

Regulation

Care

Rights

Developing an
Observatory
on Long-Term Care
in Ireland

A Human Rights Perspective

Support

Charges

Safeguarding

Governance

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Outline of Project Report

Chapter One outlines the background to the Project and the main objectives and underlying principles.

Chapter Two describes the methodology used in implementing the Project.

Chapter Three synthesises key human rights provisions relevant to long-term care.

Chapter Four outlines a number of selected Irish research findings relevant to human rights protection in the context of long-term care.

Chapter Five summarises relevant Sage Advocacy statistical data and identifies the main human rights issues emerging. It also sets out a number of key human rights issues identified by Sage advocates arising out of case management and processing.

Chapter Six describes a participatory research approach and how it could be used to capture the voice and experience of people in receipt of long-term care.

Chapter Seven identifies a number of overarching issues relevant to an Observatory on Human Rights in Long-term Care.

Chapter Eight sets out a proposed structure for a future Observatory on Human Rights in Long-term Care.

Chapter One: Introduction and Background to Project

Introduction

This Project, Developing an Observatory on Human Rights in Long-term Care, was funded by the Irish Human Rights and Equality Commission and carried out by Sage Advocacy during the period May to November 2022. Sage Advocacy provides advocacy support to adults living in vulnerable situations, older people and healthcare patients. Sage Advocacy's approach reflects a growing consensus that long-term care services should look beyond a purely medical model of 'care'. Instead, they should take a broader, more holistic view in which older people's well-being and quality of life and their preferences regarding support and care are central to the design of services, in line with existing human rights provisions.

In 2022, Sage Advocacy dealt with 1,506 advocacy cases and the Information & Support Service responded to 3,027 calls. Almost 40% of advocacy referrals related to people living at home, one-third to people in nursing homes and a quarter to people in hospital.

The Observatory on Human Rights in Long-term Care, once established and consolidated, is envisaged as having an ongoing role in monitoring long-term care in Ireland through an equality and human rights lens. It is envisaged in the first instance as contributing to the Commission on Care to be established under the current Programme for Government¹ by assessing and evaluating the current system of long-term care and making proposals for a more human rights attuned model in the future.

The need for an Observatory on Human Rights in Long-term Care has emerged from a number of Sage Advocacy reports and discussion papers² published in recent years which concluded that the current architecture of long-term care in Ireland is fundamentally flawed from a human rights perspective. Significant shortcomings of our long-term care system have also been highlighted in a 2022 Safeguarding Ireland Discussion Paper.³

Project objectives

The overarching purpose of the Project was to set out the core components of an Observatory on Human Rights in Long Term care – Terms of Reference and Modus Operandi. Related project objectives were to:

- Identify human rights provisions (international and national) relevant to people requiring long-term care and support;
- Identify the core human rights issues arising from the current system of long-term care provision in Ireland;
- Explore ways of capturing the “voice” of people using long-term care and support services.

Project underlying principles

The Project used the principles governing Sage Advocacy work:

- Protecting and promoting the rights of adults who are living in vulnerable situations;
- Promoting, facilitating and enhancing safeguards in relation to abuse and

exploitation in all its forms;

- Ensuring that the voice of the person requiring support is heard in matters affecting them - “nothing about you/ without you”;
- Promoting the full protection of people's right to liberty;
- Ensuring that care and support needed for the realisation of human rights is adequately provided at the appropriate level and within the most appropriate setting.

What is an Observatory?

The functions of an Observatory on Human Rights can include monitoring human rights through research and observation, publicising human rights issues, lobbying for change, and training and empowerment of marginalised communities. Human Rights Observatories use different methods to gather information and promote the realisation of human rights. For example, an observatory report documenting human rights violation in the Ukraine-Russian war uses methods based on commercial satellite imagery analysis and open-source investigative methods⁴. The Trinity College Covid-19 Law and Human Rights Observatory engaged in research across the full range of Ireland's legal response to the pandemic. Academics in the Observatory worked with research assistants to identify, aggregate, contextualise, explain, and analyse the legal components of Ireland's Covid-19 response with the aim of informing the public and to provoking public debate.⁵

Long-term care

Long-term care primarily includes assistance with activities of daily living (ADL), such as eating, washing, dressing, getting in and out of bed or using the toilet⁶. In addition, medical services, such as help with wound

dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care may be included. Long-term care involves not just health and social care but should also enable social participation and equality⁷. Long-term care can be provided at home, in the community, in assisted living facilities, or in residential care facilities. It can be formally provided (paid support) or informally provided (unpaid support).

Why an Observatory on Human Rights in Long-term Care in Ireland is important

People of all ages may require long-term care services, including some people with disabilities in younger age-groups and older people with a lifelong disability or those who require care as a result of, for example, dementia, stroke or frailty associated with the ageing process. While a future Observatory on Human Rights in Long-term Care is envisaged as including all adults requiring long-term care, the main focus of the Project was on the rights of older persons in nursing homes.

Most nursing home residents are aged 85 years or over and have complex conditions, with dementia and related reduced decision-making capacity affecting some two-thirds of the over 30,000 people living in nursing homes in Ireland at any given time.

Under current provision for long-term care in Ireland, in many instances, a nursing home is the only option available. This is due to the absence of adequate community and home-based care, and the shortage of supported housing options to enable ‘ageing in place’. While nursing homes should be places where residents feel safe, secure, cared for and protected, this may not always be the case.

The stark reality for nursing home residents came very much into focus with the onset of

¹ This Commission has not yet been established (May 2023)

² See in particular, Towards a Continuum of Support and Care for Older People: Choice Matters (2020), <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf> and Responding to the Support & Care Needs of our Older Population: Report of Forum on Long-term Care for Older People (2016), https://www.sageadvocacy.ie/media/1124/report_of_forum_on_ltc_for_older_people.pdf

³ Browne, M. et al. (2022), Identifying RISKS – Sharing RESPONSIBILITIES, https://www.safeguardingireland.org/wp-content/uploads/2022/05/6439-Safeguarding-Risks-Resp-Report-FA4_lowres.pdf

⁴ Yale Humanitarian Research Lab (HRL), <https://medicine.yale.edu/lab/khoshnood/projects/conflict-observatory/>

⁵ See Public Health Law During the COVID-19 Pandemic in Ireland, <https://www.tcd.ie/law/2020.21/COVID-19%20Public%20Health%20Law%20Report.pdf>

⁶ European Commission, Directorate-General for Employment, Social Affairs and Inclusion, Long-term care report: trends, challenges and opportunities in an ageing society. Volume I, Publications Office, 2021, https://data.europa.eu/doi/10.2767/677726_p.17

⁷ Katharine Schulmann and Kai Leichsenring et al., ‘WP8 Overview Report Social Support and Long-Term Care in EU Care Regimes: Framework Conditions and Initiatives of Social Innovation in an Active Ageing Perspective’. <https://www.euro-centre.org/downloads/detail/1523/1>

Covid-19. It is clear that the pandemic placed significant additional pressures on a long-term care system that was already under stress. The right of nursing home residents not to be exposed to a higher level of risk than if they lived in the community was negated in many instances. This raises critical questions about how the rights of people at the high end of the vulnerability and risk spectrum are protected. The Irish Human Rights and Equality Commission⁸ has referred to the need to develop community-based alternatives to institutionalisation with a right to live independently in the community, in accordance with Article 19 of the UN Convention on the Rights of Persons with Disabilities. This states that people should not be obliged to live in a particular living arrangement and should have the right to in-home, residential and community support services, including personal assistance, necessary to support living in the community.

The impact of the Covid-19 pandemic points to the need to radically address the role of institutionalisation in public policy on long-term care. This includes how care for older people with high dependency levels and other people who lack decision-making capacity is treated in public policy. By relying predominantly on nursing homes and other residential care facilities, we are depriving people of their right to liberty and their right to choose where they want to live. Alternative models of support and care may or may not result in higher costs but these costs are minimal compared to the psychological and social costs associated with our present system as evidenced in the Covid-19 experience.

There are a number of aspects of nursing home care that give rise to significant human rights' concerns:

- Many so-called voluntary residents in nursing homes are de facto detained and deprived of their liberty.
- There are clear safeguarding concerns associated with the prolonged isolation of people with high care needs in congregated settings with little connectedness with communities.
- The 'closed' nature of nursing homes makes it exceptionally challenging for either residents or staff to speak up and report abuse or inappropriate care.
- HIQA does not have the power to investigate specific issues relating to individual nursing home residents unless at the request of the Minister for Health.
- HSE Safeguarding and Protection Teams do not have an automatic right of access to private nursing homes.
- There continues to be a failure by nursing homes to comply with regulations as evidenced repeatedly in HIQA Inspection Reports.

It has been suggested⁹ that, since the *raison d'être* of services for older people is to improve their well-being, there is a related need to identify clearly and reflect the determinants of personal well-being in the way health and social care services are delivered. However, existing provision seems to be heavily influenced by an 'illness and disability' model of ageing, whereas a well-being model would be more inclusive of social factors such as community connectedness and social inclusion.

There is a very strong argument from a human rights perspective that the nursing home model as it currently exists in Ireland should become a thing of the past. We need a system of long-term care and provision which ensures that people are not inappropriately and unnecessarily 'placed' in nursing homes against their wishes. The appropriateness of congregated settings for older people requiring care and support needs to be fundamentally challenged from a human rights perspective.

The Irish public sector equality and human rights duty

Under Section 42 of the Irish Human Rights and Equality Commission Act 2014, all public bodies in Ireland have a legal responsibility to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans. The Public Sector Equality and Human Rights Duty (the Duty) is a statutory obligation on public bodies, in the performance of their functions, to have regard to the need to eliminate discrimination, promote equality of opportunity and protect the human rights of staff and service users. Section 42 requires public bodies to implement the Duty through a three-step process in the context of strategic planning and reporting:

- Assess:** to carry out an assessment of the equality and human rights issues relevant to their functions and purpose;
- Address:** develop policies, plans and actions to address issues raised in the assessment;
- Report:** report annually on progress and achievements in relation to identified policies, plans and actions.

The requirements have to be set out in the organisations strategic plan (assess, address) and reported on in annual reports (report) 'in a manner that is accessible to the public'. Public bodies should adopt an evidence-based approach, informed by equality data and targeted consultation with staff and

service users, particularly those from minority groups, to identify issues and actions and monitor progress.

Developing and implementing the Project

The Project analysed the existing policy discourse and research relating to human rights and applied this analysis to the domain of long-term care. This included not just health and social care but, also, broader issues of equality, social inclusion, safeguarding and right to self-determination. Areas where the human rights of people in Ireland who require long-term care and support were not upheld at all or only partially upheld were identified.

The Project explored how an Observatory on Human Rights in Long-term Care might work, viz.,

- What areas of human rights in long-term care would be observed;
- What methods of information gathering would be effective, accurate and sustainable;
- What structures of governance and funding would provide a realistic starting point for the future Observatory;
- How the 'voice' of people using long-term care and support services could be marshalled to inform the work of the Observatory.

The next chapter describes the methodology used in implementing the Project.

8 <https://www.ihrec.ie/app/uploads/2020/07/IHREC-Submission-The-Impact-of-COVID-19-on-People-with-Disabilites.pdf>

9 McKeown K. , Pratschke, J. and Haase, T.(2014), Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People, <https://www.sageadvocacy.ie/media/1562/individual-needscollective-responses-fourth-age-trust-0114.pdf>

Chapter Two: Project Methodology

Introduction

This chapter sets out the research methodology used to implement the project objectives which were targeted at providing recommendations for the establishment of an Irish Observatory on Human Rights in Long Term Care. In developing the methodology, particular attention was given to three inter-related components of a future Observatory: (a) identify key human rights issues relevant to current long-term care provision in Ireland; (b) develop an understanding of participatory methods to involve users of long-term care services in identifying rights issues; (c) identify Terms of Reference for a future Observatory and propose structures for same.

Key questions addressed by Project

The project sought to gain as extensive and accurate a picture as possible of the situation regarding how the rights of older people requiring long-term care were set out and implemented and to identify areas where rights infringements occurred and how the proposed Observatory on Long-term Care could help to address these infringements. The methodology used addressed the following questions:

1. What are the elements of a human-rights based approach to long-term care incorporating not just health and social care needs but broader issues of equality, social inclusion, safeguarding and right to self-determination?
2. What are the intersecting elements of a participatory approach to rights monitoring for a future Observatory.
3. What are the key human rights issues presented by the current system of long-term care in Ireland?

Research methods used in the project

Three main research methods were used and the related actions were carried out during the period April to October 2022.

1. Desk research
2. Analysis of Sage Advocacy statistical data
3. Consultation with Sage advocates and analysis of issues identified through the consultation
4. Consultation with other key informants

Research method 1: Desk research

The desk research had four overarching and interlinked components:

1. International and Irish human rights instruments relevant to people requiring long-term care (discussed in Chapter 3);
2. Research on rights infringements in Ireland in relation people in receipt of long-term care (discussed in Chapters 4 and 5);
3. Participatory research methods (discussed in Chapter 6);

International and Irish human rights instruments relevant to people requiring long-term care

The Desk Review examined the international, European and national legislative and policy frameworks relating to human rights in long-term care. The databases used to establish the legal and policy framework included JSTOR and Westlaw IE. References to human rights and older people, human rights and disability and general international human rights literature were used to build a picture of a human rights framework for people in long-term care. The review then explored the key themes identified by international organisations on human rights in relation to both long-term care settings and older people.

Research on rights infringements in Ireland in relation people in receipt of long-term care

The Desk Review explored the key issues in relation to human rights in long-term care in Ireland currently. Two main desk research methods were used for this purpose:

1. An analysis of selected research reports by Sage Advocacy and by Safeguarding Ireland;
2. An analysis of selected HIQA reports;

Research method 2: Analysis of Sage Advocacy statistical data

An analysis of Sage Advocacy statistical data was carried out. Two data reports on the period 01/07/2021-30/06/2022 collated by Sage Advocacy were provided to the Project team.

The first was a statistical dashboard. Information from this dashboard was used to gain a broad overview of the age breakdown, number of referrals, location of referrals and the primary reasons for referral to Sage Advocacy.

The second data report analysed provided summaries of cases where advocates identified systemic issues.¹⁰ This approach was selected on the basis that at least some of the key human rights issues relating to long-term care were likely to be related to systemic issues, e.g., lack of adequate supports to enable people to live in the community.

Research method 3: Consultation with Sage advocates

Sage advocacy cases were explored through consultation with Sage Advocacy personnel. This process focused primarily on cases where challenges to human rights realisation by people requiring long-term care were identified. Sage advocates were seen as being well placed to have a good insight into the landscape within which long-term support and care policy has operated to date in Ireland and its inherent shortcomings from a human rights perspective.

Research method 4: Consultation with other key informants

A consultative process with people with direct or indirect lived experience of long-term care was carried out. Consultees were identified through inquiries made following an on-line advertisement for members of a Project Reference Group. This resulted in people with experience of providing or receiving long-term care and/or a relationship with past Sage Advocacy events self-identifying. Digital literacy may have been a factor in people being able to self-identify. Also, due to project resource and time constraints, it was not possible to advertise and proactively promote a public consultation process in respect of establishing the Observatory. The following consultations took place:

- ✓ Ongoing consultation with the Project Reference Group (Project co-ordinator, Sage Advocacy staff, Sage Advocacy Board member, Sage Advocacy research consultant and a former HSE official) on:
 - o Implementing the project objectives
 - o Identifying key issues relevant to human rights and long-term care relevant to a future Observatory
 - o Addressing challenges in implementing the Project
 - o Recruiting people to 'test' participatory research methods
 - o Identifying ways of addressing the question of research ethics approval
 - o Developing Terms of Reference, membership and modus operandi for a future Observatory
- ✓ A Focus Group meeting with members of the Irish Independent Living Movement (ILM);
- ✓ Consultation with Directors of Nursing in a Residential Care Centre for People with Disabilities;
- ✓ On-line discussion with a nursing home provider senior manager;
- ✓ On-line discussion with a legal practitioner and former family carer;
- ✓ On-line discussion with the former HSE confidential recipient;

¹⁰ A systemic issue is understood by the Project as one that has or is likely to have a negative effect on a number of people and where, in an advocacy context, there are multiple referrals about the same issue.

- ✓ Publication of information about the Project on the Sage Advocacy website¹¹ and inviting responses from people with experience (directly or indirectly) of long-term care and inviting them to join the Project Reference Group – this resulted in a number of people with experience of long-term care making contact with the Project and joining the Reference Group.

Consultation meetings were also held with Sage Advocacy frontline personnel, a family carer and a person with lived experience of long-term care support services. This provided insights into information gathering techniques with reference to accessibility and practicality.

Challenges in implementing the methodology

Ongoing concerns about Covid-19 presented challenges in terms of consulting people who would be at a high risk from the pandemic and who would not be au fait with using digital platforms such as Zoom.

An important part of the Project as initially envisaged was to include participation of those with lived experience of long-term care and support services. Preliminary consultations with service providers and relatives of people in receipt of long-term care suggested that some people with experience of long-term care and support services would like to share their views on human rights issues arising from the current architecture of long-term care provision in Ireland.

While the Project initially envisaged ‘testing’ participatory methods with long-term care recipients and while protocols were developed for this purpose, it was not possible to complete this process for a number of reasons, including, in particular,

- Online promotional material did not result in any response from people in receipt of long-term care – lack of digital literacy may have been a factor here;
- A plan developed during the course of the project to carry out focus groups in residential care facilities could not be proceeded with because of the fact that the research ethics clearance required could not be got within the time frame that remained.

Exploration of participatory research methods

The Project explored the various intersecting elements that were considered useful for developing robust participatory methods to facilitate involvement by ‘hard to reach’ groups in a future Observatory.

A search of relevant academic databases was conducted using the following key phrases; participatory research, hard to reach communities, inclusive research, sampling for hard to reach communities, human rights monitoring research, participatory approaches in long-term care, older people and participatory research, legal capacity and research, ethical approval for research in health settings, ethical approval for research with vulnerable populations.

The Project then developed materials for evaluation by stakeholders and people with lived experience of long-term care. Literature reviewed for this purpose included accessible materials for participatory research in long-term care, easy-read guidance and barriers to participation in research for hard to reach communities.

Methods were evaluated for practicality and accessibility by a consultative meeting of people who have lived experience of long-term care and support services. A page was published on the Sage Advocacy website highlighting the participatory focus of the Project.¹²

As the Project progressed, it emerged that information gathering of this type comes within the definition of health research, and, therefore, comes within the scope of the Health Research Regulations (and under the relevant definitions of “research” and “health research” pertaining to these) and, therefore, would require ethical approval from a research ethics committee (REC). Since Sage Advocacy does not have an in-house research ethics committee, the option of applying to the HSE Regional RECs¹³ was explored given that they cover research carried out by HSE-funded services, including research carried out by external investigators. However, this proved not to be possible within the time frame of the project.

A key point that emerged from the Project experience was the need to build into the structure of a future Observatory mechanisms for dealing with this type of research, with particular reference to research ethics approval.

Another methodological challenge that arose related to the data reporting system used by Sage Advocacy where the reporting systems used pre-defined categories. This pointed to a need for a thematic framework to guide human rights monitoring by a future Observatory on Human Rights in Long-term Care.

Table 2.1 presents an overview of the research methods used by the Project, including the strengths and weaknesses of each approach and their implications for the functioning of a future Observatory on Human Rights in Long-term Care.

Table 2.1: Overview of research methods used

Research Method	Description	Strengths/ weakness of approach	Implications for the functioning of an Observatory on Long-term Care
Desk research 1: Human rights provisions and long-term care	Exploration of the dimensions of human rights provisions applicable in the context of long-term care provision.	Difficulty in identifying research or case law ¹⁴ on rights instruments being applied to older people in long-term care.	An inventory of rights relevant to people in long-term care will need to be drawn up and used by a future Observatory in its monitoring of policy and practice relating to long-term provision in Ireland.
Desk research 2: Rights infringements in Ireland in relation to long-term care provision	An examination of rights infringements in Ireland as reported by HIQA, Sage Advocacy and Safeguarding Ireland.	While highlighting the importance of rights provisions in policy and practice relating to long-term care, research has not for the most part benchmarked policy and practice against relevant rights.	Benchmarking long-term care policy and practice against basic rights provisions will be an integral part of the work of a future Observatory.
Desk Research 3:	Exploration of the domains and practice of a participatory research approach	Provided valuable information on the components of this process. It was not possible to test these in a practice environment	Collaborative research methods involving ‘hard to reach’ groups will need to be included as an integral part of a future Observatory.
Analysis of Sage statistical data	Two data reports on the period 01/07/2021-30/06/2022 collated by Sage Advocacy were provided to the Project: (i) A statistical dashboard; (ii) Summary report of cases where advocates identified systemic issues.	Information from the data reports was used to gain a broad overview of the age breakdown, number of referrals, location of referrals and the primary reasons for referral to Sage Advocacy.	The data reporting system used by Sage Advocacy uses pre-defined categories. This points to the need for a thematic framework to guide human rights monitoring by a future Observatory on Human Rights in Long-term Care.

¹¹ <https://www.sageadvocacy.ie/news/2022/july/a-new-research-project-to-give-people-who-experience-long-term-care-and-support-services-the-opportunity-to-have-their-voice-heard>

¹² <https://www.sageadvocacy.ie/news/2022/july/a-new-research-project-to-give-people-who-experience-long-term-care-and-support-services-the-opportunity-to-have-their-voice-heard>

¹³ See [RREC for Midlands Area and Corporate Division \(Regional Health Area B\) - HSE.ie](https://www.hse.ie/eng/health/research/research-ethics/research-ethics-committees/)

¹⁴ A notable exception to this was the Irish Supreme Court Judgement in the AC case (see Chapter 7 below).

Table 2.1 Overview of research methods used continued

Research Method	Description	Strengths/weakness of approach	Implications for the functioning of an Observatory on Long-term Care
Consultation with Sage advocates	<p>Establish the views and perspectives of Sage advocates in relation to:</p> <p>(a) Engaging long-term care recipients in participatory research;</p> <p>(b) Identifying rights infringements identified through Sage Advocacy casework and related data reporting;</p>	<p>Sage Advocacy works with many people in crisis situations. For the most part, clients have not to date been asked to become involved in research.</p>	<p>Sage advocates identified possible meaningful collaborative recruitment methods and provided feedback on resources and practicality of using the suggested methods and tools.</p> <p>This will be centrally relevant to a future Observatory.</p> <p>Methods of engagement appropriate in a casework situation may not be relevant in another context. This is a matter that a future Observatory will need to consider.</p> <p>The rights infringements identified by Sage advocates will form an important starting point for a future Observatory.</p>
Consultation with other key informants	<p>Exploring and refining ways of engaging people in receipt of long-term care and their carers in participatory research.</p> <p>Building on the experience of people using long-term care and support services to develop insights into information gathering techniques;</p> <p>A person with lived experience of long-term care support services joined the Project Reference Group.</p>	<p>A number of ways of monitoring human rights in long-term care services were identified;</p> <p>Ways of engaging long-term care recipients in research were identified. The hoped-for engagement by people in receipt of long-term care did not materialise – this was partly related to the challenge of getting research ethics approval within the project timeframe.</p>	<p>Engaging long-term care recipients in a participatory manner will present a significant challenge for the Observatory.</p> <p>The matter of research ethics approval will need to be addressed early on in the operation of a future Observatory; Consultative processes for a future Observatory will need to involve targeting people with lived experience of long-term care.</p>

The next chapter will discuss key human rights provisions and their applicability to people who require long-term care and support.

Chapter Three: International Human Rights Provisions: Implications for Long-term Care Provision

Introduction

This chapter describes the various international human rights instruments applicable to a rights-based approach to meeting the long-term care needs of older persons. It discusses some of the gaps in international human rights provisions as these apply to older persons. It also provides a synthesis of the provisions of the Assisted Decision-making (Capacity) Acts 2015 and 2022 which are centrally relevant to the protection of the rights of people whose decision-making capacity is in question.

What a human rights approach to long-term care involves

A human rights-based approach puts people with long-term care and support needs at the centre of the discourse, empowering them to participate in decision-making and to claim their rights. At the same time, a rights-based approach demands accountability from the State and from institutional actors who bear responsibility to uphold these rights.

The underlying principles of a rights-based approach have been summarised as:¹⁵

- The inestimable dignity of each and every human being
- The concept of autonomy or self-determination that demands that the person be placed at the centre of all decisions affecting him/her
- The inherent equality of all regardless of difference
- The ethic of solidarity that requires society to sustain the freedom of the person with appropriate social supports

A rights-based approach avoids the compartmentalisation of identities (viz. older persons, people with disabilities) and focuses on people in terms of the challenges and opportunities faced at each stage of the life-cycle rather than on people as members of ‘identity-groups’. A human rights approach does not contradict the reality of age-specific needs – on the contrary, a rights-based approach enables society to better meet needs, as required, while framing them within a human rights-based narrative.

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 points related to disability and ageing.¹⁶ 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”.¹⁷ 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”¹⁸ and that “human rights violations against older disabled people are often neither monitored nor categorised as such”.¹⁹

Despite the emergence of a strong human rights discourse, it is likely that ‘old people’ are often thought of as a burden, especially those who need high levels of support. This understanding of ageing is reflected in policy discourse which focuses primarily on the physical or decision-making ‘deficits’ associated with the ageing process, and on how these ‘needs’ should be met rather than on older people as bearers of human rights.

¹⁵ Quinn, G. and Degener, T. (eds.) with Bruce, A., Burke, C. Castellino, J., Kenna, P. Kilkelly, U., Quinlivan, S. Human Rights and Disability, United Nations, New York and Geneva.

¹⁶ 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.

¹⁷ Ibid. p.7

¹⁸ Ibid. p.5

¹⁹ Ibid. p.10

While disabled people have achieved a level of visibility through the UNCRPD, this may not be the case in relation to older persons with long-term care and support needs. The Council of Europe Statement on the Rights of Older Persons²⁰ urges Member States to provide for appropriate and effective safeguards to prevent abuse in all areas that relate to decision-making and the exercise of legal capacity of older persons, including possible restrictions which may be required for protection purposes.

Nils Muižnieks, the former Council's Commissioner for Human Rights, stated in a Human Rights Comment in 18 January 2018 as follows:

“Older persons have exactly the same rights as everyone else, but when it comes to the implementation of these rights, they face a number of specific challenges. For example, they often face age discrimination, particular forms of social exclusion, economic marginalisation due to inadequate pensions, or are more vulnerable to exploitation and abuse, including from family members.”²¹

The European Union Agency for Fundamental Rights 2018 Report²² dedicates its focus chapter to equal treatment for older people and respect for their fundamental rights. It recognises growing awareness of the issue and how policies are changing to better respect their rights. However, it advises against a one-size-fits-all approach as barriers faced by women, ethnic minorities and people with disabilities may be compounded as they age. This highlights the need to broaden protection against discrimination on the grounds of age through implementing the EU's Equal Treatment Directive²³ which extends anti-discrimination protection beyond employment to access to services, housing and healthcare.

The UN Open-ended Working Group on Ageing states that:

“Although the Universal Declaration of Human Rights proclaims that all human beings are born free and equal, it is evident that the enjoyment of all human rights diminishes with age, owing to the negative notion that older persons are somehow less productive, less valuable to society and a burden to the economy and to younger generations.”²⁴

International human rights instruments

Protecting the rights of older people is part of various UN, EU and Council of Europe conventions, action plans and recommendations. The general principles of the Universal Declaration on Human Rights and the European Convention on Human Rights are relevant to the rights of older persons.

Although no Convention expressly dealing with the rights of older persons has been adopted - as in the case of women and children - a number of steps towards the improvement of the lives of older persons have been taken under the auspices of the European Union.

Charter of Fundamental Rights of the European Union and the rights of older people

The Charter constitutes primary EU law and encompasses a very broad spectrum of rights. It does not distinguish or limit the enjoyment of rights on the basis of age. Included are valid fundamental rights relating to civil, political and socio-economic rights that are universally unequivocally applied to everyone, regardless of age:

- Human dignity
- The integrity of the person

- The prohibition of torture and inhuman or degrading treatment or punishment
- The right to private and family life
- Freedom of expression
- The right to property
- The right to access vocational training, to engage in work
- The right to social assistance and health care

The Charter prohibits discrimination on the grounds of age (Article 21) and, very importantly, sets out the rights of older people ‘to lead a life of dignity and independence and to participate in social and cultural life’ (Article 25). With this, the Charter is signalling acceptance and respect for the fundamental rights of older people. It aims to ensure their equal participation in society and their independence, which is pivotal in shifting perceptions about people's agency in older age.

Transforming the new rights-based approach reflected in the Charter of Fundamental Rights into concrete EU legislative measures and policy actions has been a slow process. The EU has not yet succeeded in delivering a comprehensive secondary legal framework ensuring substantive equality for older people. The only exception is the Employment Equality Directive²⁵ which raised awareness on the rights of older people in the area of employment and contributed to changing attitudes of state authorities and private employers on a range of issues.

European Social Charter²⁶

The European Social Charter, adopted in 1961 and revised in 1996, was the first human rights treaty to specifically protect the general rights of older people. Article 23 concerns the right of older people to social protection and seeks to ensure that older people remain full members of society for as long as possible by means of adequate resources to help them play an active part in public, social and cultural life. Article 23 stipulates that States parties undertake to adopt measures to:

- Enable older people to remain full members of society for as long as possible by providing adequate resources and information about available services;
- Enable older people to choose their lifestyle freely and live independently for as long as possible by providing adequate housing and services; and
- Guarantee support for older persons living in institutions.

Article 15 refers to the right of persons with disabilities to independence, social integration and participation in the life of the community and to the need to ensure that persons with disabilities, irrespective of age and the nature and origin of their disabilities, can exercise their right to independence, social integration and participation in the life of the community.

UN Statements on Ageing and Older Persons

In 1991, the United Nations Principles for Older Persons²⁷ identified the principles of independence, participation, care, self-fulfilment and dignity as essential to older persons. Principle 14 states that:

Older persons should be able to enjoy human rights and fundamental freedoms when residing in a shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

These UN Principles were followed up in 2002 by the Madrid Plan of Action on Ageing (MIPPA). It called for changes in attitudes, policies and practices so that the enormous potential of ageing in the 21st century may be fulfilled. This was necessary in order to ensure that people can age with dignity and security while continuing to participate in their community.

The MIPAA is the only international instrument dedicated to older persons. It was adopted by 159 UN Member States in 2002. It was

20 Recommendation CM/Rec (2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons. (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers' Deputies).

21 <https://www.coe.int/en/web/commissioner/-/the-right-of-older-persons-to-dignity-and-autonomy-in-care>

22 https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-fundamental-rights-report-2018_en.pdf

23 <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52008PC0426&from=en>

24 Report from the Eighth working session of the UN Open-ended Working Group on Ageing, 28 July 2017, <https://undocs.org/A/AC.278/2017/2> p.8

25 <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32000L0078&from=EN>

26 <https://tm.coe.int/168007cf93>

27 <https://www.ohchr.org/en/instruments-mechanisms/instruments/united-nations-principles-older-persons>

not, however, developed as a human rights document. A 2022 review references the importance of human rights in its implementation²⁸.

Because neither the principles nor the action plan are legally binding, States are under a moral as opposed to a legal obligation to follow their recommendations regarding the treatment of older people. It is noted that The UN has in place a dedicated Open-Ended Working Group (OEWG)²⁹ to consider the existing international framework of human rights of older persons and identify possible gaps and how to best address them.

Council of Europe Statement on the Rights of Older Persons

The Council of Europe Recommendation on the Promotion of Human rights of Older Persons gives guidance to duty bearers on the rights of older persons and how to implement them.³⁰ The Statement includes a requirement on States to provide medical, health and care supports in accordance with need. The following are some of the relevant provisions in the Council of Europe Statement:

1. Older persons in principle should only be placed in residential, institutional or psychiatric care with their free and informed consent. Any exception to this principle must fulfil the requirements of the European Convention on Human Rights, in particular the right to liberty and security (Article 5).
2. Older persons should be able to fully and effectively participate and be included in society.
3. All older persons should be able to live their lives in dignity and security, free from discrimination, isolation, violence, neglect and abuse, and as autonomously as possible.
4. The full and equal enjoyment of all human rights and fundamental freedoms by all older persons should be guaranteed and respect for their inherent dignity promoted.

5. Older persons shall enjoy their rights and freedoms without discrimination on any grounds, including age. Older persons are entitled to lead their lives independently, in a self-determined and autonomous manner.
6. Older persons have the right to receive appropriate support in taking their decisions and exercising their legal capacity.
7. Member States should provide adequate measures of support to enable older persons to have housing adapted to their current and future needs.
8. Member States should take appropriate measures, including preventive measures, to promote, maintain and improve the health and well-being of older persons. They should also ensure that appropriate health care and long-term quality care is available and accessible.
9. Services should be available within the community to enable older persons to stay as long as possible in their own homes.
10. Older persons should receive medical care only upon their free and informed consent, and may freely withdraw consent at any time.
11. In case an older person is unable, in the particular circumstances to give consent, the wishes expressed by that person relating to a medical intervention, including life-prolonging measures, should, in accordance with national law, be taken into account.
12. When an older person does not have, according to law, the capacity to consent to an intervention, in particular because of a mental disability or a disease, the intervention may only be carried out with the authorisation of his or her representative, an authority or a person or body provided for by law.

13. Member States should provide for sufficient and adequate residential services for those older persons who are no longer able or do not wish to reside in their own homes.
14. Older persons who are placed in institutional care have the right to freedom of movement. Any restrictions must be lawful, necessary and proportionate and in accordance with international law.
15. Member States should offer palliative care to older persons who suffer from a life-threatening illness or an illness limiting their life expectancy, to ensure their well-being and allow them to live and die with dignity.

Again, since these provisions are not legally binding, they impose a moral as distinct from a legal obligation.

The European Pillar of Social Rights³¹ includes a number of principles specifically relevant to older people:

- Equal opportunities (Principle 3)
- Work-life balance (Principle 9)
- Old age income and pensions (Principle 15)
- Inclusion of people with disabilities (Principle 17)
- Long-term care (Principle 18)

In addition to the key principles directly referring to older people, most of the rights and principles in the Pillar are recognised on equal terms, regardless of any differentiating ground, including age. This is the case, for example, regarding the right to:

- Life-long learning (Principle 1)
- Adequate minimum income benefits ensuring a life in dignity at all stages of life (Principle 14)
- Affordable, preventive and curative health care of good quality (Principle 16)

- Access to social housing or housing assistance of good quality (Principle 19)
- Access to essential services of good quality (Principle 20)

Proclaiming all these social rights and principles on equal terms to everyone, the Pillar reaffirms the importance of older people exercising their rights, and participating in all aspects of life equally, as already enshrined in the EU Charter of Fundamental Rights. While this was a positive development towards a more social and respectful EU for older people, given its non-binding nature, it is up to EU institutions and Member States to transform their expressed political commitment into concrete legal action and policies.

Human rights and long-term care

Long-term care as understood in the Project represents a broad spectrum of services and supports delivered to people with a range of identified needs. People availing of these services or supports may include older people or disabled people or people who do not identify as belonging to either of these groups.

Analysis of the various binding human rights conventions and their usage suggests that some human rights may not be adequately protected in practice in the context of long-term care for two reasons:

1. There is a lack of clarity as to the how rights provisions are integrated into long-term care;
2. The lack of a dedicated legally binding Convention on the human rights of older persons is likely to contribute to a lack of awareness by Government and health and social care providers about the need to respect the human rights of older persons seeking and in receipt of long-term care.³²

Indeed, a 2021 Update to the 2012 Analytical Outcome Study on the normative standards in international human rights law in relation to older persons³³ highlights the “silences, neglect and relative invisibility” of human rights issues experienced by older persons”.

28 ‘2022 ROME MINISTERIAL DECLARATION “A Sustainable World for All Ages: Joining Forces for Solidarity and Equal Opportunities Throughout Life”’ https://unece.org/sites/default/files/2022-11/ECE_WG.1_41_WEB.pdf

29 <https://social.un.org/ageing-working-group/>

30 Recommendation CM/Rec (2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons. (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers’ Deputies).

31 <https://op.europa.eu/en/publication-detail/-/publication/ce37482a-d0ca-11e7-a7df-01aa75ed71a1/language-en/format-PDF/source-62666461>

32 Report-“We-Have-the-Same-Rights” - [Human-Rights-of-Older-Persons-in-Long-term-Care-in-Europe.pdf](https://www.ohchr.org/en/documents/outcome-documents/ohchr-working-paper-update-2012-analytical-outcome-study-normative) (ennhri.org) p.74

33 <https://www.ohchr.org/en/documents/outcome-documents/ohchr-working-paper-update-2012-analytical-outcome-study-normative> p.5

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

The UN Convention on Rights of Persons with Disabilities (UNCRPD) seeks to ‘ensure the full, effective and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities and to promote respect for their inherent dignity’. Article 2 enshrines the principles upon which the Convention is based: dignity, freedom of choice, independence, non-discrimination, full inclusion, participation, respect for difference, acceptance of disability as part of human diversity, equality of opportunity, accessibility, equality between men and women and respect for the evolving capacities of children with disabilities and their right to preserve their identities.

The Convention sets out civil and political rights as well as economic, social and cultural rights: the right to life (Article 10), equal recognition before the law (Article 12), access to justice (including age-appropriate accommodation) (Article 13), liberty and security of the person (Article 14), freedom from torture (Article 15), freedom from exploitation, violence and abuse (Article 16), integrity of the person (Article 17), liberty of movement and nationality (Article 18), freedom of expression and opinion, and access to information (Article 21), respect for privacy (Article 22), respect for the home and the family (Article 26), education (Article 24), health (Article 25), work and employment (Article 27), adequate standard of living and social protection (Article 28) and participation in political and public life (Article 29).

The right to live independently and be included in the community is provided for in the Convention (Article 19), the right to protection and safety of persons with disabilities in situations of risk (Article 11), the right to personal mobility (Article 20), the right to rehabilitation (Article 26); and the right to participation in cultural life, recreation, leisure and sport (Article 30).

The UNCRPD is clearly applicable to older people with disabilities since developing a disability with age is a distinct possibility and, also, because people with disabilities are now living longer in most Western countries. More

importantly, the UNCRPD marks a shift from a traditional narrowed welfare state approach, based on needs to compensate for ‘deficits’, to a more comprehensive participatory approach based on dignity, autonomy and rights. It introduces the concept of “reasonable accommodation” that entails necessary and appropriate modifications in the physical environment, public transport, schools and universities or workplaces to ensure that persons with disabilities enjoy or exercise on an equal basis with others all fundamental rights.

While older people with disabilities are recognised in the text of the UNCRPD, e.g., in Article 25 (b) on the right to health services and in Article 28 (b) on the right to social protection programmes and poverty reduction programmes, the Convention does not specifically focus on the human rights of older people per se. However, in its Preamble, concern is expressed about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination, on the basis of, inter alia, age. Also, States parties are required to adopt immediate, effective and appropriate measures to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on age, in all areas of life (Article 8).

Article 19 of the UNCRPD is particularly relevant in the context of people requiring long-term care and support. It stipulates that States Parties should recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including

personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The UNCRPD Committee, in its General Comment on Article 19, stated that barriers to living independently also include the denial of legal capacity, negative attitudes, stigma and stereotypes and the lack of available services such as transport.³⁴ The Committee has stated further that often people with a disability “cannot exercise choice because there is a lack of options to choose from”.³⁵

Equality before the law is one of the key provisions provided for in Article 12 of the Convention, affirming people’s right to exercise their legal capacity. The capacity to make one’s own decisions is a precondition to individual autonomy. Depriving an individual of legal capacity – be it partially, regarding certain decisions, or fully restricting their right to make any legally binding decisions – results in a clear denial of legal personhood.

The right to personal liberty

The right to personal liberty is one of the most fundamental human rights and is particularly relevant in the context of how long-term care is provided. It includes the right to freedom of movement and freedom from arbitrary detention by others. Along with the right to life, the right to liberty is one of the most fundamental human rights. Every declaration of rights includes the right of liberty. Article 40.4.1 of the Irish Constitution protects the right to liberty, stating that no citizen shall be deprived of his personal liberty save in accordance with law.

At the international level, the right to liberty and security of the person found its first legal formulation in the Universal Declaration

of Human Rights (UDHR) which states that “Everyone has the right to life, liberty and security of person” (Article 3) and that “No one shall be subjected to arbitrary arrest, detention or exile” (Article 9).

Article 9(1) of the International Covenant on Civil and Political Rights (ICCPR)³⁶ states that “everyone has the right to liberty and security of person. No-one shall be subjected to arbitrary arrest or detention. No-one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.”

Article 5(1) of the European Convention on Human Rights (ECHR)³⁷ defines exhaustively the instances in which a person may be deprived of their liberty. These must be in accordance with a procedure prescribed by law.

The European Social Charter (revised) stipulates that persons with disabilities have the right to independence, social integration and participation in the life of the community’ (Part I No. 15).

Article 14 of the UNCRPD (Liberty and security of person) requires that States Parties ensure that persons with disabilities, on an equal basis with others:

- (a) Enjoy the right to liberty and security of person;
- (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

Long-term care provision in Ireland through a human rights lens

There is no statutory right to alternatives to residential care in congregated settings (home care, community-based day support services and social work services). This has the effect of de facto arbitrary deprivation of liberty. Ireland

³⁴ 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.

³⁵ Ibid. p. 7.

³⁶ https://treaties.un.org/doc/treaties/1976/03/19760323%2006-17%20am/ch_iv_04.pdf

³⁷ https://www.echr.coe.int/documents/convention_eng.pdf

still has not ratified the Optional Protocol to the United Nations Convention against Torture (OPCAT)³⁸, which requires States to establish a National Preventive Mechanism to inspect and monitor all places of deprivation of liberty in order to prevent arbitrary detention or torture or ill-treatment. This is of critical importance since residential care settings are places where there may be heightened risk of arbitrary deprivation of liberty.

Assisted Decision-making (Capacity) Acts 2015 and 2022

The Assisted Decision-Making (Capacity) Acts 2015 and 2022 are critically important pieces of legislation in the context of protecting the rights of people who require long-term care. The legislation has the potential to change fundamentally the way people whose decision-making capacity is compromised and who require long-term care and support are regarded.

Section 8 of the Act enshrines Guiding Principles which should inform all interventions in respect of persons covered by the legislation, viz. people whose decision-making capacity may be in question. These principles include, in particular:

- A presumption of capacity
- Supported decision-making
- Minimal intervention
- Minimal restriction to freedom of action
- Respect for self-determination, autonomy and bodily integrity
- A person's right to make unwise decisions
- Respect for individual will and preference

Under Section 8(C) of the Act, interveners are required to: (a) permit, encourage and facilitate, in so far as is practicable, the relevant person to participate, or to improve his or her ability to participate, as fully as possible, in the intervention; and (b) give effect, in so far as is practicable, to the past and present will and preferences of the person.

Where decision-making capacity is at issue, the Act establishes a framework of graduated supports – Decision Making Assistants, Co-Decision Makers and, at the upper level of need, court-appointed Decision Making Representatives. The Act provides for registration and monitoring of decision-making arrangements by the Decision Support Service. The 'will and preference principle' included in the Act marks a necessary shift away from the paternalism of the 'best interests' approach.

Overview and Conclusion

All people using long-term care services are entitled to full realisation of all human rights. There is no Convention on the rights of older people, older people are not specifically mentioned in the universal treaties and are rarely mentioned in commentary or recommendations made by the Committees established to monitor compliance with the treaties.

The absence of a framework specifically conceptualising the rights of older people can be considered detrimental to the experience of rights realisation for this group. The term 'disabled' does not fully address the human rights of older people. The failure to develop human rights standards in long-term care which reflects both the UNCRPD and human rights provisions generally has contributed to an invisibility and marginalisation of human rights in the context of long-term care provision.

Notwithstanding the fact that international charters and legal and policy texts are somewhat weak on the specific rights of older persons, they do provide crucial bases for action in relation to rights protection for older persons in long-term care. It is suggested that a future Observatory of Human Rights in Long-term Care could usefully focus on highlighting the policies and systems in Ireland that fall short of adherence to international human rights frameworks.

The next chapter provides a synthesis of rights issues relating to long-term care which have been identified in a number of research reports and discussion papers in Ireland in recent years.

Chapter Four: *Rights Issues in Long-term Care: An Analysis of Selected Irish Research and HIQA Inspection Reports*

Introduction

This chapter examines research studies and reports related to long-term care in Ireland with a particular focus on human rights issues. The chapter also assesses the extent to which various sources of information regarding rights protection in long-term care could prove valuable to any future Observatory and the methodologies that are likely to be feasible and effective.

Safeguarding Ireland research

Safeguarding Ireland has published a number of studies, guides, and resources, including research on public awareness of and attitudes to safeguarding and protection, the wardship system and the manner in which long-term care is financed.

Most recently (2022), Safeguarding Ireland has published a far-reaching discussion paper, *Identifying Risks – Sharing Responsibilities*, that sets out the case for a comprehensive approach to safeguarding vulnerable adults.³⁹

The discussion paper sets out and analyses the multi-faceted contextual factors that are relevant to the safeguarding of adults who are at risk from violence, abuse, neglect, exploitation, coercive control, or self-neglect, whether in the community generally or in health and social care settings.

The paper concludes that, while all citizens have the right to be afforded equal protection from abuse by the State, its institutions and its laws, the basic human and legal rights of adults at risk are frequently and routinely disregarded. Equally, while there has been significant progress in Ireland over recent years in recognising the rights of adults at risk, considerable challenges and shortcomings persist within and across the broad social, cultural, policy and legislative infrastructure.

Identifying Risks – Sharing Responsibilities has considerable relevance for any consideration of approaches to the development and provision of rights-based long-term care in Ireland. It notes that HIQA and the Mental Health Commission have stated that safeguarding

³⁸ Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, <https://www.ohchr.org/EN/ProfessionalInterest/Pages/OPCAT.aspx>

³⁹ Browne, M. et al (2022), *Identifying RISKS – Sharing RESPONSIBILITIES*, Safeguarding Ireland, https://www.safeguardingireland.org/wp-content/uploads/2022/05/6439-Safeguarding-Risks-Resp-Report-FA4_lowres.pdf

involves promoting and protecting people's human rights, their health and well-being, and also empowering them to protect themselves.

The report references the experience of older at-risk adults during Covid-19 when many were subjected to treatment that seriously impinged on their rights and well-being. These forms of abuse included deprivation of liberty, unnecessary exposure to infections (by being in congregated settings), inadequate health and social care supports, being isolated and dependent on family carers who were not supported, a disregarding of people's will and preferences, and a disregarding of the principle of informed consent.

The research underlying the report identified areas in which workers involved with safeguarding have reported concerns and uncertainty regarding their authority and legislative basis for undertaking various safeguarding actions. These concerns include issues such as the balance between autonomy and intervention in cases of self-neglect, limits of access to private properties and institutions, and how capacity can be determined where access to adults at risk is denied.

The report also points to shortcomings in the existing regulatory and safeguarding framework with regard to the protection of adults at-risk in nursing homes. It argues that a main shortcoming of the current regulatory and safeguarding framework is the limited form of protection afforded to adults at risk of abuse or neglect in nursing homes. The nursing home sector is regulated by HIQA, whose regulatory powers relate to compliance and quality standards generally, rather than being focused on the specific issue of promoting the rights of individuals in residential care facilities.

Similarly, the report points to the absence of regulation of the home care sector - another important component of long-term care. It notes that in contrast to its role in setting standards, and monitoring compliance in nursing homes, residential care facilities, and other health and social care settings, HIQA has no involvement in regulating the home care sector, even where home care is funded by the HSE. In addition to HSE home care and HSE commissioned home care, there are many private entities providing home care without

any regulation whatsoever. This includes private entities that provide services for profit, and not-for-profit voluntary organisations that rely on donations. There is no regulatory barrier to entering the home care sector in Ireland. Where organisations provide home care without HSE funding, there is no requirement to comply with HSE standards or policies and procedures.

The various forms of abuse to which at-risk adults are routinely exposed is discussed, as are the limited protections available to them. Many of these forms of abuse occur across the many situations in which long-term care is provided, including in the home, by family, by paid carers, by agencies, in institutional residential settings, and in the community. The prevalence of financial abuse and the protections needed to defend at-risk adults against it are analysed, as are issues including self-neglect and coercive control.

The absence of any oversight and independent assurance as to the quality and standards of home care provision exposes people in receipt of home care services to the risks of abuse, neglect and harm. There is no statutory provision for independent inspection of private home care service providers, or investigation of complaints relating to safeguarding concerns.

Furthermore, the Safeguarding Ireland report notes that, while there is an acceptance of the need for inter-agency collaboration with regard to safeguarding, no framework exists for this.

The report is critical of the current model of long-term care provision in Ireland, with its over-reliance on nursing homes and the increased privatisation of nursing home provision. It draws attention to the processes through which many people end up in these facilities which are frequently associated with the lack of a statutory provision for home care and the poor resourcing of home care. Many people in need of long-term care are effectively denied any real say in where they will live. This includes younger people with disabilities, a proportion of whom are placed in nursing homes as a result of the de-congregation of large institutional residential care settings.

The report identifies a number of major shortcomings in the current nursing home model, including - a privatised nursing home sector operating independently and largely outside of public health policy and outside the acute hospital system; little integration between health and social care supports and housing; absence of community connectedness by nursing homes; people isolated from their communities; people inappropriately 'put into' nursing homes against their wishes in the absence of community-based alternatives; people institutionalised in nursing home environments where they were more at risk of exposure to Covid-19 than if they were living in their own homes.

Identifying Risks - Sharing Responsibilities: Implications for a future Observatory on Human Rights in Long-term Care

The Project draws on the same thematic architecture as the Safeguarding Ireland report in that it uses human rights principles as a reference point against which to analyse, assess, and critique many aspects of long-term care policy and provision in Ireland, including legislative and regulatory frameworks within which long-term care is provided. This approach provides an excellent example of how a future Observatory can and will need to examine issues of long-term care across the spectrum from the practicalities of service provision to the values, policies and legislation that underpin it.

Sage Advocacy research

Sage Advocacy has published a number of reports since its establishment that address long-term care issues.⁴⁰ Of particular interest in the context of the current Project is Choice Matters; Toward a Continuum of Support and Care for Older People⁴¹ (2020). While Choice Matters examined the particular issues that arose as a result of the Covid-19 pandemic, its findings and methodology have much wider

and ongoing relevance. It called for a new and transformative long-term support and care system more fit for purpose for an ageing and more dependent population.

Choice Matters was based primarily on an analysis of feedback from and reflections by Sage Advocacy frontline personnel on the experience of Covid-19. This feedback was based on their engagement with clients, service delivery personnel and members of the public as well as on requests for advocacy support during the period March to mid-June 2020. The feedback from Sage advocates identified a number of overarching factors relating to both the policy response to Covid-19 and the overall long-term support and care infrastructure which came under the microscope during the pandemic.

Sage advocates highlighted the fact that Covid-19 placed significant additional pressures on a long-term care system that was already under stress. Private nursing homes were under-staffed, lacking in clear clinical governance and without adequate oversight. While the view of Sage advocates was that some nursing homes coped adequately with the crisis, others were perceived as not having done so.

A centrally important question highlighted was the pressure on private nursing home operators to cut costs, increase profits, pass on charges and employ a low-paid work force. At a more basic level, however, the important point was made that the current architecture for long-term support and care with its high reliance on residential nursing home care is basically flawed. Vulnerable persons were placed in a risk environment where they would not have been in the first place if there was a comprehensive and integrated home support system in place. The lack of legislative entitlement to or a regulatory framework for home care services and the inadequate supply of Home Care Packages resulted in a situation where people were already unnecessarily in a nursing home or transferred there at the outset of the pandemic. This put people at a higher risk from Covid-19.

⁴⁰ See, for example, Responding to the Support & Care Needs of our Older Population: Report of Forum on Long-term Care for Older People, https://www.sageadvocacy.ie/media/1124/report_of_forum_on_ltc_for_older_people.pdf
Delivering Quality Medical Care in Irish Nursing Homes Current Practice, Issues and Challenges, <https://www.sageadvocacy.ie/media/2111/delive-1.pdf>

⁴¹ Browne, M. (2020), Choice Matters, <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf>

The matter of people with disabilities continuing to be accommodated in congregated settings, including nursing homes was identified in the report as a matter of particular concern both during the pandemic and on an ongoing basis. The fact that there were 1,300 people with disabilities living in nursing homes needs to be addressed and those who wish to move out need to be enabled and supported to do so. This must include community-based supports relative to their needs. Many were in nursing homes because there was no alternative option available to them. Others were there because the congregated setting they used to call home were de-congregated based on government policy as recommended in Time to Move On.⁴² Since this policy was not resourced to its requirements, many ended up in a nursing home – another congregated setting and one totally unsuited to meeting the needs of many of those so placed.

The report noted that the experience of Sage advocates was that frequently there was a total lack of consultation with the people most likely to be impacted upon by policy decisions relating to support and care options generally and specifically in relation to Covid-19. The Covid-19 response was seen by Sage advocates as decisions being made for older and vulnerable people rather than with them. This was particularly important in the context of transfers to nursing homes from acute hospitals which took place at the beginning of the pandemic. While it is unclear as to what level of consultation took place prior to such transfers, it is very likely that many people ended up in nursing homes without choosing to do so. This, the report concluded was a significant human rights protection issue in that frequently people were not given a choice.

The report highlighted the fact that people with reduced decision-making capacity in residential care settings may be vulnerable, not only because of their individual needs, but also because historically the system of service provision has tended to be based on a dependency model rather than on an approach

that maximises choice, supported decision-making and independence.

Choice Matters: Implications for a future Observatory on Human Rights in Long-term Care

The Choice Matters report concludes that a key question for providers of long-term support and care is how they can build a new partnership with the people they support. This is the cultural change that is required – new ways of working alongside people rather than for them. This requires a fundamental shift of power, money and responsibility, without which more humane and relational ways of working lose out to resource efficiency, crude value for money arguments and the profit/corporate ethos.

The report also suggests that while there has been a strong policy emphasis on ‘person centred’ care in recent years, and while the need for such an approach is clearly self-evident, the fact that it has to be repeatedly stated begs the question as to the model that actually operated in the absence of a person-centred approach. This is an important consideration in long-term support and care which is particularly applicable to the current nursing home model. Many nurses in common with many other care and health professionals work in contexts and cultures that are inherently unsupportive of person-centred working. As nursing home care has become more privatised, the individual support needs of people requiring long-term support and care can easily become lost in a profit-driven system. Public residential care facilities clearly also frequently fall short as was evidenced by the experience of Áras Attracta residents.

Choice Matters argues that while there are regulations and standards in place for residential care services, people using these services are not able to define in any meaningful way outcomes for themselves or the type of supports they actually want. HIQA regulation and standards, while very necessary and important in themselves, may well be

inadequate to assure high quality individually-tailored care in accordance with people’s will and preferences. Quality standards are to a large extent limited to the enforcement of those tangibles of the environment and procedures which can be measured. The intangibles that have to do with a human setting and supportive relationships may frequently elude the controls of the regulatory process. It is also true that regulation deals only with what already exists. In a field as seriously lacking in innovation as the nursing home sector, regulation is still unable to play the role of creator of new models or planner of new systems. The report suggests that the business methods which underpin the private nursing home sector may not always provide what makes a good human environment.

The alternative model based on a rights-based approach and on social inclusion principles, proposed in Choice Matters, would seek to build relationships with and between people and to work wherever possible through partnerships, communities and networks. Nursing care units would be part of a menu of supports and residential homes would not operate as isolated stand-alone entities where frequently residents have little real say and little influence on the structures and ethos that shape these institutions.

The report suggests that, pending a radical change to the long-term support and care architecture, more direct involvement of local communities in nursing homes could provide better quality of life for residents. The best way to maintain community standards in nursing homes is to open them to the community. This means having nursing home doors open and people streaming in and out; having the community present in the institution, and nursing home residents held and protected within the community.

It is suggested that Choice Matters provides important analysis that, together with other sources of information and research

from different perspectives and observers, can provide a comprehensive and useful assessment of the issues and possibilities involved in the provision and enhancement of long-term care.

HIQA residential care inspection reports

All centres that provide long-term residential care and support must be registered with HIQA. Before registration is granted, the service provider must show that the centre meets the minimum requirements of the Care and Welfare of Residents in Designated Centres for Older People or the Care Regulations 2013 and Support of Residents in Designated Centres for Persons with Disabilities Regulations 2013. In addition to individual inspection reports, HIQA periodically publishes inspection overview reports, surveys of residents in designated centres, and position papers on related topics.

HIQA personnel conduct inspections with reference to a number of regulations⁴³ and assess the degree to which service providers are compliant with the regulations⁴⁴. A number of these regulations have direct relevance to issues of human rights, while others are concerned with more general matters such as staffing, insurance, governance and premises. While all regulations could potentially impact on a resident’s human rights, a number are more likely to be relevant in that regard. These include: Individual assessment and care plan (Regulation 5), Health care (6), Managing behaviour that is challenging (7), Protection (8), Residents’ rights (9), Visits (11), Personal possessions (12), End of life (13), Temporary absence or discharge of residents (25), and Complaints procedure (34).⁴⁵

HIQA’s 2019 review – Five years of regulation in designated centres for people with a disability⁴⁶ – shows improvements in levels of compliance year-on-year, with overall compliance with all regulations inspected

42 Report of the Working Group on Congregated Settings (2011), Time to Move On, <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf>

43 For a listing of the framework and regulations (updated 2022) https://www.hiqa.ie/sites/default/files/2018-02/Assessment-Judgment-Framework-DCOP_Guidance.pdf

44 See detailed assessment guidelines (updated 2022) https://www.hiqa.ie/sites/default/files/2018-02/Assessment-of-centres-DCOP_Guidance.pdf

45 Individual HIQA inspection reports do not normally comment on all regulations, although regulations 5, 6 and 9 are usually addressed.

46 <https://www.hiqa.ie/sites/default/files/2019-08/HIQA-DCD-5-Year-Regulation-Report-2019.pdf>

increasing from 59% in 2013 to 76% by 2018. Inspection findings showed that residents' rights and dignity were better promoted, and their social care needs were being met in most cases. Residents told inspectors how improvements had positively impacted their lives. For example, moving to houses nearer their families, going on holidays or to concerts, working in their local communities and having more control over what they do on a daily basis.

Notwithstanding these improvements, significant challenges were seen as remaining regarding the management and oversight of services, addressing infrastructural deficits and safeguarding vulnerable people. The governance arrangements in some centres had continually failed to ensure an adequate oversight of the quality and safety of the service. There were also ongoing challenges for some providers in achieving a safe and high-quality living environment for residents.

The review emphasised the importance of regulations in ensuring that people's rights were respected.

The regulations relating to residents' rights and respecting self-determination are an important indicator that describes to what degree a service is person centred. These focus on how residents should be consulted with about the care and support that they receive and about how their centre is being run. It also includes how residents have their privacy protected and dignity upheld. Supporting autonomy and personal control is a pronounced goal in a person-centred planning process.⁴⁷

The HIQA Overview report on the regulation of designated centres for older persons 2019⁴⁸ – which dealt with inspections carried out pre-Covid-19 – presented a largely positive picture of compliance within the nursing home sector. However, it also pointed to many areas where improvement was needed. It also expressed frustration at the fact that the same issues arose year after year. In 2019, the provision of adequate fire protection measures continued to present challenges for some providers. It noted that there were nursing homes where

the facilities were not conducive to modern care practices and that these should have implemented measures to ensure residents' rights to privacy and dignity were upheld.

The Overview Report highlighted the reduction in smaller nursing homes which was viewed as regrettable, as smaller nursing homes can be homely and the loss of a nursing home sometimes means that older people in need of residential care have to travel further in order to receive care. This has knock on effects for residents, particularly in terms of visitors, social activities and links to their preferred general practitioner or pharmacy.

While regulations dealing with premises, governance and management, and record keeping were the areas of highest non-compliance, the overview points out that there was a relatively poor level of compliance in relation to resident's rights. In 2019, over one fifth (20.4%) of inspections showed non-compliance in this regard, a reduction from 26.5% in 2018. It is worth noting, however, that both the overviews and individual inspection reports frequently link non-compliance with Regulation 9 (residents' rights) with an inadequate emphasis on social activities and community engagement for the residents.

HIQA's Overview Report; Monitoring and Regulation of Designated Centres for People with Disabilities in 2021⁴⁹ presents an equally positive picture of compliance, albeit in the context of Covid-19. However, as with nursing homes, the overview identifies areas where there is significant room and need for improvement.

HIQA carried out 1,220 inspections in disability services in 2021 and inspections found that the majority of centres provided a good standard of care and support to people with disabilities. However, the report also outlined concerns over poor findings in relation to governance and management in a number of settings. Poor governance and management was seen as having a negative impact on the quality and safety of care and support for residents, and impacted on their quality of life.

The Overview Report found that there was significant variance in the level of non-compliance in congregated settings compared to community group home settings. Residents living in congregated settings were more likely to experience a poorer quality of life with notable inequalities in the overall quality and safety of the services being provided to residents. Residents living in smaller, community-based homes were found to experience a better quality of life, live in safer services and be more likely to experience better personal outcomes.

For the first time, the report compared the level of compliance and experiences of children and young people living in or accessing designated centres with adults receiving services. HIQA found that as children transition into adult services, they can experience a poorer level of service. However, this is less likely if they stay in a smaller community-based or non-congregated setting.

HIQA also conducts surveys of residents in designated centres, both nursing homes and centres for people with a disability. The National Nursing Home Experience Survey (2022)⁵⁰, found that overall, most residents and relatives and friends of residents said they had either a good or a very good experience in their nursing home. However, residents gave lower ratings to questions relating to accessing advocacy supports, information on moving into the nursing home, and being involved in planning ahead for changes in their circumstances. For example, some residents would like more input in decisions that affect their lives, including their care planning and their day-to-day experiences. Other important areas for improvement related to the food provided to

residents, and the availability of staff to talk to residents about their worries and fears. The results for relatives and friends were similar to those of residents in many respects.

The five lowest-scoring questions on the survey related to involvement and being informed. Most residents said that they did not know how to access advocacy services or organisations that could help them to express their views and wishes, and to help them to assert their rights. Some residents said that they did not receive enough information about what life would be like in the nursing home before they moved in. Some also said that they were not as involved as they would like to be in decisions about the care and support they received, the decision to move into the nursing home, and planning ahead for any changes in their circumstances and their preferred care in the future.

HIQA's Resident Forums in Centres for People with Disabilities in 2021⁵¹ provides equally important and direct insights into the issues that are important to people who live in designated centres and how they view their living and social conditions. While these surveys are inevitably limited in how deeply they can probe and investigate, they are an important resource in compiling an integrated and comprehensive view of how rights issues are being addressed or ignored.

Other important sources include the HSE Confidential Recipient Annual Reports. The 2021 report⁵² identified issues such as the impact of staffing shortages in both residential and community-based settings, people being moved into nursing homes – sometimes against their will – due to inadequate personal assistant or home care packages, and the implications of inadequate respite provision.

47 Ibid. p.27

48 https://www.hiqa.ie/sites/default/files/2020-12/DCOP_Overview_Report_2019.pdf

49 <https://www.hiqa.ie/reports-and-publications/key-reports-investigations/disability-overview-report-2021>

50 The National Nursing Home Experience Survey <https://yourexperience.ie/wp-content/uploads/2022/11/Nursing-Home-Overview-Report-2022-V2.pdf>

51 <https://www.hiqa.ie/sites/default/files/2022-10/Resident-forum-report-2021.pdf>

52 <https://www.hse.ie/eng/services/publications/disability/confidential-recipient-annual-report-2021.pdf>

Themes emerging in HIQA inspection reports

In May 2022, HIQA published 35 reports on nursing home compliance⁵³. Of the 35 centres inspected, 13 achieved levels of compliance indicating a good standard of care and support in all areas. The remaining reports detail areas of non-compliance including governance and management, premises, infection control, healthcare, fire precautions, residents' rights, risk management, individual assessment and care plan, staffing, training and staff development, and managing behaviour that is challenging. All of these areas have implications for the rights of residents.

The Project carried out a review of four of these HIQA inspection reports of nursing homes in order to explore the extent to which human rights themes were addressed. The review looked for information with regards to the key human rights issues outlined earlier. This small sample of reports - in conjunction with wider overviews and reports, as discussed above, was seen as a useful way of providing a snapshot in relation to key human rights-based issues in the Irish nursing homes context and of aligning key human rights themes with the inspection report findings.

Autonomy

Inspection reporting for Residents' rights (Regulation 9) rarely mentions decision-making support in GP care, admission, contracts of care or end-of-life care plans.

Right to participation and social inclusion

Three reports reference only participation in activities in the summation of findings for Regulation 9 (Residents' rights). A high level of participation in provided activities may indicate quality and meaningful activities and choice. Evidence that everyday choices are respected by the nursing home are an important indicator for inspectors and reports often detail the amount of choice available

for food and activities. Some reports mention consultation with residents in relation to care planning and three reports mention resident meetings and access to advocacy which is indicative of some participation by residents in decision-making.

The exercise of civil, political and legal rights is clearly much more complex than choice of in-house activities. Only one report mentions activities in the community. This is the most basic of requirements in relation to preventing the negative effects of institutionalisation.

Right to family and private life

It was clear from the reports that family visits were subject to Health Protection Surveillance Centre Guidance and sometimes required preapproval.

Right to privacy

Three of the four inspection reports reviewed by the Project indicated multi-occupancy rooms. Sharing a room in an institution could clearly result in an increased risk to health and life in a pandemic situation. While it is important that those who wish to live with their loved ones and share a room can be facilitated, this evidently should be an individual choice.

Access to justice, including the right to an effective remedy

All four HIQA reports that were reviewed found that there was compliance with complaints regulation. This would indicate that the procedures in place for making complaints are effective and that complaints are noted and followed up within a certain time frame. However, for those with more complex communication needs, complaints frameworks may or may not be accessible. It is not possible to establish how complaints are supported and made accessible to residents from the information provided in the reports.

Review of a sample of inspection reports

Analysing a small sample of inspection reports is regarded as effective and applicable on an ongoing basis. Depending on resources available, a future Observatory could decide to replicate this sampling approach at intervals in order to gain an understanding of the overall picture. While the sample chosen here dealt solely with nursing home inspections, it should be noted that a similar inspection regime applies to residential care facilities for people with disabilities, with regular publication of inspection reports.

HIQA inspection reports contain substantial information regarding issues that relate to the rights of residents in designated centres. Studies that draw on a much more substantial sample of reports and that focus on selected rights-oriented regulations could prove valuable and practical, particularly as a tool for identifying examples of both good and poor practice, the prominence or otherwise of important rights issues, and the prevalence or otherwise of measures to respect and uphold human rights.

Summary and Conclusions

This chapter drew on a number of reports and studies that had relevance for the task of identifying issues relating to long-term care, for devising a framework of themes that could give coherence and guidance to future explorations, and that utilised various approaches to gathering evidence related to the quality of the provision of long-term care. These actions were carried out with a view to contributing to a discussion of what any future Observatory should examine, how it might structure its approach, and what methods it should adopt in collecting information.

The methodology adopted in the Safeguarding Ireland paper illustrates the value of drawing on the many insights and analyses provided by a range of interested parties as well as drawing on the variety of published data made available by state agencies with responsibilities for various aspects of long-term care provision

or monitoring.

The Choice Matters report identifies issues and themes that will be relevant and appropriate for any future Observatory. While accepting that the methodology involved was limited in that it relied on intermediaries rather than on service users for inputs, it nevertheless was grounded in the experiences of independent and skilled informants.

The analysis of selected HIQA reports points to these a potential source of data on how human rights are/are not protected in residential care facilities.

It is evident that differing approaches will prove necessary, as each has its own limitations, focus, and strengths. Taken together, a variety of methods, sources and perspectives has the potential for yielding a comprehensive and inclusive picture of all aspects of long-term care and the challenges that surround its delivery from a human rights perspective.

The next chapter provides a synthesis of issues identified through a systematic analysis of selected Sage Advocacy data as well as issues arising from casework identified by Sage advocates.

⁵³ See <https://www.hiqa.ie/hiqa-news-updates/older-peoples-services-publication-statement-19-may-2022> and <https://www.hiqa.ie/sites/default/files/2022-05/List-of-reports-on-designated-centres-for-older-people-published-19-May-2022-by-county.pdf>

Chapter Five

Human Rights Issues: The Sage Advocacy Experience

Introduction

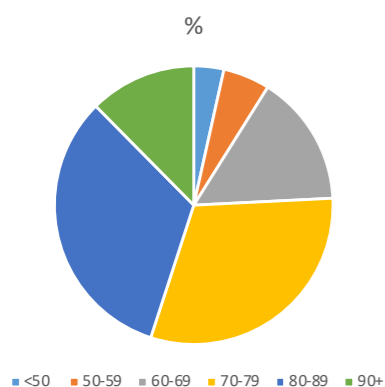
The Sage Advocacy experience was explored through consultation with Sage Advocacy personnel and through an analysis of selected Sage Advocacy statistical data. Firstly, the Project examined statistical data from the Sage Advocacy platform, Salesforce, presented in dashboard format. This provided detail on the number of referrals received, source and location of referrals, and age breakdown of clients. Secondly, systemic issues were analysed based on summaries of cases provided by Sage Advocacy. Thirdly, Sage advocates were asked to identify actual or potential rights infringement issues that emerged from casework.

Profile of Sage Advocacy clients July 2021 to June 2022

Age range of Sage Advocacy clients

There were 1426 new referrals to Sage advocacy during the period reviewed. While the majority of referrals were made by/on behalf of people aged over 70 years, there were also referrals from people in younger age groups, including some from people under 59 years. Table 5.1 shows that Sage Advocacy provides services to adults who may be experiencing vulnerable situations across all age ranges.

Table 5.1: Sage Advocacy referrals by age



Source of referrals to Sage Advocacy

The Project was particularly interested in where referrals to Sage Advocacy came from with particular reference to referrals from people in a long-term care situation. For example, a picture of where people are when they seek independent advocacy support could indicate key themes in relation to gaps in long-term care service provision and any human rights implications.

Table 6.1 shows that the highest proportion of new referrals (almost 40%) came from or on behalf of people living at home. The Project was interested in this information in that it suggests that gaps in long-term care service provision in the community is a matter for concern. Almost one-third of referrals related to people in nursing homes. The number of referrals (352) made by or on behalf of people in a hospital setting is significant in that, while not all of them, referred to long-term care service provision, the majority (88%) did. These mainly included those who are 'trapped' in an acute hospital because they could not get a home care package commensurate with their care and support needs.

Table 5.2: Where people referred to Sage Advocacy lived

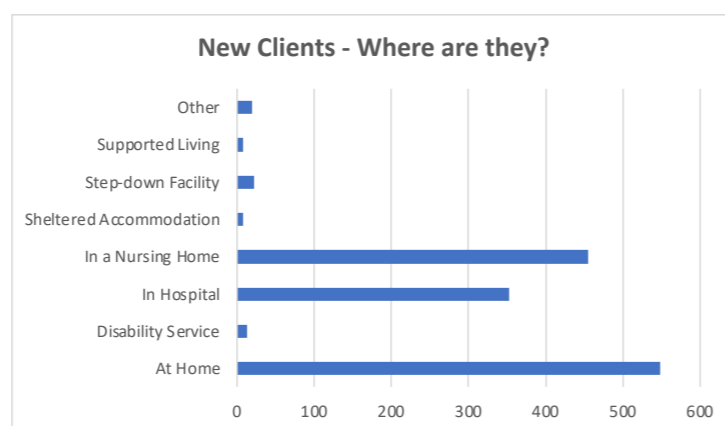


Table 5.3 shows that safeguarding and protection was identified as the primary referral issue in 130 cases, financial abuse in 70 cases and other types of abuse in 52 cases. Wardship was the primary issue in 27 cases and 13 cases involved legal matters.

Table 5.3: Primary rights issues identified through the case management process

Safeguarding component	130
Financial abuse	70
Other abuse	52
Wardship	27
Legal matters	13

*The total number of cases on the Dashboard for the period reviewed was 1426.

Table 5.4: Difficulties in accessing health and social care services

Home Support Services	20
Suitable housing	10
Home adaptation	6
GP	4
Primary Care Social Worker	2
Other (various)	5

Table 5.4 shows that 47 cases from the period reviewed related to access to community services. These included access to home support services, housing, home adaptation services, and primary health and social care services. Difficulties with accessing a GP were identified in four cases. This is an important issue in that access to a GP and other primary care professionals is a basic public health service available to all citizens in Ireland with a Medical Card.⁵⁴ This matter was explored in detail in a 2020 Sage Advocacy Report, Delivering Quality Medical Care in Nursing Homes.⁵⁵

Systemic issues identified in the statistical report

The Project was interested in looking at data on systemic issues identified by Sage advocates. The systemic issues category is one that advocates are asked to fill in when the issue or issues arising in the case are seen as recurring and linked to shortcomings in policy.

Table 5.5 provides a breakdown by regularity of the systemic issues identified.

Table 5.5: Breakdown of primary issue in cases where a systemic issue was identified

Primary issues presented	
Desire to move residence	32
Financial	21
Access to community services	11
Barriers to supported decision making	10
Family/relationship	5
Legal	3
Acute Hospital	2
Health/clinical	1
Total	85

Systematic issue data summaries show that 32 cases involved a desire to move residence. This suggests that people either wanted to move out of residential care or that their current home living environment was unsuitable. The lack of control of personal finances was a key issue for some of those seeking support and was a factor in 21 of the cases where a systemic issue was identified. It can be reasonably suggested that this is due to variety of different factors including a lack of appropriate support, financial systems present in long-term care settings and family control of finances.⁵⁶

54 https://www.citizensinformation.ie/en/health/medical_cards_and_gp_visit_cards/medical_card.html.

55 Browne, M. (2020), Delivering Quality Medical Care in Nursing Homes, <https://www.sageadvocacy.ie/media/2111/delive-1.pdf>

56 See Browne, M. et al. (2022), Identifying RISKS - Sharing RESPONSIBILITIES, Safeguarding Ireland, https://www.safeguardingireland.org/wp-content/uploads/2022/05/6439-Safeguarding-Risks-Resp-Report-FA4_lowres.pdf

Sage Advocacy cases with an identified actual or potential rights infringement issue

Sage advocates reported that their casework experience indicates that many Sage Advocacy clients experience rights infringements of one form or another. Independent advocacy support is frequently required in order to ensure that people's rights are upheld. A number of rights-related issues were identified by Sage advocates based on their casework experience.

Rights issue 1: Obtaining valid consent from people in decisions relating to health and social care

Valid consent to decisions affecting them is a key factor in the protection of a person's human rights. The following matters have been identified by Sage advocates as relevant to valid consent:

- A person may consent to receive care and treatment in a residential care service but not consent to the restrictions on liberty that the place of residence has in place;
- A person may consent to receive care and treatment but not consent to be in a particular place of residence;
- A person may consent to receive care and treatment in a particular place of residence and may subsequently change their mind;
- A person may consent to receive care and treatment in a residential unit for a respite period but not to this becoming a long-term arrangement;
- A person may consent to receive care and treatment without having all relevant information and all options being explained to the person in a way that is understandable to them and in a manner which gives them choice;
- An assessment of care needs, an assessment of capacity to consent to care and an assessment of capacity to consent to a living arrangement where there is a potential deprivation of liberty are clearly separate assessments and

determinations but are not always treated as such;

- A lack of resources for appropriate care and supports in the community, and a lack of a statutory right to home care, can result in a person being forced to live in a residential facility against their wishes.

Rights issue 2: Enabling the 'voice' of the individual to be heard

Sage Advocacy casework indicates that a difficulty sometimes arises because the communication with the person requiring care is inadequate. This can arise because the person has communication difficulties (e.g., associated with a particular condition or cognitive impairment), insufficient time for professionals to engage with and listen to people, under-developed skills relating to the latter and an over-reliance on the views and perspectives of relatives.

People with complex care and support needs frequently have difficulty in verbal communication but yet are fully capable of understanding and communicating in other ways. This is an important factor in establishing both people's decision-making capacity and their preferences in relation to how care and support is provided.

An underlying issue reported by Sage advocates is that key professionals (those with a decision-making role in relation to care) typically do not spend sufficient time and build a sufficient relationship with people to fully ascertain their will and preferences and their ability or otherwise to make informed choices and to give consent. This deficit is regarded by Sage advocates as particularly important when a person wishes to return home or find other suitable accommodation after hospitalisation following a stroke, an accident or other adverse incident that affected a person's mobility and ability to communicate.

Sage Advocacy experience is that in some instances the voice of the individual involved was not fully heard by professionals. There is a perception among Sage advocates of there being only a vague understanding of the need to ensure that people's decision-

making capacity is maximised and a perception that people whose decision-making capacity may be in question are sometimes not encouraged or facilitated to articulate their will and preferences because of a risk aversion approach.

A view expressed by Sage advocates was that in some instances there had been a lack of consultation with the people most likely to be impacted upon by decisions relating to support and care options generally. In other words, decisions were made for a person rather than with them. The result in some instances, for example, was that a person ended up in nursing homes without choosing to do so.

Rights issue 3: Presumption of capacity not evident in some instances involving at-risk adults

A key factor in ensuring that a person's human rights are protected is that people are presumed to have capacity unless it is determined otherwise. Sage advocates reported instances where health and social care professionals seemed to ignore the principle of presumption of capacity contained in the Assisted Decision-making (Capacity) Act 2015 on the basis that the Act had not yet commenced.

Sage Advocacy casework suggests that the presumption of capacity may not always be the starting point and that sometimes other factors intervene to undermine this presumption. These factors include people having made what appeared to be 'unwise' decisions in the past, engaging in high-risk behaviour or anecdotal information provided by relatives. The absence of a strong presumption of capacity results in an approach to decision-making where a person may be marginalised and where other people make decisions about what is regarded as in the 'best interests' of a

person. This approach also undermines the basic principle that all people have legal capacity⁵⁷ even if their decision-making capacity is reduced. Article 12 of the UNCRPD guarantees that persons with disabilities have a right to legal capacity, which means that the law should recognise their capacity to be the bearers of rights, and their capacity to act. In other words, persons who have reduced decision-making capacity have the very same legal rights as persons whose decision-making capacity is not under question.

There were a number of cases reported by Sage advocates where people's decision-making capacity was called into question even though it had never been formally assessed. (It should be noted that research⁵⁸ has shown that almost 28% of patients in acute hospitals in Ireland lacked decision-making capacity).

Rights issue 4: Assessment of capacity

Sage advocates have reported encountering situations in which decisions regarding the future care of a person are made by a number of professionals – medical and social – without providing any meaningful opportunity for the wishes and preferences of the person to be voiced, either directly by the individual or by an independent advocate.

Assessing a person as not having decision-making capacity is clearly a major decision which has major consequences for the person involved. Sage advocates suggest that assessing capacity is sometimes not carried out as thoroughly or comprehensively as it should be given its central importance in a person's life. In some cases, it was unclear who did the capacity assessment and in others it appeared to have been carried out without due effort to communicate with the person.

⁵⁷ 'Legal capacity' means the capacity to have rights and the power to exercise those rights. Article 12 of the UNCRPD guarantees that persons with disabilities have a right to legal capacity, which means that the law should recognise their capacity to be the bearers of rights, and their capacity to act. In other words, persons who have reduced decision-making capacity have the very same legal rights as persons whose decision-making capacity is not under question.

⁵⁸ Ruth Murphy, Sean Fleming, Aoife Curley, Richard M. Duffy & Brendan D. Kelly (2019) Convergence or Divergence? Comparing Mental Capacity Assessments Based on Legal and Clinical Criteria in Medical and Surgical Inpatients, *Journal of Legal Medicine*, <https://www.tandfonline.com/doi/full/10.1080/01947648.2019.1622476?scroll=top&needAccess=true>

Other instances identified by Sage advocates referred to situations where the person's capacity had not been questioned by anyone and yet decisions were being made on their behalf by other parties, usually next-of-kin who have no right to make any such decisions. In some instances, the person involved only became aware of such decisions when informed by the Sage advocate involved. (It should, of course, be noted that the recent commencement of the assisted decision-making legislation will address many of these issues.)

Rights issue 5: Right to self-determination

Some Sage Advocacy cases involve supporting people to exercise their right to self-determination and their right to take reasonable risks (which they are aware of) in accordance with their will and preferences. 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' or controlling the person's finances in such a manner as to make these unavailable for the purchase of home care.

The experience of Sage Advocacy is that there is an in-built practice of preventing people returning home because of a hospital's concern about things going wrong and the hospital being held legally accountable for any adverse outcomes.

Health care staff and legal teams are perceived by Sage Advocacy as sometimes being reluctant to acknowledge that people are knowingly willing to accept the risks involved in living at home rather than being detained in a hospital or sent to a nursing home. This is a critical component in the protection of liberty and a key question is how to achieve the proper balance between protecting a person's liberty and ensuring that they are protected from risk. Some Sage Advocacy clients state explicitly that they are fully aware of the risks involved in living at home but want to make that choice, a choice that they believe is rightfully theirs to make.

Rights issue 6: Applications for wardship

Consideration of or planning for wardship when a person has some decision-making capacity, and without exploring other options, can result in an unnecessary interference and restriction on a person's rights. Sage advocates reported instances where a decision to apply for wardship was made by health professionals in consultation with family members against the express wishes of the individual. Sage advocates identified instances where a client who was the subject of a wardship application was unaware of the process which was managed by a relative. Instances were also identified where information or documentation relating to the wardship application were sent to relatives and not to the person who was the subject of the application. Also there were instances identified where the Sage Advocacy client was not supported to attend court where the application was heard or offered the services of an independent advocate.

Health and social care and legal practitioners are generally seen by Sage advocates as being aware of their obligation to take a person's wishes into consideration when making a decision about their future. However, Sage advocates believe that in many instances where a person's decision-making capacity is in question, the option of wardship is the only one explored especially when there are conflicting opinions about a person's decision-making capacity and the potential risks involved in acting in accordance with a person's wishes.

Because of concerns of health and social care services (understandable) regarding a person's capacity to assess risk, Sage advocates believe that there is in practice a default position of applying for wardship as the only viable alternative where there was a question about a person's capacity, for example, where a person wanted to discharge themselves against a hospital's wishes. (It should, of course, be noted that the recent commencement of the assisted decision-making legislation will address many of these issues.)

Rights issue 7: Inappropriate involvement of relatives

An area where a person's human rights may be curtailed is where relatives exercise coercive control over a person by controlling their finances or by influencing key decision-makers in relation to a person's care and support options. Sage Advocacy casework indicates that in some instances there is an inappropriate dynamic between relatives and health and social care professionals. This is manifested in an application being made for the NHSS or for wardship or for both simultaneously. While Sage advocates report that some families do their utmost to enable a relative to return home or to find alternative appropriate accommodation, there are others who seek to thwart the process of supporting a person to return to live in the community. Some Sage Advocacy cases involved relatives providing what appeared to the Sage advocate to be inaccurate or misleading information to services in order to ensure that a person did not return home.

Rights issue 8: People's right to liberty not protected

Sage advocates reported that clients have experienced an actual or potential infringement of liberty due to insufficient services in the community to enable and support a person to remain living in their own home. The shortfalls in community care provision for vulnerable adults in effect result in people being detained in hospital or a residential care facility against their will. 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.

Sage advocates suggest that their case evidence shows that some people required relatively little assistance to live in the community, e.g., night-time support or Personal Assistance, but could not do so

because such support was not available. Another issue identified by Sage advocates emerging from their casework is that frequently neither the hospital or community care services use a Quality of Life Indicators⁵⁹ 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.

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. The long-term care and support infrastructure which currently exists in Ireland is fundamentally at odds with people's right to choose. A related issue is that some services (for example, Personal Assistance) tend not to be even envisaged if the disability is acquired after the age of 65.

The main factors associated with deprivation of liberty identified by Sage advocates were:

- Hospital discharge delayed due to a person wanting to but not being facilitated to return home;
- A risk aversion approach by health care professionals where a person's will and preference to remain at home is not supported despite the fact that the person is fully aware of the risks;
- Lack of suitable housing, lack of suitable home support services and a shortage of home support workers resulting in people being de facto detained in a nursing home;
- Lack of independent advocacy support.

A 2018 campaign by Sage Advocacy to highlight deprivation of liberty issues detailed Rosie's story.

“She was 85 and had been in a nursing home for nine months to recover from an illness. Now fit and ready to return home to her friends and her cat, her red suitcase had been packed for six weeks - She missed her home and the life she had before going into the nursing home. Some staff thought she needed her family’s permission to leave. They threatened to call the Gardaí. She went to her room, ate humble pie and cried herself to sleep. She contacted Sage and is now back in her own home and content.”

Rights issue 9: Deprivation of liberty as a feature of nursing home care facilities

Sage advocates highlighted the fact that their casework has demonstrated that many so-called voluntary residents in nursing homes are de facto detained: they live in a closed unit and are not allowed to leave the institution without prior permission. Buildings are commonly secured by key code locks as a safety mechanism, requiring residents to ask permission to leave the premises. In the experience of Sage advocates, the de facto detention can extend as far as limiting people’s access to recreational grounds outside of the building, justified by an assessment that the resident is a “falls risk” or likely to “escape”. While explanations for policies point to efforts to introduce safety measures to protect some of the people in a residential care centre, the impact of such measures can be the de facto detention of all the people who reside within that centre.

Rights issue 10: ‘Substitute’ decision-making

Cases were identified by Sage advocates where decisions regarding a client’s future care were made by relatives and supported by a hospital multi-disciplinary team which were contrary to the will and preferences of clients. This was sometimes done on the basis that the person involved lacked the capacity to follow through and implement their will and preference. In some such situations, the role of the Sage advocate was challenged and questioned, as was any suggestion that an

independent advocate should be allowed to participate in the proceedings of the multi-disciplinary team where decisions would be made. (It should be noted that many instances have been identified where Sage advocates were allowed to participate and to support a client at MDT meetings).

Rights issue 11: People’s finances inappropriately controlled by others

Managing and dealing with financial affairs can be challenging for many adults living in vulnerable situations. The complexities of dealing with property, inheritance matters, nursing home charges, and debt were identified by Sage advocates as particularly challenging for people with reduced decision-making capacity. Instances were identified where inappropriate control was being exercised over an adult by another family member. In such situations, there is potential for people to be manipulated into handing over money or property without wanting to do so.

The matter of financial abuse also emerged in cases in the form of, for example, bank or credit card fraud and the manipulation of the ownership and inheritance of properties. There was a sense on the part of some Sage advocates of clients being afraid to make a complaint about potential abuse within the household that affects them because of fear of repercussions⁶⁰.

Rights issue 12: Poor understanding by professionals of communication challenges

A potential rights infringement identified by Sage advocates referred to the fact that a proportion of clients would have difficulty in receiving, comprehending and responding to official communications and documentation as a result of issues such as intellectual ability, housing arrangements, attitudes of care providers, and other such factors. In some cases, the breakdown in communications related to errors and omissions on the part of other parties including the legal profession.

Instances were identified where professionals, including lawyers, Gardaí and others lacked an adequate appreciation and understanding of the particular challenges that some clients face in formulating and communicating information, especially when they are in stressful or traumatic situations. It was sometimes the case that people were regarded as ‘confused’ because they had difficulty in communicating their views or because they changed their minds. These failures in communication were perceived by Sage advocates as impacting on the ability of some people to protect their rights. This sometimes resulted in an application for wardship being made without other avenues of support being explored. The involvement of a Sage advocate regularly facilitated a person in convincing professionals, including solicitors, that a person could articulate their wishes provided the appropriate communication mechanisms and time were in place. However, the involvement of a Sage advocate was sometimes resisted by legal practitioners.

Rights issue 13: The way ‘transitional care’ operates

Sage advocates highlighted what they regarded as an emerging trend in health services that is giving rise to de facto deprivation of liberty issues. This trend refers to what appears to have been a recent policy shift to establishing ‘transitional care units’ under the governance of the HSE as a place of care for those previously referred to as ‘bed blockers’ in acute hospitals. These units are set up by nursing home groups and although the residents there are said to be “in transition”, they are in reality living in long-term care units under a different name.

While, in theory, the residents can leave these units, in practice they cannot do so as they are all people who need assistance to live in their own homes. Since home care packages and/or care assistants are not available commensurate with their support needs, the reality is that these people are left in such units indefinitely.

Sage advocates also highlight the fact that

although notionally the residents of these units still come under the jurisdiction of the hospital that transferred them to the units, the reality is that there are no therapies being provided for people in those units to prepare them for going home. This, Sage advocates believe, leads to deconditioning and institutionalisation of residents so that when they do eventually transition out of these units, it will have to be to a nursing home.

Sage advocates raised a number of questions about the role and functioning of such units:

- Where is it envisaged that these residents will transition to, and have they given their consent to be “held” in the unit?
- If the resident wishes to transition home what efforts are the HSE making to achieve this both by training carers themselves to provide the home care packages and by preparing the residents to care for themselves?
- Are these units fulfilling the statutory duty of the HSE to look after older people according to their needs and ensure that a person’s ability to perform the activities of daily living does not deteriorate while in these units?
- Is it acceptable that the HSE, knowing that the cohort of older people upon leaving the hospital will not be able to return home without a home care package, offload this responsibility to private providers through Service Level Agreements?
- Are there any procedures for reviewing the residents who find themselves “stuck” in these units for long periods?

Sage Advocacy casework and data: Implications for a future Observatory on Human Rights in Long-term Care

What is particularly notable from the analysis carried out by the Project is the interrelatedness of the key human rights issues presenting⁶¹. As outlined above, the right to

⁶⁰ This matter is dealt with in detail in the 2022 Safeguarding Ireland Report, Identifying RISKS: Sharing RESPONSIBILITIES, <https://www.safeguardingireland.org/wp-content/uploads/2022/05/6439-Safeguarding-Risks-Resp-Report-FA4-lowres.pdf>

⁶¹ Park, B., Greene, M., and Colaresi, M., Human Rights are (Increasingly) Plural: Learning the Changing Taxonomy of Human Rights, *American Political Science Review*, 114(3), 888-910. <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/F202F327EA8F4CF52D2E65EB48D409D3/S0003055420000258a.pdf/human-rights-are-increasingly-plural-learning-the-changing-taxonomy-of-human-rights-from-large-scale-text-reveals-information-effects.pdf>

choice and full recognition of legal capacity are paramount to the effective realisation of human rights. The following is a summary of the main outcomes of the analysis of Sage data and Sage Advocacy case material provided to the Project by Sage advocates and the implications for a future Observatory.

Statistical Dashboard reports

Relevant statistical reports providing information on the age, primary referral issue and the place where the referral originated were provided by Sage Advocacy. This information provided a useful starting point for exploring key human rights issues in long term-care services. This method is reasonably accurate and sustainable. The data provided was accessible through the categorisations already in place and could be used by a future Observatory to establish the volume of referrals in relation to particular information. Reports could be generated to a timeframe and created quickly with little resources expended. The information categories on recording software used by Sage Advocacy staff could offer an effective method of establishing initial statistical information with regard to these issues which would be a useful tool for a future Observatory.

Since the Sage Advocacy database is not sufficiently tailored to human rights issues, it would need further refinement in order to be easily accessible to a future Observatory. In this regard, the Project utilised the expertise of Sage Advocacy personnel with extensive experience of using, collating and analysing data within this system to ensure as far as possible that accurate and useable information relating to rights issues could be mined from the database.

Any civil society organisation planning to partner with a future Observatory on Human Rights in Long-term Care in a rights monitoring process could update their reporting systems to reflect the themes and categorisations identified. (See Chapter 7 below for a summary of rights issues identified by the Project). However, some further research would be required to establish the validity and reliability of this method. Staff may also require training to help them to identify and record inter-related themes.

It is suggested that this approach (with a significant amount of front-loading of resources) could result in regular, accurate, effective and sustainable information gathering with reference to rights issues. However, more detail with regard to structure, process and outcome measures will be necessary to further the effectiveness of this approach.

Summary and Conclusions

The data collected by advocates in case management can offer a valuable insight into key issues for human rights in long-term care. People who have engaged the services of Sage Advocacy typically experience a wide variety of challenges, many of which are related to the need for and/or experience of long-term care services. Many cases are indicative of actual or potential human rights infringements relating to choice, protection of liberty and right to self-determination.

The Project was guided by the knowledge and experience of Sage Advocacy personnel with extensive experience of using, collating, analysing and reporting data within this system. However, like all software and recording systems set up primarily for case management purposes, the inter-related nature of human rights themes is not built into the reporting mechanisms.

Notwithstanding these limitations, this approach offers a useful initial monitoring tool for a future Observatory in establishing the systemic issues that act as barriers to human rights realisation. However, in the longer-term a significant amount of research would need to be carried out to reflect the interrelated nature of a human rights based approach and to establish a more effective human rights-related classification system as these apply to long-term care.

The issues outlined in the chapter based on Sage Advocacy data and the experience and perspective of Sage advocates provide a valuable insight into the nature and extent of actual and potential rights infringements associated with long-term care provision in Ireland. However, the important matter of capturing in a more inclusive manner the voice of users of long-term care services (discussed in the next chapter) was not possible within

the time frame of the project. This, and the related matter of research ethics clearance (discussed in the next chapter) are key challenges for a future Observatory. The next chapter will explore the components

of a participatory research approach to identifying rights issues in long-term care and the challenges associated with using such an approach.

Chapter Six Participatory Research Methods

Introduction

The Project regarded the effective participation of those with lived experience of long-term care as essential to the functioning of a future Observatory.⁶² This was based on the premise that monitoring and related research should be based on the principle of ‘nothing about us/without us’. Therefore, the Observatory was envisaged as seeking to capture and analyse information through participation by people with lived experience of long-term care and support services. This approach would seek to explore the impact of service structures and processes on the realisation of human rights from the perspective of those who use these services. It is suggested that a participatory research approach would significantly enhance the functioning of a future Observatory by generating new and transferrable insights and knowledge from long-term care recipients.

Participation: Key underlying principles

Participation can be defined as the process through which all stakeholders influence and share control over priority setting, policy-making, resource allocations and outputs. It is a key component in ensuring long-term sustainability, transparency and accountability, and in doing so, enhances the effectiveness of policies and programmes.

Broadly speaking, citizen participation can

be defined as a redistribution of power that enables citizens excluded from the political and economic processes to be deliberately included. It is also the strategy by which all stakeholders are involved in a meaningful manner in determining how information is shared, goals and policies are set, resources are allocated, programmes are operated and outcomes are disseminated.

Arnstein (1969) discusses eight types of participation in A Ladder of Citizen Participation. These can be broadly categorized as nonparticipation, tokenism, and citizen power. She defines citizen participation as the redistribution of power that enables the ‘have not’ citizens, often excluded from the political and economic processes, to be deliberately included in the future.

Four participation domains have been identified:⁶³

- (i) The distinction between private and public
- (ii) The distinction between individual and group participation
- (iii) The nature of the participation, and
- (iv) The need for the participation to be inclusive

Inclusive participation may be challenging when the population group is considered ‘hard to reach’. For example, children may be considered hard to reach if there are limited communication channels through which to

62 Williams, V. J., Webb, J. C., Read, S., James, R., Davies, H., & Forget-me-Not Research Group (2020). ‘Future lived experience’: inclusive research with people living with dementia. https://research-information.bris.ac.uk/ws/portalfiles/portal/212993683/FINAL_paper_as_accepted.pdf

63 Hart, R. A. (1992), Children’s Participation: From tokenism to citizenship, <https://www.unicef-irc.org/publications/100-childrens-participation-from-tokenism-to-citizenship.html>

access or to hear the voice of children.⁶⁴ Some people with disabilities may be hard to reach because they may have reduced capacity or communication difficulties and some older people may be hard to reach because of their place of residence (e.g., a nursing home).

Effective participation: Key components

- There is an essential difference between consultation and participation – those who are consulted offer their opinions which are taken into account more or less by those making the decisions while those who participate share directly in the decision-making process and the outcomes.
- Good participation practice recognises social, cultural and biographical diversity and develops diverse and appropriate mechanisms to ensure that people from diverse backgrounds are effectively included.
- There is a critical difference between going through empty rituals of consultation and giving stakeholders real power to affect outcomes.
- Participation is a dynamic and ongoing process (as distinct from one-off consultations) and real participation by target groups requires investment in time, energy and commitment by the agency concerned.

What is participatory research?

While participatory research began as a concept for working with people who had an intellectual disability, it is now being used with a wide variety of research populations. It has a number of inter-related components.⁶⁵

- Participatory research operates on the basis of research as a collaborative process which acknowledges the active role of target groups in shaping research questions and implementing an inclusive research approach.

- There is a need to balance the need to manage risks of involving at-risk groups in research across the life-cycle with the right of those groups to be heard in order to avoid gate-keeping them out of research purely on the basis of potential risk to them.
- The terms and conditions within which target groups are included in research need to take account of the individual agency of each person – people’s competence, determination, dependency and vulnerability – rather than excluding people simply because they are ‘hard to reach’.
- The dialogical approaches central to participatory research involving particular target groups (children/ young persons, people with disabilities and older persons with reduced decision-making capacity) require time, training, resources and a disposition to accommodate the complexity and ambiguity of particular narratives and accounts – for example, children’s accounts are very likely to be different from those of adults.
- A participatory approach to research respects and promotes the entitlement of the target group to have their opinions heard based on the premise that they are persons of value, their experiences are of interest to themselves, and to others, and that they have a valuable contribution to make to social and political life and to policy development.
- From a human rights perspective, involving people with disabilities and older people in research vindicates their right to have their views heard, as afforded to them under Human Rights Conventions and Charters.
- It is during the research process that target groups are afforded a ‘right of correction’ and are afforded an opportunity to define themselves

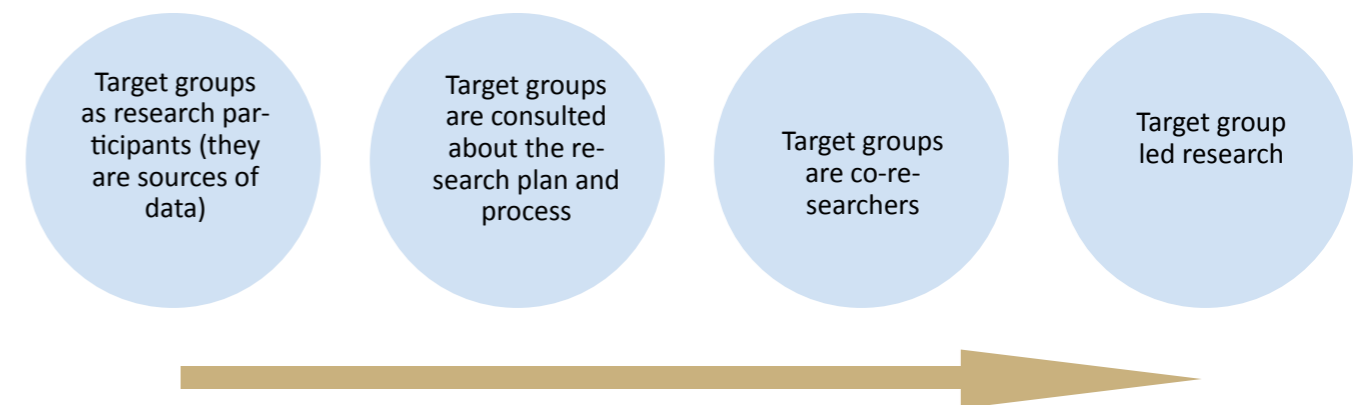
through collaboration rather than to be defined solely by outside research interests, biases and agendas.

The idea of ‘co-constructing knowledge’ with members of the target group implies that researchers open themselves to the possibility of change in response to the expressed views of the members of the target group.

Involving target groups in research

Bigby et al.⁶⁶ have identified three broad approaches to the inclusion of people in research.

Spectrum of target groups involvement in research⁶⁷



An important consideration in participatory research is that power dynamics are dispersed throughout the entire process and that there is what is termed ‘a scaffolding for inclusion’ built into the process – this includes design of supporting documents, provision of facilitation, reaction to prompts from participants and flexibility in relation to meetings.⁶⁸

Based on the foregoing analysis, the Project identified five key components of participatory research as essential for a future Observatory:

1. The shared and distinct purposes of all participants equally valued,

1. Where people with an intellectual disability give advice about what to do;
2. Where people with an intellectual disability lead and control research;
3. Where people with and without intellectual disability work together as a group with different jobs based on their different interests and skills.

The diagram below illustrates the spectrum that could be aspired to in terms of the target group’s participation in research, in this instance, people in receipt of long-term care.

2. Shared involvement and distinct contributions equally valued,
3. Flexible, adapted research methods,
4. Working as a group with trusting relationships and dispersed power, and
5. Scaffolding for inclusion.

64 See Kennan, D., Fives, A., and Canavan, J. (2011), ‘Accessing a Hard to Reach Population: Reflections on Research with Young Carers’, Child and Family Social Work https://www.researchgate.net/publication/230284146_Accessing_a_hard_to_reach_population_Reflections_on_research_with_young_carers_in_Ireland

65 Park, P., (2006). ‘Knowledge and Participatory Research’ in Handbook of Action Research, https://books.google.com/books?hl=en&lr=&id=oSTkb90xofOC&oi=fnd&pg=PA83&dq=what+is+participatory+research&ots=3r5qobIBN_&sig=KK-qjpo_zazKVdOumFKimefnJ8

66 Bigby, C., Frawley, P., Ramcharan, P., Conceptualizing inclusive research with people with intellectual disability, <https://onlinelibrary.wiley.com/doi/10.1111/jar.12083>

67 Adapted from the National Children’s Bureau model of children and young people’s involvement in research, https://www.researchgate.net/publication/269688025_Involving_children_and_young_people_in_research_the_usual_suspects

68 Bigby, C., Frawley, P. and Ramcharan, P., A Collaborative Group Method of Inclusive Research <https://onlinelibrary.wiley.com/doi/10.1111/jar.12082>

Ethical considerations

Research ethics is an essential component of all types of all health research. Health research is defined by the Statutory Instruments associated with the Data Protection Act 2018.⁶⁹ An example of health research provided is: research with the goal of improving the health of the population as a whole or any part of the population through a better understanding of the ways in which social, cultural, environmental, occupational and economic factors determine health status.⁷⁰ This situates many of the key issues associated with the Project firmly under a health research remit.

The Project examined a number of ethical research guidance documents publicly available in Ireland. Many ethical research boards require a proxy decision maker to co-consent to participate in research for what are termed “vulnerable groups”. For example, a research project investigating how the right to legal capacity is experienced by disabled people was asked to ensure that a proxy consent was obtained in relation to any participant with an established decision making support need.⁷¹

While many research ethics guidance documents contain useful advice on how to ensure free and informed consent through additional supports, it is clear that barriers to participation are present due to the complexity of ensuring ethical practice.⁷² Research Boards are rightly concerned with achieving a balance between ensuring that people are not exploited in research and allowing participation. This is a critical consideration because the international evidence suggests strongly that people receiving long-term care

services and supports are not adequately represented in research.⁷³ Inclusive research approaches, as used by Williams et al. have used the term ‘trusted consultees’ to build a supportive and trusted person into the consent process without using language that indicates a substitute decision -maker or proxy.⁷⁴

It is important that a future Observatory considers that some people receiving long term care may have different communication and decision -making support needs. This can present challenges for ensuring informed and free consent to participation in research.

Research methodologies suitable for monitoring human rights issues in long-term care

The Project gathered information in relation to best practice for human rights research and participative methods.

The participatory research approach described above aligns with current human rights scholarship. While traditionally human rights scholarship relied on qualitative methods of research, current scholarship in the area strongly suggests consideration of both quantitative and qualitative approaches when researching human rights.⁷⁵ The European Union Agency for Fundamental Rights has developed guidance on indicators for the transition from institutional care to community based support for persons with disabilities in the context of Article 19 of the UNCRPD.⁷⁶

Akerblad et al. have noted the value of integrated research methods where one method can be enriched with the results of the other.⁷⁷ This type of approach will enable the

methods to complement each other. Fetters has described integration as “the linking of qualitative and quantitative approaches and dimensions together to create a new whole or a more holistic understanding than achieved by either alone”.⁷⁸

Project assessment of research methods in the context of a participatory approach

As stated in Chapter Two above, the Project process included consultation with a number of people with experience of long term care services and supports. The central consultation question was: How can the future Observatory promote participation by people with experience of long-term care in research activities and monitoring? Five key points emerged from this consultation:

1. Physical participation in research focus groups would be challenging for many people in receipt of long-term care;
2. For people living in residential care facilities, the provider of the service would need to support the research;
3. Obtaining consent and research ethics clearance would be an essential requirement;
4. There was a view that payment of expenses may encourage people to participate;
5. More awareness of human rights through information dissemination and independent advocacy would help to create a ‘climate’ for people seeing the important role of research and the need for them to become actively involved;

Online survey as a method of collecting information

This method was considered effective for families and carers but less so for the people with lived experience consulted. Only one had any experience of this and described their experience of online surveys as “tricky”. This experience had been with support. Training support and access to internet and/or a device

were identified as possible ways to improve accessibility. However, in general people with lived experience of long term-care consulted did not see this as a valid approach for participation.

Questionnaire

The Project generated a questionnaire from preliminary identification of potential rights issues which could be used as a participatory methods tool for the future Observatory. Questions were focused on exploring a possible relationship between barriers or supports to rights realisation in long-term care settings identified in the desk review and the actual experience of long-term care recipients. The questionnaire was designed to be fillable on-line and printable.

Evaluation of Questionnaire as a method of collecting information findings:

Family members and carers considered that this approach would require support from families or supporters. People with lived experience of long-term care found the questionnaire too long and a suggestion was made to divide the questionnaire into smaller sections.

The Microsoft word version and fillable versions of the questionnaire were considered by some with lived experience to be too difficult to read. The text to speech function in general was found to be helpful but more detailed instructions were requested on how to enable it within the accompanying information.

Only one participant with lived experience of long term care felt competent to complete the questionnaire independently. Sage Advocacy frontline personnel suggested that a questionnaire approach could be facilitated with one-to-one support. This would have resource implications for a future Observatory. However, feedback from a service provider indicated that this exercise could be provided by staff in long-term care settings and feedback from families indicated that support for this activity could be provided. This approach may have implications from a

69 DATA PROTECTION ACT 2018 (SECTION 36(2)) (HEALTH RESEARCH) REGULATIONS 2018, <https://www.irishstatutebook.ie/eli/2018/si/314/made/en/pdf>

70 Ibid. Section 3 (2(a)(5)).

71 Voices of Individuals: Collectively Exploring Self-Determination. ‘Ethical Issues & Consent’, <https://cordis.europa.eu/project/id/638768>

72 Lasseeter, G. et al., ‘Is the Mental Capacity Act Reducing Generalizable Research in Care Homes?’, <https://www.sciencedirect.com/sdfe/pdf/download/eid/1-s2.0-S0033350611001387/first-page-pdf>

73 Lam, H.R. et al. (2018), ‘Challenges of Conducting Research in Long-Term Care Facilities’, <https://bmccgeriatr.biomedcentral.com/articles/10.1186/s12877-018-0934-9>

74 Williams, V. J., Webb, J. C., Read, S., James, R., Davies, H., & Forget-me-Not Research Group (2020). ‘Future lived experience’: inclusive research with people living with dementia. Qualitative Research. https://www.researchgate.net/publication/338410680_Future_lived_experience_inclusive_research_with_people_living_with_dementia

75 Hafner-Burton, E. and Ron, J. (2009), ‘Seeing Double: Human Rights Impact through Qualitative and Quantitative Eyes’, Murdie and Watson, ‘Quantitative Human Rights’, https://ehb.ucsd.edu/pdfs/seeing_double.pdf

76 European Union Agency for Fundamental Rights, Human Rights Indicators on Article 19 CRPD, <https://fra.europa.eu/en/content/human-rights-indicators-article-19-crpd>

77 Åkerblad, L., Seppänen-Järvelä, R., and Haapakoski, K. (2020), ‘Integrative Strategies in Mixed Methods Research’ https://www.researchgate.net/publication/344869608_Integrative_Strategies_in_Mixed_Methods_Research

78 Fetters, M.D., (2019), The Mixed Methods Research Workbook: Activities for Designing, Implementing, and Publishing Projects, SAGE Publications, p. 293

privacy point of view and may also present conflict of interest issues. There may be scope here for the future Observatory to develop a peer support network of volunteers to support with questionnaires. Alternatively, the Observatory could forge a working relationship with an organisation that has established volunteer capacity.

Focus groups

There was a consensus that the questionnaire process could provide an introduction for focus group participants to common themes and indicators concerning key human rights issues presented by our current systems of long term care. A future Observatory could use this information to facilitate Focus Groups to generate first hand lived experience of key human rights infringements. The Focus Group approach would have the obvious benefit of facilitating and encouraging peer to peer discussion and exchange of views.

Evaluation of a Focus Group approach as a method of collecting information

This approach was considered primarily from a practical point of view. Many people who reside in nursing homes or long-term care settings may have difficulty traveling to attend a focus group. This may require that some focus groups would have to be held within the long-term care settings. Privacy and confidentiality was identified as a potential issue in such an approach.

Overview and Conclusions

The exploration by the Project of how participatory research methods could be used to further the “voice” of those who experience long-term care identified some methods that could be implemented by a future Observatory. From a participatory research perspective, some people within these ‘hard to reach’ populations require significant ‘supportive scaffolding’ to ensure that their voice can

be facilitated. This will require a future Observatory to consider sustainability with regard to the resources needed to facilitate this kind of research. This will also include resourcing monitoring projects to ensure that real inclusion is promoted. Materials used will need to be accessible and supportive to individuals who may not benefit from a traditional consent form or questionnaire. Appropriate one-to-one questionnaire support will often be required.

The process of information gathering from the perspective of those with lived experience will fall under the remit and legal requirements of health research. This will require a future Observatory to take into account timing and the resources required to prepare and submit proposals to ethical research boards.

The commencement of the Assisted Decision-making (Capacity) Acts 2015 and 2022 and, specifically, the introduction of supported decision-making will give effect to the principle of presumption of capacity to make decisions. The legislation provides both an impetus and a framework for a robust participatory research approach by a future Observatory. A participatory research approach which combines the skills of academic researchers or others with those of the target group to generate new knowledge that neither group could do alone offers a useful template for a future Observatory on Human Rights in Long-term Care. Integrating participatory research methods into the work of a future Observatory could also include involving long-term care recipients in disseminating research findings in formats accessible to the target groups as well as actively involving them in the research processes.

The next chapter identifies a number of rights issues regarded as centrally relevant to a future Observatory on Long-term Care.

Chapter Seven

Issues Relevant to an Observatory on Long-term Care

Introduction

Based on the analysis carried out in previous chapters, this chapter identifies a number of rights issues regarded as centrally relevant to a future Observatory on Long-term Care. These are:

- ✓ Deprivation of liberty as a fundamental breach of human rights
- ✓ Safeguarding adults living in vulnerable situations
- ✓ The right to choose
- ✓ Valid consent
- ✓ The long-term care needs assessment process
- ✓ Inappropriate involvement of next-of-kin in decision-making
- ✓ Adequacy of HIQA regulation and standards from a human rights perspective
- ✓ Lack of regulation of home care services
- ✓ Implications of the 2018 Supreme Court judgement in the AC case
- ✓ Protecting the rights of older people with long-term care needs in the context of an ageing population
- ✓ Younger people with disabilities forced to live in nursing homes
- ✓ Social connectedness as a key component of well-being among older persons
- ✓ The need for a participatory research approach
- ✓ The human rights implications of our current long-term care architecture

Deprivation of liberty as a fundamental breach of human rights

Concerns have been expressed in a submissions to the UN Committee Against Torture⁷⁹ regarding possible deprivation of liberty of adults in congregated care settings such as nursing homes, hospitals and other institutions. The Irish Human Rights and Equality Commission (IHREC)⁸⁰ has identified significant concerns regarding the lack of systematic safeguards, vulnerability assessment, and independent regulation across a range of institutional and quasi-institutional settings where people may be at risk - such as health and social care services, accommodation services for homeless people, drug treatment facilities, direct provision centres for applicants for international protection, and residential settings for older people and disabled people.

A UCD study of the experiences of 38 social workers supporting 788 older people in Ireland found that ‘many older people with a mental health issue and/or cognitive impairment/dementia were excluded from the decision-making process [about their care] regardless of their level of functional capacity’.⁸¹ The study found that older people with dementia were particularly likely to be excluded due to ‘[a] status approach to dementia, where people were deemed to lack capacity’, because their ‘family didn’t want them involved’, because they had ‘communication difficulties which impacted on their involvement’ and/or because they had ‘no opportunity to be involved’ or their expressed preference was that ‘they didn’t wish to be involved’.⁸²

79 See, for example, <https://www.sageadvocacy.ie/news/2017/june/sage-makes-submission-to-un-committee-against-torture>

80 Submission to the UN Committee against Torture on the List of Issues for the Third Examination of Ireland <https://www.ihrec.ie/app/uploads/2020/01/Submission-to-the-UN-Committee-against-Torture-on-the-List-of-Issues-for-the-Third-Examination-of-Ireland.pdf>

81 Donnelly, S., O’Brien, M., Begley, E. and Brennan, J. (2016). “I’d prefer to stay at home but I don’t have a choice” Meeting Older People’s Preference for Care: Policy, but what about practice? Dublin: University College Dublin. https://researchrepository.ucd.ie/bitstream/10197/7670/1/IASW.AGE_ACTION.ASI.UCD_Research_Report_on_Care_of_Older_People_2016.pdf

82 Ibid. p.6

This research echoes the finding of the UN Independent Expert on the enjoyment of all human rights by older persons that institutional care 'can often take the form of forced institutionalization and compulsory placements, especially when no other form of care is available for the individual or when relatives are unable or unwilling to provide care'.⁸³

A key aspect of ensuring that individuals are not arbitrarily deprived of their liberty in care settings is protection of the right to recognition of one's legal capacity, and the right to informed consent to care. The UN Special Rapporteur on Torture and the UN Special Rapporteur on Health have both highlighted that 'while informed consent is commonly enshrined in the legal framework at the national level, it is frequently compromised in the health-care setting. Structural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised'.⁸⁴

The UN Committee on the Rights of Persons with Disabilities has stated that 'The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including...the right to liberty'.⁸⁵

Safeguarding adults living in vulnerable situations

The abuse and mistreatment of older people generally remains severely under-reported^{86,87} and monitoring mechanisms for safeguarding are often lacking or ineffective.

There is consensus among stakeholders that primary safeguarding legislation is vital to achieve an adequate standard of safeguarding and related rights protection. A recent (2022) Safeguarding Ireland Report⁸⁸ strongly endorses calls for safeguarding legislation made by various agencies (statutory and NGO) in recent years, including, by HIQA, the National Safeguarding Office, Safeguarding Ireland, the Irish Association of Social Workers, Sage Advocacy and Inclusion Ireland. The need for such legislation arises because of a number of factors, including, in particular,

- The need to broaden the issue of safeguarding at-risk adults beyond the domain of health and social care;
- The need for an independent adult safeguarding oversight body;
- The need for HSE Safeguarding and Protection Teams to have stronger rights of entry and inspection;
- The need for better intra- and inter-agency liaison, collaboration and data sharing;
- The need to ensure that people who experience abuse in any form have easy access to safeguarding and to redress (where the latter is relevant);
- The need to ensure that nursing home residents and other people in long-term residential care facilities are fully safeguarded from abuse and exploitation and that their human rights protected.

In 2018, the Law Reform Commission published an Issues Paper on A Regulatory Framework for Adult Safeguarding⁸⁹ and is due to publish its report on the matter in 2023. A Private Members Adult

Safeguarding Bill 2017 provided for a Safeguarding Authority to be established with a range of powers. This Bill passed Second Stage but was not progressed.⁹⁰

There is a clear need for stronger monitoring of how people in receipt of long-term care services generally are safeguarded and protected from abuse and exploitation. This is a matter that would fit well with a future Observatory on Human Rights in Long-term Care.

The right to choose

While a person who has decision-making capacity is generally free to make their own choices, however foolish, irrational or idiosyncratic others may consider those choices, the same should apply to those who lack capacity. However, the latter group need to be supported in their decision-making in order to ensure that, as far as possible, they are making informed decisions. It has been argued⁹¹ that there is a need for a more collaborative conception of agency (involving others in a supportive role), one that is, in reality, appropriate to all, but especially useful in relation to people with reduced decision-making capacity. This includes being enabled to have control over one's accommodation, daily routines, activities, and general life direction.

In terms of optimising people's right to choose, it is critically important that people are encouraged to communicate their will and preferences with regard to 'place of care decisions.' This would evidently be greatly facilitated if such a decision was included in an Advance Healthcare Directive (AHD). While such decisions can be made in an Enduring Power of Attorney (EPA), in order to create an EPA, it is necessary to obtain legal advice and also an EPA does not come into effect until it is registered. Therefore, there is obvious merit in making provision for encouraging people

who interact with a healthcare professional to make a valid directive with regard to 'place of care' decision that can be acted upon in the event that they subsequently lack capacity to consent.

Residential care as the only 'choice' available

A 2020 Sage Advocacy Discussion Document (referred to in Chapter 4 above) has noted that, under current provision for long-term care, in many instances, a nursing home is the only option available. This is due to the absence of adequate community and home-based care, and the shortage of supported housing options to those that require long-term care and support services.⁹² Also, centrally relevant is the fact that there is no statutory entitlement to home care in Ireland in contrast to statutory provision for nursing home care.

The right to choice of long-term care services is currently not explicitly protected by the international human rights framework. However, the argument can be made that older people do currently have the right to choose the care that they receive protected as a derivative of their legally enshrined right to health, specifically its acceptability in light of culture and community needs.⁹³

Various conventions contain references to the right to equal access to healthcare services, the right to independent living, the right to social security (covering affordable health care) and the requirement for consent to residential care. Equal access to appropriate long-term services including support in the community is a legitimate claim under a human rights based approach. For example, Article 35 of the Charter of Fundamental Rights of the European Union states that everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.⁹⁴

83 UN Human Rights Council, Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, UN Doc A/HRC/30/43, https://www.ohchr.org/sites/default/files/HRBodies/HRC/RegularSessions/Session30/Documents/A_HRC_30_43_ENG.docx

84 <https://www.right-docs.org/doc/a-hrc-22-53/> Par. 29

85 General comment on Article 12: Equal recognition before the law, <https://digitallibrary.un.org/record/779679?ln=en> Par. 8

86 Ludvigsson et al. (2022), Experiences of elder abuse: a qualitative study among victims in Sweden, <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-022-02933-8>

87 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>

88 Browne, M. et al (2022), Identifying RISKS - Sharing RESPONSIBILITIES, Safeguarding Ireland, https://www.safeguardingireland.org/wp-content/uploads/2022/05/6439-Safeguarding-Risks-Resp-Report-FA4_lowres.pdf

89 Law Reform Commission (2019), A Regulatory Framework for Adult Safeguarding' <https://www.lawreform.ie/fileupload/Issues%20Papers/LRC%20IP%2018-2019%20A%20Regulatory%20Framework%20For%20Adult%20Safeguarding.pdf>

90 Oireachtas, 'Joint Committee on Health Debate - Wednesday, 11 Oct 2017'.

91 Carlson, K. and Kittay, E. F. (2010), Rethinking Philosophical Presumptions in Light of Cognitive Disability, https://www.researchgate.net/publication/229726037_Introduction_Rethinking_Philosophical_Presumptions_in_Light_of_Cognitive_Disability

92 Browne, M. (2020), Choice Matters, Sage Advocacy, <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf>

93 Baer, B. et al, (2016), The Right to Health of Older People, https://academic.oup.com/gerontologist/article-pdf/56/Suppl_2/S206/17700727/gnw039.pdf

94 Charter of Fundamental Rights of the European Union, https://www.europarl.europa.eu/charter/pdf/text_en.pdf

A 2016 study on the preferences of older people in relation to long-term care highlighted the gap between policy aspirations and what occurs in practice.⁹⁵ A 2020 Safeguarding Ireland report noted that, while our cultural and attitudinal perspective on the matter was in favour of facilitating long-term care in the community, financial factors, including inheritance, were a factor in relation to decisions about long-term care.⁹⁶

Sláintecare emphasises the need for the right level of care in the right place at the right time which is somewhat at odds with the current two-tier health system generally and long-term care provision specifically.⁹⁷ Key deliverables for Slaintecare include increased access to home support services and planning for long-term care services including intermediate support services.⁹⁸

Valid consent

Consent is at the very core of human rights protection. The UN Independent Expert on the enjoyment of all human rights by older persons has stated that: 'safeguards to free and informed consent should be adopted through legislation, policies and administrative procedures in conformity with international and regional standards. Particular attention should be given to older persons with underdeveloped literacy skills or persons with less formal education.'⁹⁹

The three foundational principles of what is valid consent have been identified as: voluntariness, information giving and decision-

making capacity.¹⁰⁰ The matter of undue influence has also been raised in the context of giving consent in Irish law¹⁰¹ It has been suggested that undue influence can come from many sources within the health care system. This phenomenon has been described¹⁰² as 'hostage bargaining syndrome' whereby people tend not to speak up to assert their views in the presence of clinicians whom they would view as a higher authority. In such situations, an individual may become disempowered and unable to control their own situation thus allowing significant decisions to be made by others on their behalf.

Another issue that arises in relation to voluntariness is the availability of choice. In effect, consent without choice is meaningless as then it becomes a form of coercion. Also, it is likely that in many instances, people may not be advised that consent to a residential placement may also involve consent to loss of autonomy, deprivation of liberty, loss of functional independence and loss of privacy.

The HSE National Consent Policy¹⁰³ stresses that a service user should have the capacity to make that decision and not act under duress in making their choice. Consent is defined in the HSE Policy as

"... the giving of permission or agreement for a treatment, investigation, receipt or use of a service or participation in research or teaching (intervention). Consent involves a process of communication about the proposed intervention in which the person has received sufficient

information to enable them to understand the nature, potential risks and benefits of the proposed intervention".¹⁰⁴

'Informed consent' has been defined¹⁰⁵ as having the competence to do so, the decision being voluntary while having the core information available to assist in the process of making that decision.

The inter-relationship between informed consent and autonomy has been noted.¹⁰⁶ The HSE National Consent Policy affirms that no other person can give or refuse consent on behalf of an adult service user even in cases whereby the service user lacks decision-making capacity. These persons include family members, friends, carers, and organisations – specific legal authority must be in place, e.g., in the form of an Enduring Power of Attorney (EPA). The policy notes that this is not widely known, and family members, for example, may assume that they can provide or refuse consent when a person lacks capacity to make a decision.

The long-term care needs assessment process

When accessing the long-term care needs of older people, countries typically implement an individual needs assessment with frameworks that access activities of daily living, cognitive limitations, and other criteria to determine a person's need for care or services. In Ireland, this is currently carried out through a combination of The Common Summary Assessment Report (CSAR) CSAR and the Single Assessment Tool (SAT).

The CSAR is the main standardised document used to assess the care and support needs of applicants for long-term care. The assessment relates to abilities to carry out activities of daily living, including cognitive ability, degree of mobility, ability to dress and take food

unaided, and ability to communicate. This HSE CSAR Guidance Document¹⁰⁷ states that:

"All older people seeking HSE support for continuing care should have a clinical assessment by either a Consultant Geriatrician or a Consultant in Psychiatry of Old Age and associated members of the MDT prior to the decision being made. This assessment should be specifically to address the appropriateness of the proposed admission into long term residential care. Adults under 65 years may seek additional assessments including neurology or rehabilitation" (Section 10 (b) p.82).

However, the Guidance is not prescriptive on this important matter.

In more recent years, the Department of Health and HSE selected interRAI¹⁰⁸ as the instrument for the assessment of care needs of older people across the spectrum of care, including community, nursing home and hospital. A Single Assessment Tool (SAT) has been developed to uniformly assess dependency levels, allow resources to be targeted towards those with the greatest needs and enabling supports and services to be designed in the most appropriate way possible.¹⁰⁹ Since May 2016 three acute hospitals have started a trial implementation of SAT – Beaumont Hospital, Tallaght Hospital and University Hospital Galway. Multidisciplinary staff in these hospitals were nominated to become SAT assessors and were equipped with and trained to use the standard HSE tablet device. Under SAT, continuity and integration of care between acute and community sectors is facilitated and promoted through the implementation of SAT. Staff in the community areas surrounding these hospitals – Dublin North, Galway and Dublin South West were involved in the implementation of SAT.

95 Donnelly, S., O'Brien, M., Begley, E. and Brennan, J. (2016). "I'd prefer to stay at home but I don't have a choice" Meeting Older People's Preference for Care: Policy, but what about practice? Dublin: University College Dublin, <https://researchrepository.ucd.ie/entities/publication/d9ba66e2-2e85-40f0-9a04-77264c9e47ae/details>

96 Browne, M. (2020), Funding Long Term Support and Care for Older People – A Safeguarding Perspective, <https://www.safeguardingireland.org/wp-content/uploads/2020/10/Web-Version-Funding-Long-Term-Support-and-Care-for-Older-people.pdf>

97 Social Justice Ireland (2021). 'No Going Back to the Two-Tiered Health System'. <https://www.socialjustice.ie/content/policy-issues/no-going-back-two-tiered-health-system#:~:text=People%20should%20be%20assured,on%20the%20expectations%20of%20society.>

98 Sláintecare 2022 Action Plan, www.gov.ie/en/publication/Od2d60-slaintecare-publications/#slaintecare-action-plan-2022

99 https://www.ohchr.org/sites/default/files/HRBodies/HRC/RegularSessions/Session30/Documents/A_HRC_30_43_ENG.docx

100 Mills, S. and Mulligan, A. (2017), Medical Law in Ireland cited in Duffy, M. (2019), The Nursing Home Scheme and Respect for Applicant Autonomy, Dissertation submitted in partial fulfilment of the requirement for the Masters in Healthcare Ethics and Law, Department of General Practice RCSI.

101 https://www.ohchr.org/sites/default/files/HRBodies/HRC/RegularSessions/Session30/Documents/A_HRC_30_43_ENG.docx

102 Berry L., Danaher T., Beckham D., Awdish R. and Mate S. (2017) When Patients and Their Families Feel Like Hostages to Health Care. <https://www.mayoclinicproceedings.org/action/showPdf?pii=S0025-6196%2817%2930394-4>

103 <https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/consent/hse-national-consent-policy.pdf>

104 Ibid. p. 118.

105 Beauchamp and Childress (2013) cited in Duffy, M. (2019), The Nursing Home Scheme and Respect for Applicant Autonomy, Dissertation submitted in partial fulfilment of the requirement for the Masters in Healthcare Ethics and Law, Department of General Practice RCSI.

106 O'Keefe, S. (2008), A Clinician's Perspective: Issues of Capacity in Care. *Medico-Legal Journal of Ireland*,14:41-50. https://www.researchgate.net/publication/255568576_Clinician's_perspective_on_issues_of_capacity_in_care

107 <https://www.hse.ie/eng/services/list/4/olderpeople/national-guidelines-and-procedures-for-the-standardised-implementation-of-the-home-support-service-hss-guidelines.pdf>

108 <https://interrai.org/>

109 https://data.oireachtas.ie/ie/oireachtas/debates/questions/supportingDocumentation/2019-02-05_pq82-5-2-19_en.pdf

The HSE's National Service Plan 2016¹¹⁰ referred to phased implementation being planned with an initial focus on access to long-term care, resulting in a minimum of 50% of NHSS applications assessed using SAT by the end of 2016 with implementation for applications to home care services following resulting in a minimum of 25% of Home Care Packages applications assessed using SAT by the end of 2016. Following an evaluation of the implementation process in these locations, SAT was to be implemented nationally on a phased basis. However, the extent to which this is happening is unclear.

Inappropriate involvement of next-of-kin in long-term care decision-making

The findings of a Red C Public Opinion Survey carried out for Sage Advocacy in January 2018 show that, when asked if a family member has authority to make decisions for someone, without their consent, who is frail but still has decision-making capacity, 30% said that yes the family member does have this authority, 28% did not know and just 40% recognised that the decision continues to lie fully with the person as long as they have decision-making capacity.

More than two-thirds (70%) of respondents answered, correctly, that 'next of kin' is "someone, such as a close relative or friend, who I would like contacted in an emergency".

However, more than half (57%) of people believed that 'next of kin' was "someone who can make healthcare decisions about me if I am unable to". More than half (54%) believed it was "someone who can make personal decisions about me if I am unable to" and more than half (52%) believed that it was "someone who can make a decision about life support treatment for me". More than one-third (35%) believed that 'next of kin' was "the only person to be given medical or personal information about me". Also, almost one-third (32%) believed that 'next of kin' was someone who "can access my bank accounts and assets if I am unable to".

In the context of ensuring that a person's will and preference is to the fore in all decisions

affecting them, it is vital that there is absolute clarity that 'next-of-kin have no legal rights. This is important in order to ensure that people do not get trapped into conflicts between relatives and the concomitant risk of being abused psychologically or financially.

The correct understanding of the limited role of 'next-of-kin is a crucial factor in ensuring that people's right to autonomy and choice is fully respected. The fact that more than half of the population believe that 'next-of-kin' was "someone who can make healthcare decisions about me if I am unable to" is rather startling from a human rights perspective.

Adequacy of HIQA regulation and standards from a human rights perspective

HIQA regulation and standards, while very necessary and important in themselves, may well be inadequate to fully assure high quality individually-tailored care in accordance with people's will and preferences. Regulations and standards are to a large extent limited to the enforcement of those tangibles of the environment and procedures which can be measured. The intangibles that have to do with a human setting, including safeguarding and supportive relationships, may frequently elude the controls of the regulatory process. It is also true that regulation deals only with what already exists. In a field as seriously lacking in innovation as the nursing home sector, regulation is still unable to play the role of creator of new models or planner of new systems. It is almost certain that business methods which underpin the private nursing home sector cannot always provide what makes for a good human environment where people are fully safeguarded and have their human rights upheld.

The 2018 HIQA overview report highlighted the need for stronger safeguarding measures to protect people who live in nursing homes.

"Safeguarding is a basic function of any health or social care service and all service providers need to take this responsibility seriously. There is a clear obligation on registered providers to have

a Garda vetting disclosure for all staff and volunteers available for inspection in the nursing home. However, almost half of Health Service Executive (HSE) services were failing to provide evidence of Garda vetting on inspection in 2018".¹¹¹

Lack of regulation of adult community-based social care services

HIQA is mandated to inspect residential centres but currently has no role in regulating home support services. Currently, home care is provided by the HSE directly or is purchased from a large number of private and voluntary agencies with funding provided by the HSE. Many of these and other private agencies also provide home care privately to clients. Many of those in receipt of home care are among the most vulnerable in that there is limited statutory oversight of the care provided and an absence of nationally mandated standards. Since there is significant potential for abuse and exploitation of people in receipt of health and social care services in the community, there is a clear need for regulation of all adult social care services, including independent and private providers.

As far back as 2011, the Law Reform Commission recommended that HIQA should be empowered to regulate and monitor undertakings that provide professional home care (whether public sector or private sector, and whether for-profit or not-for-profit).¹¹² While it is understood that HIQA is to be given powers to regulate home care services, relevant enabling legislation has not to date been put in place.

While the HSE, in awarding a tender for home care, must satisfy itself that an agency meets certain standards, Standards only describe best practice to be aimed at and, in this sense, are very different from statutory regulation requirements.

In 2021, HIQA published a research report, *Regulation of Homecare*¹¹³ which outlined and

analysed the current landscape of home care in Ireland. The report notes that home care services are not currently regulated to ensure their quality and safety and called for immediate reform, including the introduction of regulation and overhaul of Ireland's home care services. The HIQA Report referred to complex conditions around home care services affected by funding, availability and geography and to the fact that the current system is unsustainable and not meeting the needs of people.

The report calls for an inclusive home care scheme that protects everyone who receives care at home and states that, in order to achieve this, a needs-led, integrated home care system is required, where age is removed as an access barrier. The HIQA report makes the important point that service users should expect the same quality of service regardless of who is providing that service. Thus, standards and regulations for home care services should be applied to all types of providers equally – statutory, private¹¹⁴ and NGO.

It is noted that the current Programme for Government has committed to introducing a statutory scheme to support people to live in their own homes. Such a scheme was to be implemented in 2021 but this has not yet happened.

Implications of the 2018 Supreme Court Judgement in the AC Case

The AC case which refers to a woman who was being "detained" by Cork University Hospital (CUH) against her wish (allegedly) and against the wishes of her adult children is of considerable relevance to the protection of the rights of adults living in vulnerable situations.¹¹⁵

The Supreme Court held that under the doctrine of necessity a hospital had the right to lawfully detain a person briefly in circumstances where there was a concern that the person would be put at risk if they

111 HIQA, Overview report on the regulation of designated centres for older persons – 2018 <https://www.hiqa.ie/sites/default/files/2019-08/2018-DCOP-Overview-Report.pdf> p.51.

112 LRC 2011 Paper, Legal Aspects of professional Home Care, https://www.lawreform.ie/_fileupload/Reports/r105.htm

113 <https://www.hiqa.ie/sites/default/files/2021-12/Regulation-of-Homecare-Research-Report-Long-version.pdf>

114 It should be noted that HIQA currently has no role in monitoring compliance with national standards in private hospitals.

115 The Irish Human Rights and Equality Commission exercised an Amicus Curiae role in the AC Case.

were discharged, but that such a right is only temporary while further investigations are made. The Court set out the procedure to be followed in circumstances such as AC's which have been synthesised as follows.¹¹⁶

1. Whether a person has decision-making capacity or not does not in any way diminish their constitutional rights including their right to liberty (Para 322);
2. The fact that a person may not have the capacity to make a decision about a particular matter does not mean that their wishes in relation to that matter can be totally disregarded (Par. 394);
3. A person always has the right to have their voice heard or represented in any process concerning them. If the person cannot speak for themselves, then they must have a legal representative or other advocate who is otherwise not involved in the dispute to hear their voice and then have it heard in court. (Par. 6 and Par. 393);
4. In principle, when the risk to a person is from a third party (for example, a family member), it is far better that any legal measures are taken against that party rather than restricting the rights of the person at risk in order to deal with it (Par. 381).

Legality of the detention of a person by a hospital/healthcare facility

The following are further relevant points which arise from the Supreme Court judgement in the AC case:

1. A hospital has no overriding legal right to appoint itself as a substitute decision maker for a patient, no legal right to decide how a patient's right to liberty is to be balanced against other rights and general welfare of the patient and no general right to detain (Par. 348).
2. A hospital has, however, a duty of care (in

the context of discharging a patient) to ascertain whether the patient themselves wants to leave or is being pressured into leaving by a third party. Where a hospital has reasonable grounds for believing that a patient may be being pressured into leaving the hospital, or that the patient does not have sufficient decision-making capacity to decide where to go for themselves post-discharge, the hospital should consult the courts and, pending that, can prevent the patient's departure for a short period, but "two weeks would in most cases be too long" (Pars. 351 and 392).

3. The fact that a patient does not have the ability to decide for themselves whether they want to leave or not does not mean that the hospital can make the decision for them – the hospital must seek the assistance of the courts (Par. 393).

Protecting the human rights of older persons with care needs in the context of an ageing population

Ensuring that the rights of people with reduced decision-making capacity are fully protected will present greater challenges as our population ages. More people living to older ages increase the risk of chronic, non-fatal diseases, and therefore, the likelihood of developing disability are higher.¹¹⁷

The number of people with dementia in Ireland (estimated currently to be 55,000¹¹⁸) is expected to grow at an average rate of 3.6 per cent per year over the next thirty years. By 2036, the number of people with dementia in the country will have doubled and by 2046, the number will have almost trebled.¹¹⁹

This growth in numbers will present very significant challenges in ensuring that people's liberty is fully protected. 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 points

related to disability and ageing¹²⁰. 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".¹²¹ 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"¹²² and that "human rights violations against older disabled people are often neither monitored nor categorised as such".¹²³

Younger people with disabilities in nursing homes

The issue of younger people with disabilities in nursing homes has been the subject of debate and public comment in recent years. The Ombudsman carried out an investigation into the placement of persons under 65 years of age in nursing homes. The Ombudsman's Report¹²⁴ (published in May 2021) identified systemic issues, which are compounded by a fractured funding model.

The personal experiences of a number of people who were interviewed during the Ombudsman's investigation were regarded as giving rise to a concern as to whether they fully understood the long term consequences of availing of the Nursing Home Support Scheme. This raises the important issue of ensuring that each individual gives fully informed consent to go into a nursing home on a long-term basis.

The Ombudsman's Report concluded that the framing of policy in respect of people under 65 in nursing homes needs to be underpinned by a rigorous objective assessment of their needs, both at an individual and an aggregated level. This is also necessary in setting

targets, assessing progress against targets and meeting policy objectives. The report noted that, while it is important to address the situation of persons under 65 currently in nursing homes, it is equally important that appropriate measures be put in place in order to reduce the possibility, in so far as is practicable, of other people under-65 finding themselves in the same situation. The Ombudsman acknowledged that, in a very small number of cases, a nursing home may be the most appropriate placement, provided that this is the will and preference of the individual.

It is noted that the Programme for Government commits to reducing and providing a pathway to eliminate the practice of accommodating young people with serious disabilities in nursing homes and that €3m has been allocated to a pilot project by the HSE which aims to facilitate 18 people currently placed in nursing homes to move to more appropriate housing options in the community.

Social connectedness as a key component of well-being among older persons

The significance of social connectedness as a key to well-being for older people has been identified as an important finding of TILDA (The Irish Longitudinal Study on Ageing)¹²⁵. "Social connections, in the broadest sense, have a particularly large influence on personal well-being among older people".¹²⁶ Such connections typically involve the quality of relationships with partners, children, relatives and friends.

McKeown et al. conclude that, since the *raison d'être* of services for older people is to improve their well being, there is a related need to identify clearly the determinants of personal well-being. They state, however, that existing provision seems to be heavily influenced by an

¹¹⁶ Mary Condell, Legal Advisor Sage Advocacy, <https://www.sageadvocacy.ie/media/1665/notes-on-ac-v-cork-university-hospital.pdf>

¹¹⁷ Living Longer, With or Without Disability? A Global and Longitudinal Perspective, <https://academic.oup.com/biomedgerontology/article/75/1/162/5287969>

¹¹⁸ https://dementia.ie/wp-content/uploads/2020/01/Developing_and_Implementing_Dementia_Policy_in_Ireland.pdf

¹¹⁹ https://www.genio.ie/system/files/publications/Dementia_Prevalence_2011_2046.pdf

¹²⁰ 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.

¹²¹ Ibid. p.7

¹²² Ibid. p.5

¹²³ Ibid. p.10

¹²⁴ <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>

¹²⁵ McKeown K., Pratschke, J. and Haase, T. (2014), Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People: Assessment of National Business Case, Dublin: Fourth Age Trust. <https://www.sageadvocacy.ie/media/1562/individual-needscollective-responses-fourth-age-trust-0114.pdf>

¹²⁶ Ibid. p.17.

'illness and disability' model of ageing, whereas the TILDA analysis suggests that a well-being model may be more appropriate and more inclusive of the relevant influences on older people's well-being.

The analysis carried out in the McKeown et al. report suggests that a focus on developing and maintaining well-being, as opposed to focusing on illness and disability, must be central to any long-term care strategy. Enhancing well-being can, of course, be particularly challenging in the case of people who are socially isolated and outside of networks of social engagement, information and supports. This is a key consideration and one which should be to the forefront of policy deliberations relating to long-term care and support. The links between socio-economic status and health and well-being also need to be taken into account in understanding the well-being of older people.¹²⁷

Quality of life in nursing homes is thus also a key element in long-term care policy. As far back as 2000, a National Council on Ageing and Older People Report, *A Framework for Quality in Long-Term Residential Care for Older People in Ireland*¹²⁸ noted that quality standards for long-term residential care need to be addressed in the context of, inter alia, quality of life, having regard to the dignity, independence and autonomy of the older people resident in long-term care settings.

Balancing the requirements of care and people's needs to avoid over-care and learned helplessness is an important quality of life consideration. The distinction between decisional autonomy and the autonomy of execution is an important one in empowering people living in all residential care facilities and is likely to be centrally relevant to their well-being.

The need for a participatory research approach

The Project has explored (Chapter 6) the concept of participatory research in the context of including the voice of people with lived experience of long-term care as a monitoring mechanism for human rights in long-term care provision. Ways of including these groups in the work of a future Observatory were explored in respect their ability to recruit hard to reach participants and ease of use and relevance from the perspective of those participating

Exploring a participatory research approach which combines the skills of academic researchers or others with those of the target group to generate new knowledge and insights that neither group could do alone offers a useful template for a future Observatory on Human Rights in Long-term Care. The Observatory will need to plan research, monitoring and partnerships with a participatory research focus in mind.

The human rights implications of our current long-term care architecture

The overarching factor relevant to all of the above issues is the current architecture of our long-term care system in Ireland which is fundamentally at odds with the full protection of all of the human rights of people who require long-term care and support.

The case for the need to reconfigure our long-term support and care system and to develop structures and services that protect people's rights by moving them out of nursing homes into safe, supportive communities has been clearly articulated in a 2020 Sage Advocacy report.¹²⁹ We need to champion the right to community living for older people with care needs. Fundamentally, we need a health and social care system that supports citizens to live at home, or a place that feels like home, with care organisations that are part of and controlled by the local community. At its very

core, 'home' means small, personal and living with people a person has chosen to live with. It is almost certain that the absence of strong community connections for nursing home residents with its concomitant isolation and loneliness made their experience of Covid-19 worse than it might have been.

While we rebuild our long-term support and care systems, we can hardly want to reconstruct the current fractured nursing home system. The State currently spends over 1 billion euros a year on the Nursing Home Support Scheme, a figure that will undoubtedly increase as the population ages and if the current system remains intact. We need to find a better way to spend this money.

We need to find sustainable, creative and more humane ways to care for people with long-term support and care needs. We need a more comprehensive and holistic approach rather than the one currently pursued which is underpinned by a profit agenda, sectional interests and a dangerous architecture of intertwined but unintegrated state agencies. Responsibilities, resources, and risks need to be more evenly and transparently shared. Formal support and care services, whether in the community or in a residential care facility cannot be run remotely, nor owned offshore. Obscure corporate entities are the antithesis to a socially inclusive and human rights long-term care system.

The way our long-term care services are organised has been the subject of policy debate for over 30 years. The need to evolve from nursing homes to cost-effective, stay-at-home alternatives has been consistently and regularly referenced in policy documents and reports since *The Years Ahead Report*¹³⁰ was published in 1988. The issue will need to be at the very core of the work of a future Observatory on Human Rights in Long-term Care.

Implementing the public sector duty

The implementation of the statutory obligations within Section 42 IHREC Act 2014 will significantly contribute to the proposed Observatory on Long-term Care.

In accordance with section 42(1) of the Act, public bodies involved in the development of long term care should in the performance of its functions, have regard to the need to:

- (a) Eliminate discrimination
- (b) Promote equality of opportunity and treatment of its staff and the persons to whom it provides services, and
- (c) Protect the human rights of its members, staff and the persons to whom it provides services

The implementation of the Duty as set out in guidance from the Irish Human Rights and Equality Commission,¹³¹ Implementing the Public Sector Equality and Human Rights Duty, which provides a key mechanism to ensure delivery of the equality and human rights agenda identified in this project.

Overview and Conclusions

This chapter has set out a number of overarching issues relevant to the protection of human rights in long-term care. Existing practice has been shown to frequently fall short when examined through a human rights lens. The system is permeated by practices that fail to give 'voice' to people with long-term care and support needs, including, in particular, the way needs assessments are carried out and the practice in many instances of wardship being the only option pursued when there is a question about a person's decision-making capacity. There is a need for vigilance in protecting the human rights of older people with care and support needs in the context of an ageing population where there are likely to be higher levels of dependency. In this regard, the links between social connectedness and well-being must be centre-stage as we design a new human rights based architecture for long-term care.

The next chapter will set out a proposed structure and design for a future Observatory on Long-term Care.

¹²⁷ Layte, R. and Fahey, T., (2001), "Living Standards and Health of Older people" in Towards a Society for All Ages: Conference Proceedings, National Council on Ageing and Older People;

¹²⁸ National Council on Ageing and Older People (2000), A framework for quality in long-term residential care for older people in Ireland <https://www.lenus.ie/bitstream/handle/10147/46364/10718.pdf?sequence=1&isAllowed=y>

¹²⁹ Browne, M. (2020), Choice Matters, <https://www.sageadvocacy.ie/media/2026/choicematters2020.pdf>

¹³⁰ The Years Ahead, <https://www.lenus.ie/bitstream/handle/10147/46365/1305.pdf?sequence=1&isAllowed=y>

¹³¹ <https://www.ihrec.ie/documents/implementing-the-public-sector-equality-and-human-rights-duty/>

Chapter Eight

Proposed Structure and Design of a Future Observatory on Long-term Care

Introduction

The Project was tasked with identifying a framework for a future Observatory on Long-term Care and with proposing a sustainable structure for such an Observatory. This chapter sets out a conceptual framework, terms of reference and an operational structure for the Observatory.

Key factors that will inform the work of an Observatory

- Despite the fact that the Covid-19 Expert Group on Nursing Home Care has called for a new approach to long-term care and support,¹³² including new models and approaches, there is no meaningful progress in this area and the same system continues in place.
- There are considerable challenges facing the home care sector in the run-up to regulation, especially a shortage of skilled staff and a failure to adopt any innovative approaches to community-based home care.
- There is still no date from Government for the establishment of the Commission on Care which was promised in the Programme for Government.
- There is a serious deficit in public discourse regarding long-term care – for example, media coverage on nursing homes tends to be dominated by the agenda of representative organisations for private sector interests.
- The Nursing Home Support Scheme with its heavy and growing reliance on the private nursing home sector is totally inadequate as a mechanism for long-term care – both because it is confined to residential care and

because of its heavy reliance on private nursing home providers.

- There are growing concerns about the increase in the size of nursing homes – while smaller ones are closing, major developments, including acquisitions and buy-outs in the private nursing home sector, are being regularly reported in the media.
- As more small-scale nursing private home operators leave the market and are replaced by conglomerates, it is reasonable to suggest that any benefits associated with local and ‘small is better’ will be lost, to the detriment of the human rights of current and future residents.
- Pressure on private nursing home operators to cut costs, increase profits, pass on charges to residents is a major concern in terms of enabling a rights protection living environment in nursing homes.

Purpose of the Observatory

The Project has identified the following objectives for the Observatory:

1. To develop a public interest counterbalance to the current outsourced market-driven approach to long-term care provision;
2. To provide informed commentary on the current architecture of long-term care in Ireland using a human rights lens;
3. To monitor existing policy and practice on long-term care taking into account the provisions *inter alia* of the UN Convention on the Rights of Persons with Disabilities, the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and

the Assisted Decision-making (Capacity) Acts 2015 and 2022;

4. To carry out research on long-term care provision in Ireland relating to key human rights issues, in particular, deprivation of liberty, degrading treatment and the right to self-determination;
5. To inform the deliberations of the proposed Commission on Care and any similar Commission established in the future;
6. To promote a participatory research approach to policy development and related research – ‘nothing about us/without us’.

Conceptual framework for a future Observatory on Long-Term Care.

The Project examined the Donabedian model which has been used to conceptualise quality assurance in healthcare settings¹³³ and which has been widely applied to research on human rights in health care provision.¹³⁴

The European Centre for Social Welfare Policy and Research (ECSWPR) has developed a conceptual framework¹³⁵ of a human rights-based approach to care and support for older persons in Europe using this model. It is suggested that this model could usefully be applied to a future Observatory on Human Rights in Long-term Care.

The ECSWPR conceptual framework is presented in graphic form in Figure 8.1 below. It comprises three levels:

1. Desired outcomes: Fulfilment of rights
2. Enabling processes: Monitoring and enforcement
3. Structural conditions: Legal recognition

The first level – Desired Outcomes: Fulfilment of Rights – focuses on identifying and elaborating the ten universal rights most fundamental to older persons with care and support needs. These rights are centrally placed within this level.

¹³² COVID-19 Nursing Homes Expert Panel Report, <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>, p.78 ff.

¹³³ Donabedian, A. (1980), Explorations in Quality Assessment and Monitoring: The Definition of Quality and Approaches to Its Assessment, PhilPapers

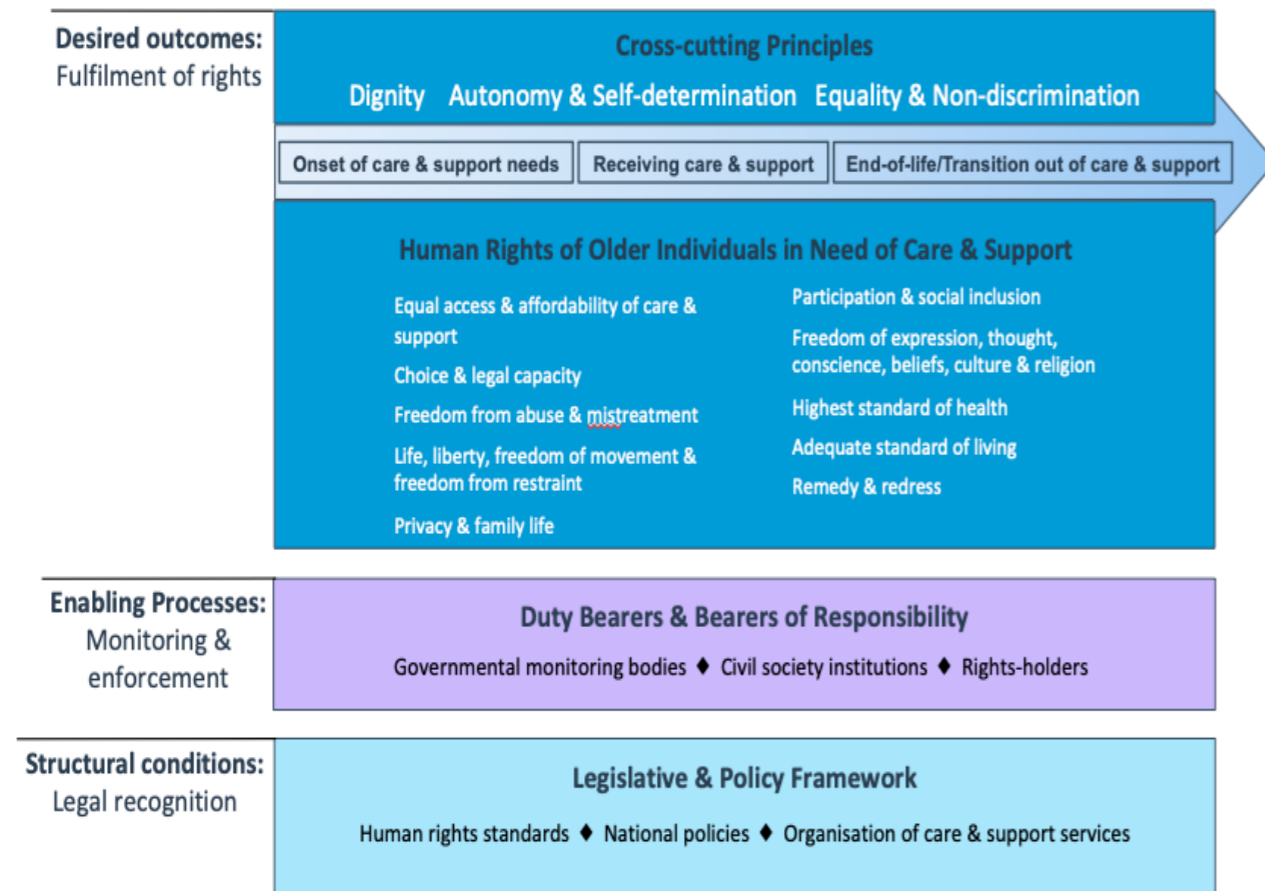
¹³⁴ Sundler et al., Unmet Healthcare Needs and Human Rights – A Qualitative Analysis of Patients’ Complaints in Light of the Right to Health and Health Care

¹³⁵ Towards a Rights-Based Approach in Long-Term Care – European Centre for Social Welfare Policy and Research. Project website <https://www.euro.centre.org/projects/detail/85>.

See also Schulmann, K., Ilinca, S. & Rodrigues, R. (2018). From disability rights towards a rights-based approach to long-term care in Europe: European Centre for Social Welfare Policy and Research, <https://www.euro.centre.org/publications/detail/3094>

Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K. (2019). From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people. Vienna: European Centre for Social Welfare Policy and Research. <https://www.euro.centre.org/downloads/detail/3511/1>. Schulmann et al. (2019). Rights-based approach to care and support for older persons. Policy Brief 2019/1. European Centre for Social Welfare Policy and Research <https://www.euro.centre.org/downloads/detail/3364>

Figure 8.1: Conceptual framework of a rights-based approach to care and support for older persons



Source: Schulmann, K. et al., *Rights-based approach to care and support for older persons*, European Centre for Social Welfare Policy and Research <https://www.euro.centre.org/downloads/detail/3364> p.5.

Underpinning the ten universal rights are three cross-cutting principles:

- Dignity
- Autonomy and self-determination
- Equality and non-discrimination

These principles are enshrined in all human rights instruments and are widely considered¹³⁶ to be the cornerstone of a human rights approach.

Running across the width of the framework is the **Care Trajectory Arrow**. This represents the dynamic nature of the interaction between older people and the providers of care and

support, from the onset of care and support needs, through the period during which care and support is received, to end-of-life care or a transition out of care and support. Depending on the point at which a person finds themselves in the care trajectory, the application of each of the universal rights will likely be qualitatively different due to changing care needs and preferences.

The second level - **Enabling Processes: Monitoring & Enforcement** - signifies the duty of national governmental bodies to uphold human rights through well-defined monitoring and enforcement instruments. Importantly, it notes the role and efforts of both

governmental institutions and civil society organisations in achieving the fulfilment of rights.

The third level - **Structural Conditions:**

Legal Recognition - reflects the legislative commitments of States to the human rights of older persons with care and support needs, and serves to cement the importance of legally binding standards for human rights at the international, regional and national levels. A human rights approach that has no basis in law is likely to suffer from poor implementation and will always be subject to political cycles.

The conceptual framework presented in Table 8.1 above suggests that the legislative and policy framework (Level Three), while a prerequisite for the protection of rights, is in itself insufficient for their fulfilment. Just as important are monitoring, enforcement, and the resources allocated to implement legislation, that is, the enabling processes depicted at level two in the framework. In turn, the structures and processes that enable rights to be fulfilled, i.e., through appropriate enforcement mechanisms and sufficient resources, are a crucial component.

The FREDA principles

The Observatory on Long-term Care would be based on an analysis of current long-term care practice through a human rights lens.¹³⁷ HIQA and Safeguarding Ireland have published guidance on a human rights-based approach in health and social care services.¹³⁸ The guidance is built around five principles – fairness, respect, equality, dignity and autonomy (FREDA) which provide a framework for how frontline health and social care professionals can support human rights in their daily work. It is suggested that the FREDA principles approach offers a useful benchmark for analysing and critically evaluating long-term care provision in Ireland and could be used by an Observatory to develop an index of rights to be monitored.

Functioning of the Observatory

It is proposed that the Observatory would carry out the following activities:

- Research (including operational and market analysis and issues related to design and the physical environment);
- Observation and human rights monitoring across all forms of long-term care provision (using a participatory research approach where possible);
- Lobbying policy-makers, decision-makers, public influencers and public representatives;
- Public commentary based on the development of new models of long-term support and care;
- Developing mechanisms for participatory research involving long-term care recipients and their families and care providers;

These activities would occur simultaneously or separately depending on the capacity and strategic and implementation plans of the Observatory and any partner organisations at the time.

Structure of the Observatory on Long-term Care

The Project identified two options regarding how the Observatory could best be structured.

Option A Structure

A stand-alone organisation with secured annual funding. This structure may not be immediately feasible but could be worked towards incrementally.

Option B Structure

The Observatory would be adopted by an existing appropriate parent organisation which possessed similarly aligned goals and principles. This provides a feasible option particularly for the beginning and initial establishment of the Observatory. It would also allow for access to shared personnel and other resources.

¹³⁶ Schulmann et al. (2018). From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people, Working Paper II: Conceptual framework for a human rights-based approach to care and support for older individuals. Vienna: European Centre for Social Welfare Policy and Research. <https://www.euro.centre.org/publications/detail/3094>

¹³⁷ Fitzgerald, Sarah; Behan, Laura; McCarthy, Shauna; Weir, Linda; O'Rourke, Niamh; and Flynn, Rachel (2020) "Translating a Human Rights-based Approach into Health and Social Care Practice," *Journal of Social Care*: Vol. 3, Article 3. Available at: <https://arrow.tudublin.ie/jsoc/vol3/iss1/3>

¹³⁸ <https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF>

Both options would require the establishment of partnerships with other relevant organisations promoting human rights in long-term care and both would require additional revenue streams to deliver on the Observatory goals.

It is recommended that, in the short-term at least, the Observatory on Long-term Care would be established under the auspices and governance of Sage Advocacy and that additional funding be sought by Sage Advocacy for this purpose.

This approach would enable the Observatory to commence its work with immediate effect. This would be very important in the context of informing the Commission on Care and other legislative provisions presently in the pipeline relating to, for example, deprivation of liberty, adult safeguarding and home care provision.

Stakeholder involvement in the Observatory

One of the elements in the functioning of a future Observatory identified by the Project was the need to have in place an Expert Advisory Committee with representation from key stakeholders. The following is an indicative list of stakeholders identified by the Project as Expert Advisory Committee members is:

- ✓ Those with lived experience of long-term care
- ✓ Independent advocacy providers
- ✓ Academic researchers
- ✓ Long-term care service providers
- ✓ Public interest representatives
- ✓ Health and social care regulatory authorities

*Advisory Committee membership:
Expertise and skills required*

- ✓ Chair: A person commanding wide-ranging respect with regards to human rights/social inclusion or a related field
- ✓ Academics with a specific interest in long-term care and/or human rights
- ✓ People with experience of supporting/providing human rights in long-term care settings
- ✓ Expertise arising from experience of being in receipt of long-term care and support services

- ✓ Independent advocates
- ✓ Experience of promoting leadership and empowerment for people with reduced decision-making capacity

Suggested operational structure for the Observatory

The Project has identified the following as an indicative operational structure for the Observatory. (see Figure 8.2 below).

Figure 8.2: Indicative operational structure for Observatory



Conclusion

This Project has explored the multi-faceted dimensions to a human rights approach to long-term care. It has identified the key issues arising in relation to human rights for older people and long-term care recipients. It has located these issues within a framework that can effectively monitor the human rights situation for those availing of long-term care and support services in Ireland.

The Project examined the key human rights instruments and legislation relevant to a human rights approach. A number of issues arising from the current architecture of long-term care in Ireland have been identified based on existing research and monitoring and on the experience of Sage Advocacy. The importance of and challenges to a participatory research approach have been identified - in particular, with reference to the need to include the voice of recipients of long-term care in order to give this group a 'voice'. Ethics research considerations will be an essential component of this.

The issues identified by the Project have highlighted the need for a single tier long-term support and care system and for a new vision in this regard which would result in sustainable, creative and more humane ways to care for people with long-term support and care needs.

There is a clear need for a more comprehensive and holistic approach rather than the one currently pursued which is underpinned by a profit agenda. Responsibilities, resources, and risks need to be more evenly and transparently shared and all of society - citizens, front line services, and Government - need to take radical action to achieve this vision.

The proposed Observatory on Long-term Care has significant potential to contribute to bringing about the required change. It can act as a witness to human rights infringements in the way long-term care is currently delivered and can raise public and political consciousness about these critically important issues. The Observatory can have a necessary and vital role in exposing issues that have been for too many years 'hidden in plain sight'.

Sage Advocacy, because of its significant engagement with human rights issues, with both individuals and systemically, is well placed to manage an Observatory on Long-term Care. It can get the Observatory established speedily and set in motion mechanisms to implement the various Observatory objectives set out above. Critically, it can ensure that the work of an Observatory can inform the important work of the Commission on Care once that is established by Government.



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