regulatory framework for people in long term residential care. 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*”²³ is important. 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. The commitment in the current Programme for Government to Introducing a statutory scheme to support people to live in their own homes needs to be implemented without further delay.

Article 16: Issues identified by Sage Advocacy

It is the Sage Advocacy experience that that adults with a disability of any kind remain insufficiently protected under Irish Law due to a lack of safeguarding legislation. For example, adult residents of nursing homes are at risk of abuse by sexual predators who are also residents due to the absence of adequate data processing regulations which would allow the sharing of information between relevant agencies. In short adults who are

²¹ Safeguarding Ireland Incidence of Adult Abuse in Ireland Red C October 2020 <https://63273-593977-raikfcuaxqncofqfm.stackpathdns.com/wp-content/uploads/2020/10/Incidence-of-Adult-Abuse-in-Ireland-during-COVID-19-5.10.20-FINAL.pdf>

²² National Safeguarding Office, Annual Report 2019, <https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/national-safeguarding-office-annual-report-2019.pdf> p.40.

²³ 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/> .

vulnerable on account of any disability at any stage of their lives need State protection in much the same manner as children and yet the State has failed to provide this to date.

While the Domestic Violence Act 2018 did introduce a new offence of “coercive control” it limited the offence to where the perpetrator and victim are related to one another as spouses of partners only. It therefore does not cover situations where the coercive control is by an adult child or sibling over the vulnerable adult. This urgently needs to be rectified so that the offence of coercive control is extended to all relationships.

While it is likely that the majority of persons supporting people to manage their finances act out of a genuine caring disposition and in good faith, there is an increasing awareness and evidence of the financial abuse of vulnerable adults which has been documented in research.²⁴

Specific issues relating to Article 16 regularly highlighted in Sage Advocacy casework refer to coercive control exercised by relatives over vulnerable adults, for example, people not being allowed to have access to or manage their social welfare payments, and people being isolated in their home environment and not given access to people from outside their home.

The agency system for receipt of social welfare payments for people unable to do so themselves is far from satisfactory. It is noted that the Department of Social Protection is in the process of reviewing and revising the general use of agents for receiving the State payments of adults who may be vulnerable to financial abuse. To this end, a Working Group was established to examine and make recommendations on the adequacy of the current procedures and processes.²⁵ The Group is assessing the implications for processes and procedures for agent arrangements in the context of the ADM Act 2015 and the Codes of Practice being developed by the National Disability Authority under the Act. Sage Advocacy believes that greater regulation of the social welfare payment agency system is urgently required.

²⁴ Safeguarding Ireland Report <https://www.safeguardingireland.org/wp-content/uploads/2018/10/the-national-safeguarding-office-report-2017.pdf>

RED C Poll National Public Opinion Survey in relation to Vulnerable Adults in Irish Society <http://familycarers.ie/wp-content/uploads/2017/06/Red-C-Survey-Vulnerable-Adults-in-Irish-Society-060417-1.pdf>

Fealy, G., Donnelly, N., Bergin, A., Treacy, M.P., Phelan, A. (2012) Financial Abuse of Older People: A Review, NCPOP, University College Dublin. <https://www.safeguardingireland.org/wp-content/uploads/2018/10/Financial-Abuse-Older-People--A-Review.pdf>

²⁵ See <https://www.gov.ie/en/publication/3f6bc5-safeguarding-vulnerable-adults/>

Article 19 – Living independently and being included in the community

Ireland Draft Report: Key points

The Ireland Draft Report states that a significant number of actions committed to under the National Disability Inclusion Strategy address the provisions of Article 19. Overall, under Article 19, the Ireland Draft Report is forward looking as distinct from reporting on progress made to date.

The Report identifies *Time to Move on from Congregated Settings – a Strategy for Community Inclusion* (2011) as the primary policy to enable people to move from congregated settings to their own homes in the community with the support they need. The policy set a target of closing all institutions with a move to community living in 7 years (by 2018). At the time there was slightly over 4,000 people living in institutions, this target has now been missed and the report states that the number of people in congregated settings has reduced by 2,146 since the strategy was introduced i.e. a little more than half of the target.

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 2019²⁶. Of these, 65% were aged between 18 and 59 years of age with many having spent a very considerable period of their lives in congregated settings.

It is important to note the language of the Report - “the number of people in congregated settings has reduced” as this does not exclusively encompass moves to the community but all movements including transitions, deaths, emergency admissions and other discharges and transfers.²⁷

The Ireland Draft Report points to what the challenges were in implementing “Time to Move On”, including delays in the process, sourcing additional funding schemes and the increasing costs of properties.

Other points included in the Draft Report do not represent progress *per se*, but indications of actions such as the putting in place of a National Housing Strategy for People with a Disability 2011-2016, an extended timeline for the strategy to allow further opportunity for its outcomes to be delivered and a post-2020 review of the strategy (currently being undertaken).

The Ireland Draft Report discusses the supports needed to live independently and the references the Task Force on Personalised Budgets (Paragraph 246). This Task Force was established in 2016 and reported in June 2018. The Draft states that that a pilot programme was initiated in 2019 and will run up to the end of 2021. While the Ireland Draft Report

²⁶Time 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>

²⁷ *Ibid.*

states that the National Disability Authority is evaluating the project, there is no timeline given for this review. (It is over 5 years since the Task Force on Personalized Budgets first engaged on this policy matter).

Surprisingly, given the critical importance of independent living and the need for supports commensurate with this, the Ireland Draft Report is relatively short in relation to Article 19. It focuses largely on describing initiatives that have been put in place to meet the housing needs of people with disabilities with little focus enabling independent living. The section on “enabling and supporting community living” (Pars. 241-246) focuses largely on general provisions to support people with disabilities in the community. 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 transport²⁸, all of which are reflected in Sage Advocacy’s casework as barriers to community inclusion.

The UNCRPD Committee has stated that often, people with a disability “cannot exercise choice because there is a lack of options to choose from”.²⁹

Sage Advocacy casework shows the important role that informal care and support plays in facilitating independent living. In instances where family support falls down, e.g. because of illness or death of a primary carer, the only option available is institutional care. The Ireland Draft Report makes scant reference to family support in relation to Article 19 and to supporting people to live independently. It simply recognises (Par. 406) the “valuable contribution of carers who care for family members, relatives and friends... [and] seeks to support those who provide care through the actions outlined in the National Carers’ Strategy.”

Article 19: Issues identified through Sage Advocacy casework

The impact of the failure to commence the ADM Act 2015 results in individuals not being facilitated and supported to make their own decision about where to live, particularly, where there is a perception of risk. The UNCRPD Committee has pointed out that a failure to recognise legal capacity is a barrier to Article 19 implementation.

As already noted, Sage Advocacy casework repeatedly highlights the fact that when basic public services are unsuitable or unavailable, community inclusion becomes more difficult. The realisation of Article 19 depends on the availability of basic public services which are available and accessible to all. This is not currently the case. Also, relevant is the dearth of suitable and supported housing options. The latter are frequently not available which results in people either having to go to residential care facility or remain there despite a clearly expressed wish to live in the community.

²⁸ 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> ps. 3-4.

²⁹ *Ibid.* p. 7.

The absence of adequate Personal Assistance (PA) services referenced in Article 19 is a significant barrier to independent living. It is also the case that PA services are not adequately distinguished from home help and other support services. Clearly, there are people with a physical or sensory disability who do not require social care support but who do need assistance with living independently.

Article 22 – Respect for privacy

The Ireland Draft Report notes (Pa. 271) that HIQA has issued a Privacy Assessment Impact Toolkit specifically for the health and social care sector. It also notes that HIQA's National Standards for Residential Services for Children and Adults with Disabilities include standards for the protection and respect of the privacy of service users. HIQA monitors adherence to privacy standards in residential disability services as part of its role in the monitoring, inspection and registration of designated centres for adults and children with a disability.

Breaches of Article 22 identified through Sage Advocacy casework

Through Sage Advocacy's work, we have encountered issues and situations that are not respectful of the right to privacy. These have included decisions concerning a patient or a service-user being discussed with a relative and their views taken into consideration as distinct from the patient's own view as well as information about a patient gathered from patient's relative without consent and subsequently used in decisions which were contrary to the person's wishes.

In one case, a Sage Advocate was denied access to client in the nursing home to deliver private & confidential information - instead, staff advised that a member of staff or a family member would read the correspondence to client.

Other matters relating to privacy from Sage Advocacy's case work include;

- A person's access to inheritance funds delayed by solicitor apparently at a relative's request and in accordance with the relative's wishes as opposed to person's own wishes.
- Nursing Home staff not respecting client's privacy such as a denial of a key to lock the room while not in the room and, more generally, by entering their room without knocking at the door at all or by knocking, but not waiting for a response from the residents.
- Nursing home staff not respecting privacy regarding resident's correspondence by allowing family member to intercept correspondence, sometimes under the excuse of "not upsetting/confusing them".
- Nursing home staff interfering with and accessing resident's correspondence, either at the instruction of resident's next-of-kin and/or by offering to read correspondence for residents rather than supporting them to access the necessary aids to read correspondence themselves.
- Nursing home staff being present during resident's consultations with their GP, instead of allowing for privacy or asking the resident for consent to same.

An issue that has emerged through Sage Advocacy casework refers to photographs of residents published publicly, including on social media, and in some specific instances to be linked to opportunities for advertising goods and services to the general public. While residents may agree with their photograph being taken in the moment, there is often no evidence of consent from the residents themselves for the purposes that the photographs are eventually used. Through our work, Sage Advocacy understands that on some occasions, residents were pictured with props which might not have been chosen by them, or that they have been asked to display various written messages without any evidence that this was their wish or that they understood the wider implications.

Article 25 – Health

Breaches of Article 25 identified through Sage Advocacy casework

The Ireland Draft Report (Par.327 refers to the fact that one of the themes of the NDIS focuses government action on health and wellbeing for persons with disabilities, in order to ensure that they are supported to achieve and maintain the best possible physical, mental and emotional well-being. This is important for people with disabilities as is the description of the various initiatives being taken to improve health outcomes for all.

In considering the implementation of Article 25, Sage Advocacy takes the view that health must be broadly interpreted to include social care since the latter is a critical determinant in the health of people with disabilities or adults who are otherwise vulnerable. Issues relating to Article 17 (protecting the integrity of the person) are included on commentary on Article 25.

The ongoing systemic failure to provide integrated health and social care services for individuals with multiple disabilities/health issues is a major shortcoming of health and social care policy. An example of lack of service integration is the fact that disability funding is cut off at age 65 necessitating that people transfer to older person's services which sometimes does not meet their needs.

Access to health and social care services: Issues identified through Sage Advocacy casework

- Adults aged under 65 with a disability or illness resident in a nursing home because their care and accommodation needs could not be met in the community.
- Long-term residential care the only option offered on discharge from hospital.
- People being placed in a nursing home setting for rehabilitative or respite care indefinitely because of lack of proactive engagement in marshalling the necessary supports for the person to return home.
- Shortage of qualified professionals to assess, support, assist and care for individuals with ongoing or developing health and social care needs in the community.

- 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.
- Lack of statutory right to home care and a lack of qualified, appointed and available health and social care professionals.
- Lack of appropriate community infrastructure in place for adults with evolving care needs to remain in their communities or access services.
- Lack of a comprehensive, integrated and standardised needs assessment.
- HSE Safeguarding Social Workers not engaging with referrals for individuals in private nursing homes.
- Physiotherapy having to be paid for privately by residents in private nursing homes when available free in public nursing homes.
- Lack of services for parents of children with disabilities who have to fight for basic services on behalf of their child.
- Significant differences in the availability of services and waiting lists across the country.
- Minimal access to Personal Assistant (PA) service and lack of differentiation between home care supports and PA services.
- Inadequate respite and day care services for adults with an intellectual disability.
- Ageing parents having to provide care for adults and advocate for services and future-planning.
- Absence of integrated planning for future care for adult children with a disability (a significant concern for ageing parents).
- Difficulties in putting in place adequate supports to discharge a person home from hospital resulting in residential long-term care being the only option offered.

Based on the above factors, it is reasonable to suggest that equal access to free and affordable health care is not being provided to all citizens equally.

Article 28 – Adequate standard of living and social protection

Sage Advocacy notes that organisations working with people with disabilities have 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.³⁰

Addressing the issue of the cost of disability is linked intrinsically with equality of access. Budget 2019 announced funding for research into the cost of disability and in June 2019, Indecon International Consultants were commissioned to carry out the research. In October 2020, a confidential survey was launched. However, there are no further updates on the gov.ie website about this important research and while the Ireland Draft Report

³⁰ It is noted that research on this issue has been commissioned by the Department of Social Protection.

confirms that the research is underway, it states that “it is expected the research, when complete, will provide a roadmap to inform policy direction in the future”, without a clear timeframe for the completion of the research or the implementation of the policy.

Issues identified through Sage Advocacy casework

- Failure to provide for additional costs associated with having a disability.
- The Nursing Home Support Scheme (NHSS) leaves people whose only income is the Non-contributory State Pension with inadequate personal income.
- The lack of person-centred supports in practice resulting in all people living in the same care setting receiving generalised services.
- The use of joint bank and post-office accounts controlled by a relative meaning that access to personal income is curtailed.
- Additional financial burden on spouse/partner of person with disability to maintain household when one enters long term care under NHSS application, and no allowance for this is included in the financial assessment.
- Inadequate facilities and equipment in private nursing homes leading to additional costs for person with a disability.
- Financial abuse by some agents of social welfare payments.

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

Issues identified through Sage Advocacy casework

Sage Advocacy is particularly concerned about people in nursing homes and who 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.
- For some people in residential care, whose sole source of income is the Disability Allowance or an Old Age Pension, the income left after paying social charges, is barely sufficient to cover the cost of toiletries, prescription fees, medication and other necessary items – therefore, any expenditure relating to sports/ cultural/ recreational events remain out of reach.
- Some people with a disability have their funds managed by their families, who might not see any value in person attending social and cultural events.
- The requirement by nursing homes that someone accompany resident on any trips outside of nursing home affects those without external informal supports - if they do

not have a family member/friend, they must pay for a carer to accompany them – the services of such a person may not always be available or affordable.

Article 33 – National implementation and monitoring

Sage Advocacy’s overall view is that there are many laudable and developmental strategies in place which have been referenced in the Ireland Draft Report. As a general observation, it is reasonable to suggest that these strategies and initiatives are very strong on aspiration but very weak in terms of actual implementation, particularly in relation to outcomes for and positive impact on end users. The issues highlighted throughout this submission paint a stark picture. In reality, for many people with disabilities and other vulnerable adults, the ratification by Ireland of the UNCRPD has made no meaningful difference in their lives.

Section Three

Overarching Considerations

Failure to fully adhere to the UNCRPD provisions is having a significant negative impact on persons with disabilities – their overall quality of life, their general wellbeing and their mental health. Some Sage Advocacy clients with a disability state that they feel that they have been ‘dumped’ into nursing homes unnecessarily and against their will. In some instances, there is clear deprivation of liberty. While the position of those vulnerable adults who have managed to get support from an independent advocate may improve somewhat as a result of an advocacy intervention, there are many whose situation cannot be changed due to a combination of resource issues, outdated thinking in relation to people’s right to choose and coercive control, the latter by relatives.

The policy of de-congregation for people with disabilities and people with mental health difficulties who have extra support needs often fails because people are not provided with an appropriate support infrastructure in the community.

A centrally important issue is the delayed commencement of the Assisted Decision-Making (Capacity) Act 2015. The voices of people with disabilities and adults who are otherwise vulnerable is frequently not being heard. Sage Advocacy experience is that, in some instances, a vague understanding of a lack of decision-making capacity and an overly cautious approach to risk-taking is being used to block a person asserting and acting on their will and preferences.

Related issues include lack of suitable assisted or supported living accommodation, lack of suitable technology to assist people with disabilities to remain living in their own home. Frequently, it is the case that the easiest option is the only one seriously pursued, *viz.* placing a person in a nursing home and telling them that there are no suitable alternatives available. Regrettably, under the current long-term care and support system in Ireland, the latter is the case. As already stated, the long-term care and support structure which currently exists in Ireland is fundamentally at odds with UNCRPD provisions.

The lack of a universal standard of service is particularly evident in the area of consent. It is the experience of Sage Advocacy that the National Consent Policy is not always followed by

health and social care professionals and that there continues to be a lack of awareness of human rights. People with disabilities are not equally treated specifically in the area of choice, autonomous decision making and the right to take personal responsibility for risk.

Another issue that undermines UNCRPD rights is that some services (for example, Personal Assistance) tend not to be even envisaged if the disability is acquired after age 65. In this regard, it is noted that the 2019 Report of the UN Special Rapporteur on the Rights of Persons with Disabilities makes some very relevant points³¹. As that report states, the UNCRPD applies to disability experienced at any age but medical definitions and approaches dominate international discussions of ageing, with older people still largely perceived as “mere beneficiaries of care and welfare”.³² The Special Rapporteur states that the fragmentation of policies for older persons and for persons with disabilities results in the “invisibility in law and in practice of experiences of disability in later life”³³ and that “human rights violations against older disabled people are often neither monitored nor categorised as such”.³⁴

Independent advocacy is regarded by Sage Advocacy as at the very core of safeguarding and protecting people’s human and legal rights and their dignity and thus essential to UNCRPD implementation. Independent advocacy is particularly important where people are made vulnerable because of place of residence or a lack of trusted relatives or networks characterised by trust, honour and integrity and, even more so, for people who have reduced decision-making capacity. There is no current effective mechanism to compel service providers to support people with disabilities to exercise their autonomy and to access an independent advocate which is a requirement under HIQA Standards.³⁵

Independent advocacy has been described as a practice without context or a legislative base.³⁶ This matter is not addressed at all in the Ireland Draft Report. Legislative provision needs to be made for the practice of professional independent advocacy, particularly in relation to commencing the ADM Act 2015. Indeed, it is chastening to note that 25 years ago the 1996 Report of the Commission on the Status of People with Disabilities, *A Strategy for Equality*, recommended that authority for independent advocacy should be set out in legislation and that access to an advocate should be a legislative entitlement, where necessary to ensure access to justice or access to essential social services.

The Mental Health Act 2001 provides for a person to be appointed independent legal representation in the review process of involuntary detention.³⁷ This narrow construction of advocacy was criticised at the time by the Forum of People with Disabilities who argued

³¹ United Nations (2019) *Report of the Special Rapporteur on the rights of persons with disabilities: General Assembly 74th Session. (A/74/186, 17 July 2019)* <https://undocs.org/en/A/74/186> p.5.

³² *Ibid.* p.7

³³ *Ibid.* p.5

³⁴ *Ibid.* p.10

³⁵ Sage Advocacy notes that the NAS has sought legislation to give NAS statutory powers of access.

³⁶ See <https://www.safeguardingireland.org/wp-content/uploads/2018/10/Advocacy-Scoping-Document-Final-310818.pdf>

³⁷ Section 16(2)(b), Mental Health Act 2001

for a broader approach to advocacy and suggested that advocacy should be a legislative entitlement for all vulnerable individuals in society, not just people with mental health difficulties.

The context and the dynamic have changed radically in the past decade with the publication of the UN Convention on the Rights of Persons with Disabilities and the development of a related policy emphasis on the rights of people with disabilities at international and national levels. The Assisted Decision-Making (Capacity) Act 2015 was a watershed in the Irish context. In relation to advocacy, it makes provision for the Director of the Decision Support Service to prepare and publish a Code of Practice (or approve of a Code of Practice prepared by another body) for the guidance of persons acting as advocates on behalf of relevant persons. The Adult Safeguarding Bill 2017 made provisions for adults at risk to have access to an independent advocate (Adult Safeguarding Bill 2017, Section 12). However, as already stated, that Bill fell with the dissolution of the 32nd Dáil in January 2020. Sage Advocacy welcomes the fact that the Legislative Programme for Spring 2021 includes a Health (Adult Safeguarding) Bill – however, as already stated, this is narrow in scope.

It is noted in the Ireland Draft Report (Par.195) that “The Law Reform Commission developed an Issues Paper on A Regulatory Framework for Adult Safeguarding”. Sage Advocacy understands that the Law Reform Commission intend to report on this matter in early 2022 and that this report will contain crucial recommendations for reform.

Sage Advocacy is of the view that new legal provision for an independent advocacy service is essential for the State to comply with the requirements of the UN Convention and the Assisted Decision Making (Capacity) Act. An independent advocacy service with statutory rights and provision for more proactive investigative mechanisms is clearly necessary, particularly to ensure that people with reduced decision-making capacity residing in institutions and congregated care settings (whether public, private or charitable) are informed of their legal rights and assisted in accessing them.

An advocacy service with statutory rights would also be important to underpin the practice of non-instructed advocacy where an advocate acts independently of the individual. This is necessary in some cases as an individual’s decision-making capacity may be significantly reduced as a result of reduced cognitive functioning and they may not be able to give consent to an advocacy intervention. Safeguarding often demands that independent advocates must intervene in order to ensure that those responsible for the care of such individuals are at all times guided by the legal and human rights of vulnerable adults in their care. This is essential in order to fully implement UNCRPD provisions.

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