



**Submission**

**to**

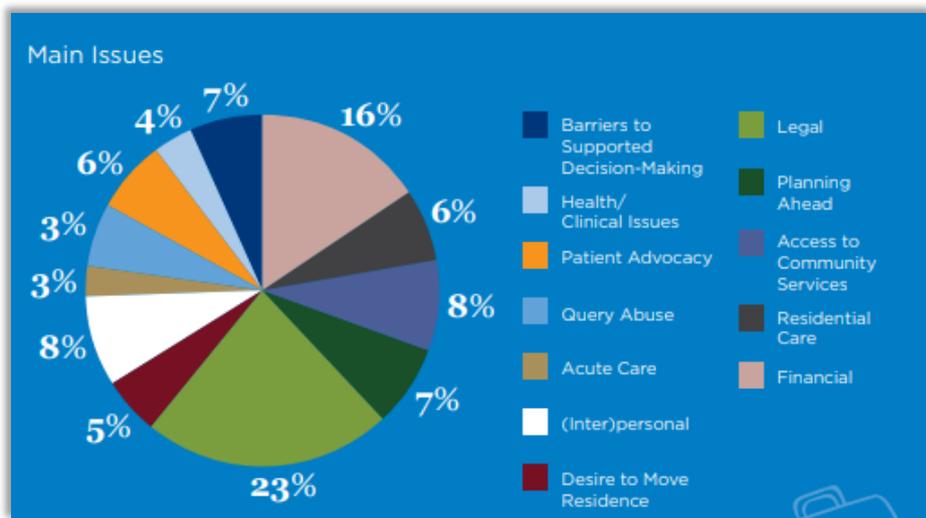
**The Joint Committee on Disability Matters**

**13<sup>th</sup> November 2020**

## About Sage Advocacy

Sage Advocacy is a support and advocacy service for vulnerable adults, older people and healthcare patients. Our mission is to promote, protect and defend the rights and dignity of the people we represent.

Sage Advocacy conducts its work through a core of paid staff with trained volunteers who work directly with individuals who need our support. Sage Advocacy also engages in systemic advocacy as directed by our case work. We provide information and support by telephone and email and we receive thousands of calls every year. The primary enquiries centre around legal or financial matters, but barriers to decision-making and access to community services also feature strongly as illustrated in the table below.



Many of the people that Sage Advocacy work to support find themselves in a very vulnerable situation and as a result, much of our work centres on cases involving safeguarding. In some cases, action is initiated to make the person a ward of court and Sage Advocacy has seen an increased use of the wardship system, notwithstanding the enactment of the Assisted Decision-Making (Capacity) Act of 2015, which we refer to later.

The current Covid-19 crisis has also made obvious the fault-lines in our care system with an over-reliance on congregated models of care leading to damaging outcomes for many of our citizens.

Sage Advocacy is grateful for the opportunity to make a short submission to the Joint Committee on Disability Matters. Sage encourages the committee to take a broad view on disability and to ensure that older people with disabilities are part of the committee's considerations.

The UN reports that more than 46 per cent of older persons – those aged 60 years and over—have disabilities and this is also recognised in the UN Convention on the Rights of Persons with a Disability (UNCRPD) which requires State Parties to provide health services needed by persons with disabilities designed to minimize and prevent further disabilities, including among older persons. Additionally, access by older persons with disabilities to social protection programmes and poverty reduction programmes is to be assured by States parties.

Similarly, the matters that affect the lives of all people with a disability cut across all factors of life and we encourage the committee to examine the health, well-being, financial and justice matters, some of which we include in our brief submission.

### **The UN Convention on the Rights of Persons with Disabilities (UNCRPD)**

It is a welcome development that this Committee has been established to consider all disability matters including monitoring the implementation of the United Nations Convention on the Rights of People with Disabilities. The UNCRPD, and the associated monitoring mechanisms, has the potential to ensure equality for people with disabilities, including older people with life-long or acquired disability or decision-making capacity problems.

In 2018, Sage Advocacy welcomed the State's action to finally ratify the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This ratification came after an 11-year delay as government stated that as a dualist state, we were required meet the obligations assumed under the terms of an international agreement from the moment of its entry into force for Ireland and cited preparatory work that was needed to meet this commitment. Having delayed for this reason, it is particularly important that Ireland is seen to have progressed matters that may not be in compliance, particularly as the State goes into a monitoring phase.

The UNCRPD has adopted a broad categorisation of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. Sage Advocacy would urge the Joint Committee to fundamentally 'unpack' disability and the terminology and categorisations used which results in de-personalisation and undermines the principles of autonomy, self-determination and self-realisation which are often cited in discourse on disability policy.

Similarly, the UNCRPD takes a broad social view across the life course of people with a disability and the committee should examine not just matters pertaining to health but also justice, social protection, housing, employment and culture. The Committee could usefully focus on how to create a climate whereby society generally (as distinct from relatives and service providers) takes greater responsibility for supporting and including people with disabilities.

The Convention sets out an essential role for civil society, in particular persons with disabilities and their representative organizations, to be involved and participate fully in the monitoring process and Sage Advocacy asks that consultation across the broad spectrum of people with a disability in Ireland takes place, including older people with a disability.

### **Advocacy & the UNCRPD**

The UNCRPD sets out the need to promote and protect all persons with disabilities. Advocacy, both legal and non-legal, can be an essential tool in accessing and realising human rights and is an essential function in a democracy<sup>1</sup>. While the Convention does not specifically mention advocacy, the preamble does include reference to support with specific reference made to individuals who may need more intensive support.

Another specified aim of the Convention is to “promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information”<sup>2</sup>, “support they may require in exercising their legal capacity”<sup>3</sup>, “age-sensitive assistance and support to prevent all forms of exploitation, violence and abuse”<sup>4</sup>

There is a need to support the voice of people with a disability, in particular intellectual disability where frequently their participation in decision-making is non-existent or tokenistic. Sage Advocacy research<sup>5</sup> found that independent advocacy was not integrated into services and that while people with intellectual disability have experienced increased efforts to facilitate rights, social inclusion and social integration, a number of issues persist, in particular in relation to ensuring choice and control.

### **Assisted Decision-Making (Article 12 – Equal Recognition)**

When it was enacted, the Assisted Decision-Making Act 2015 was seen as a major missing piece of the jigsaw in Ireland’s progress to ratification of the UNCRPD and an important aspect of guaranteeing people with a disability the right to enjoy legal capacity on an equal basis with others in all aspects of life.

While Ireland enacted this law in 2015, it has only partially commenced, with the Lunacy Regulation (Ireland) Act 1871, a Victorian-era law that underpins the ‘wards of court’ system, remaining in force. Once commenced, a review of existing wards of court must take place, but as this is within a 3-year time frame that means that Ireland will still have people living as ward of court for the next number of years and will not be compliant with Article 12 in relation to those individuals.

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<sup>1</sup> Kinlen, L. (2013), ADVOCACY & AGENDA SETTING

<sup>2</sup> Article 9.2.f

<sup>3</sup> Article 12.3

<sup>4</sup> Article 16.2

<sup>5</sup> Phelan A. & Meighan E. 2017 ‘The need for my voice to be heard’ Citizen Advocacy Project

The Joint Committee should also ensure the enactment of the promised amendments to the Assisted Decision-Making (Capacity) Act 2015, to provide that the wardship court in reviewing the capacity of each ward must give effect to the Guiding Principles as contained in Section 8 of the 2015 Act and that a ward participating in such review shall qualify for legal advice similar to that already provided for a relevant person under Part 5 of the Act.

The Joint Committee should consider the urgency for the full commencement and removal of remaining barriers to the Assisted Decision-Making (Capacity) Act as a key pillar of its work so that Ireland can be satisfied it is working towards Article 12 compliance.

Research by Sage Advocacy looked at the readiness for the assisted decision-making system and pointed to a need for additional education and training to ensure understanding of the implications of the 2015 Act and any liberty protection safeguards<sup>6</sup>. Sage advocacy suggests that the Joint Committee could consider the training needs of a wide group of stakeholders.

### **Liberty Protection (Article 12 and Article 14 - Liberty and security of person)**

Sage Advocacy has highlighted the de facto detention and potential deprivation of liberty experienced by people in various care and residential settings and while the listing of the “Protection of Liberty Safeguards” Bill on the most recent legislative programme is welcome, that the heads are merely in preparation indicates that this will not be conducted in as urgent a manner as is required. The legislation must be prioritised and must comply with the UNCRPD.

Ireland does not currently have any legislation, legal safeguards or procedures in place for a person who is being de facto detained in a care setting when their capacity is in question. This can be contrasted with the legal protections available to adults detained under the State’s Mental Health legislation. Through Sage’s advocacy work, we know that congregated care facilities are often secured by key code locks as a safety mechanism, meaning that those who reside there are essentially detained as they need to ask for permission to leave.

Similarly, Ireland does not have any legislation on the use of chemical restraint for non-therapeutic purposes. Through Sage Advocacy’s work, we have seen the use of sedation purely for the management of a person’s behaviour within care settings, without independent monitoring or review.

Legislative safeguards and a right of complaint and investigation under the auspices of a competent independent authority are therefore urgently required to ensure that vulnerable adults are not subjected to chemical restraint.

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<sup>6</sup> ibid

## **Community Living and Care (Article 19 - Living independently and being included in the community)**

In its General Comment on Independent Living<sup>7</sup>, the United Nations CRPD Committee established the core elements of community living.

These were

- The right to legal capacity.
- Non-discrimination in accessing housing, including the elements of both income and accessibility.
- Facilitating formal supports so that informal support by families is not the only option.
- Access to basic mainstream services to achieve societal equality.
- Basic, personalised, non-shared and rights-based disability-specific support services and other forms of services.
- To use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.

As can be seen by the breadth of these core elements, the right to independent living can only be realised through the provision of not only suitable accommodation, but also the correct support that is rights-based and personalised.

Unfortunately, in Ireland, much of our provision of care is based on congregated models. Through Sage's work, we have seen the lack of accessible suitable care and support which can result in adults who may be vulnerable due to an intellectual disability and who are ageing, being transferred from one institution to a new institution which focuses just on geriatric care. The result is often the loss of previously available supports and services, continuity of service, and familiarity with surroundings essential to ensure a good quality of life.

Overall, there is an overreliance on long-term residential care, particularly through private providers, which may not be the individual's preferred choice. The lack of alternative flexible models of care to respond to a person's individualised needs and quality of life considerations to enable a person to live with dignity according to their wishes means that Ireland may not be in compliance with Article 19.

As a society, we are ageing and we need to urgently address how we are going to achieve sustainable funding for long-term support and care funding. Sage Advocacy has called many times for a political roadmap for long-term support and care financing and we ask the Joint

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<sup>7</sup> Committee on the Rights of Persons with Disabilities General comment No. 5 (2017) on living independently and being included in the community CRPD/C/GC/5

Committee considers this in their work, feeding into the Commission for Care promised in the plan for Government.

As well as the lack of choice for older people, Sage Advocacy has ongoing cases working with people who are under 65 and are receiving care in a Nursing Home due to a lack of alternative care options. In many cases, the requirement for care comes about following a major trauma such as immediate changes to life circumstances, loss of independence, adapting to a cognitive and/or physical impairment, loss of livelihood and the impact extends to a person's family and supports who also experience dramatic changes to their lives.

A lack of appropriate care and supports to enable a person to live a life with dignity in a place of their choosing can interfere with their right to health, right to liberty, right to an adequate standard of living, and the right to live with dignity and the right to autonomy. Options for long-term care and support for this cohort is through the Nursing Home Support Scheme for care in a congregated setting or through the Home Support Scheme.

It is estimated that 1,600 people a year in Ireland experience major trauma. A submission from the National Rehabilitation Hospital to the Department of Health on Home Care Supports noted that the 15-20% of beds in the hospital are routinely not available due to delayed discharges and 50-70% of these are as a result of lack of appropriate home support.

Sage had previously called for a dedicated funding stream for care and support for people who have experienced life changing traumatic events.

### **Safeguarding (Article 16 - Freedom from exploitation, violence and abuse)**

Article 16 asserts a right to freedom from "all forms" of abuse and this includes mental and physical violence, sexual abuse, financial abuse, neglect and negligent treatment, and inhuman or degrading treatment.

Recent research by Safeguarding Ireland<sup>8</sup>, found that 12% of adults have experienced abuse since the start of the COVID-19 pandemic in March, while one third (32%) of adults report abuse during their lifetime. The HSE National Safeguarding Office reports a year on year increase in safeguarding concerns, with their most recent reports showing a 14% increase in 2018 and a further 11% increase in 2019<sup>9</sup>

It has been clear that Ireland needed to put in place Adult Safeguarding Legislation and the Adult Safeguarding Bill (2017) was introduced to establish the National Adult Safeguarding Authority. Unfortunately, the bill fell with the Oireachtas in March 2020.

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<sup>8</sup> Red C / Safeguarding Ireland, Incidence of Adult Abuse in Ireland, October 2020

<sup>9</sup> National Safeguarding Office Annual Report 2018 / 2019

The recent legislative programme<sup>10</sup> indicates that preparatory work is underway on a Health (Adult Safeguarding) Bill to “underpin a planned national health sector policy on safeguarding vulnerable or at-risk adults in the context of their interactions with the health sector”. While progress on legislation is welcome, that it is limited to the health sector and only at preparatory stage is concerning. Sage Advocacy asks the Joint Committee to ensure that adult safeguarding, across all aspects of life, is considered in the work plan.

There is also a role for the Committee to take a look into the role of the public / society in ensuring that people with a disability and in particular people with intellectual disability are safeguarded and protected from all forms of exploitation and abuse.

### **Social Protection and Poverty (Article 28 – Adequate standard of living and social protection)**

Article 28 of the UNCRPD is concerned with an adequate standard of living and social protection and requires States to “ensure access by persons with disabilities...to social protection programmes and poverty reduction programmes”.

Poverty is a significant barrier to the enjoyment of rights and an adequate income for people with a disability and older people should be a priority for government. Additionally, it has been long-established that people with disabilities face extra costs. The research into the cost of disability that is ongoing is welcome. However, it is essential that it examines the impact of the cost of disability on all people with a disability, including older people, and not just those in receipt of a disability allowance.

Additionally, Sage Advocacy has conducted research into the carer’s allowance system and believe that key reforms are needed in order to ensure that the rights of the person being cared for are protected. At present, the Carer’s Allowance system puts the primary emphasis on the carer rather than considering the care recipients’ will and preferences. The view of the care recipient is not central to the application process, nor are their views on the care they require and how they want it delivered as well as choice of care.

Sage Advocacy acknowledge the important role carers play in our society and asks the Joint Committee to consider a review of the role of the care recipient in the administration of the Carer’s Allowance system.

### **Conclusion & recommendations**

Sage Advocacy thanks the committee for considering its submission and wishes the committee well in its essential work. Ireland is at a crucial time in terms of our international reputation for how we treat our citizens who have a disability, having belatedly ratified the UNCRPD long after our European counterparts.

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<sup>10</sup> Programme for Government – Our Shared Future

Sage Advocacy asks that the Joint Committee considers the following in its workplan

- Ensuring that people with a disability are heard directly by the committee in the course of its work.
- Older people with disabilities in general are heard from as well as those from other diverse and minority backgrounds.
- Considering all aspects of social, cultural and economic rights in its deliberations and not just health.
- Considering the legislative and policy reforms required to ensure UNCRPD compliance, specifically
  - Commencement of the Assisted Decision-Making (Capacity) Act 2015.
  - Adult Safeguarding legislation.
  - Protection of Liberty legislation
- The need to examine the provision of care and the bias towards congregated models of care.
- Develop a political roadmap for long-term support and care financing.
- Exploring the suitability of congregated care for the under-65s or following a traumatic life event.
- Examining the role of society in constructing disability and the role society can play in greater social inclusion.
- Considering the training needs of stakeholders, in particular in relation to supporting decision-making and the need to fund and support self-advocacy initiatives.
- Ensure that the cost of disability research includes all people with a disability, including older people.
- Review the participation of the care-recipient in the administration of carer's allowance.

For further information contact;  
Sarah Lennon, Executive Director, Sage Advocacy,  
[sarah.lennon@sageadvocacy.ie](mailto:sarah.lennon@sageadvocacy.ie)  
087 9704942