



sage
advocacy



Coimisiún na hÉireann
um Chearta an Duine
agus Comhionannas
Irish Human Rights and
Equality Commission

The Project

*"Establishing an Observatory for
Human Rights in Long Term Care"*

Origins of the Project 2020

- Government pledged to establish a **Commission on Care** in its Programme for Government 2020
- Sage Advocacy and other stakeholders recognise this as an opportunity for stakeholders to influence policy toward forwarding Human Rights in Long Term Care.
- Sage Advocacy takes the lead and secures a grant from IHREC for the project, **“Establishing an Observatory for Human Rights in Long-Term Care”**

Draft Project Report!

- The project is currently in Preliminary Draft stage and elements are subject to change.

WHAT IS LONG-TERM CARE:

- The term long term care can be applied to a broad range of services and assistance to people who require support to complete daily tasks over an extended period of time.
- Care and support services expected to be in place for a duration of longer than six months are often referred to as long-term care services.
- May include rehabilitation, basic medical treatment, home nursing, social care, housing and services such as transport, meals, occupational assistance and help with managing one's daily life.
- Care is usually provided to disabled persons or people who lack energy due to age or past illness.

WHAT IS AN OBSERVATORY?

- Human Rights Observatory's worldwide employ a variety of different methods to establish information and promote the realisation of Human Rights.
- These methods are selected to best serve the aims of the observatories.
- An Observatory can take on many functions. Some functions include monitoring human rights through research and observation, publicising human rights issues, lobbying for change, training and empowerment of marginalised communities.

The project is tasked with looking at ways through which people with lived experience of long term care can participate, looking at the key issues in human rights and long term care currently in Ireland and recommending possible terms of references, structures and approaches for the future Observatory.

Older People, Human Rights and Long-Term Care

- All people using Long-Term Care Services are entitled to full realisation of all human rights.
- The presence of an impairment or categorisation of disability does not fully address the human rights experience for older people.
- The failure to develop human rights standards in Long-term Care reflecting both the UNCRPD and a convention focused on the realisation needs of older people has had the unfortunate result of older people suffering from the invisibility endured in the past by other marginalised groups.
- The Future Observatory of Human Rights in Long-Term Care may focus on possible policy and systems gaps identified in Ireland to increase visibility in respect of Human Rights for Older people.

Aims of the Project

Identify

key human rights issues relevant to current long-term care provision in Ireland



Develop

an understanding of participatory methods to involve users of long-term care services in identifying rights issues



Identify

Terms of Reference and propose structures for a future Observatory.



Research method 1: Desk research

The desk research had four overarching and interlinked components:

1. Participatory research methods, how can the observatory be designed to ensure participation of those with experience of using long-term care services?
2. International and Irish human rights instruments relevant to people requiring long-term care.
3. Research on rights infringements in Ireland in relation people in receipt of long-term care.
4. The current model for the delivery of long-term care in Ireland and its implications for protecting the rights of people who require such care.

*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.

Human Rights Based Approach (HRBA)

- A human rights-based approach to Long-Term Care attempts to anchor all policies, and systems in principles derived from international human rights treaties.
- The participation of rights-holders in this process contrasts with a traditional needs-based approach.
- A needs-based approach recognises care needs assessed by a competent authority not by the recipients themselves.
- Characteristics of a HRBA to long term care and support services focuses on the empowerment of people receiving services.

Human Rights Based Approach

- The Madrid International Action Plan on Ageing (MIPAA) has been criticised for lacking effective participation from older people.
- Participation and empowerment in relation to people with experience of long-term care requires systems to be receptive and reactive to their participation.
- The Future Observatory will seek to empower the voice of those with lived experience of Long-Term Care through information gathering **and** in its lead and design.

Human Rights Based Approach and Active Citizenship

- The European Network of National Human rights institutions have identified that a key element of a HRBA approach to long-term care would be;

“all key stakeholders are empowered and can participate in achieving the realisation of rights”.

The future Observatory will seek to create a forum where all key stakeholders are represented, including independent advocacy services, regulators, providers, civil societies, Funders etc

The project wanted to find out; how can the Future Observatory encourage empowerment and participation for people who use Long Term Care services and supports?

- The project researched challenges to participation for people use long term care services and supports and research models that supported empowerment.

Participation

- As we heard from Katja on Wednesday, Older people (>65 years old) are underrepresented in research (*Forsat et al. 2020*)
- At present internationally it is clear that people receiving long term care services and supports are not adequately represented in research. (*Lam et al. 2018*)

Protection and Participation

- Participation in research activities for people who may experience vulnerable situations such as living in a long-term care setting or requiring additional support to make decisions is ethically scrutinised to ensure that research is not exploiting people who may be vulnerable.

Consent to participation

- One of the reasons for this explored by the project was respect for the right to decide to consent to participation in research.
- We found that guidance for research for people who may be considered vulnerable was in some ways problematic from the point of view of empowerment and respect for decision-making and self determination.
- Many ethical research boards require a proxy decision maker to co-consent to participate in research for what are termed “vulnerable groups”.
- In Ireland there is no legal weight to what a “proxy decision-maker” may decide however this is considered a safeguarding mechanism to protect research participants
- The amendments currently pending to the ADMA 2015 include provisions to support participatory research for people who may be considered vulnerable.

How will the Future Observatory Promote Participation of people with lived experience of long term care?

- Collaborative group approach respects the purposes of participants equally valued, shared involvement and distinct contributions equally valued, flexible, adapted research methods, working as a group with trusting relationships and dispersed power, and scaffolding for inclusion.

'A Collaborative Group Method of Inclusive Research - Bigby - 2014 - Journal of Applied Research in Intellectual Disabilities - Wiley Online Library'.

- Establishing an Advisory Board to lead and govern the Observatory, including members with lived experience of long-term care in order to work within a collaborative group approach and facilitate expertise in lived experience.
- The Project has developed a guide to participatory research methods for use by the Future Observatory this guide outlines the “supportive scaffolding” required to promote participation of people with experience of long term care.

*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 desk research methods were used for this purpose:
 - 1) An analysis of selected HIQA reports
 - 2) An analysis of selected research reports by Sage Advocacy and by Safeguarding Ireland

Analysis of HIQA Reports Sample

Key Rights	1	2	3	4
Right to life	End of life care judged appropriate Substantial Compliance in protection from Infection	End of life plans in place with resident consultation. Substantial Compliance in Protection from Infection	No information available Substantial Compliance in Protection from Infection	No information available Protection from Infection Not Compliant

Findings

- Our snapshot of 4 reports from the perspective of Key human rights issues found possible rights related examples in the areas of autonomy, the right to participation and social inclusion, the right to family and private life, access to justice and safeguarding. These findings will feature in our chapter Exploration of Topics to be considered by the Observatory based on existing Research and Experience.

Evaluation of Method for use By the Future Observatory

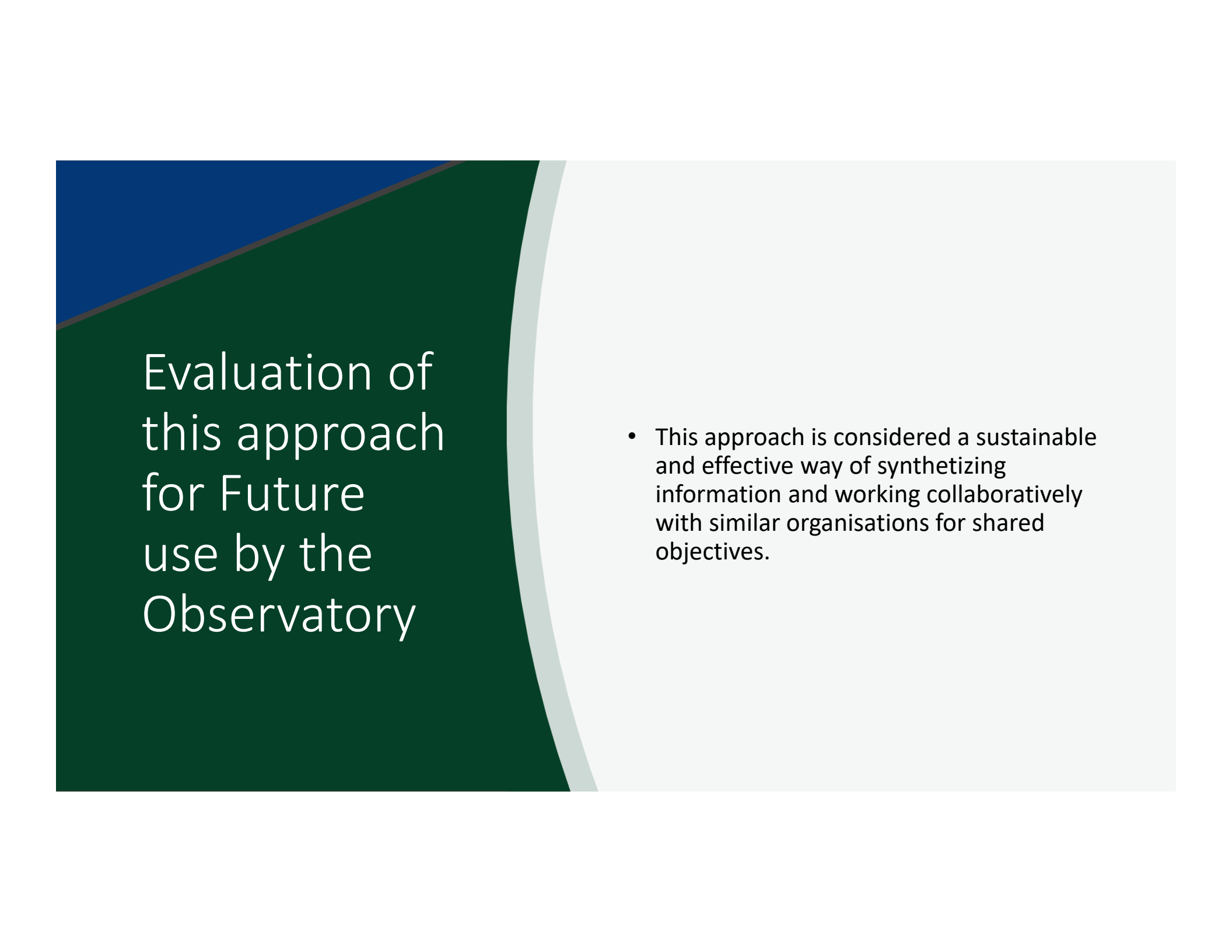
- This method produced a snapshot of the situation in nursing homes from a human rights perspective. The method was considered practical and effective. Depending on resources available the Observatory could decide to replicate the snapshot situation intermittently to gain an understanding of the current overall picture. Another option would be to focus a larger study on individual key issues.

Key Findings Sage Advocacy and Safeguarding Ireland

- Communication support issues resulting in problems establishing will and preference
- Presumption of Capacity Principle not respected
- Consent procedures not adhered to
- Finances inappropriately controlled by others.
- Right to liberty not protected
- Inappropriate involvement of relatives in decision making.

Key Findings Sage Advocacy and Safeguarding Ireland

- Use of wardship
- Lack of protection against Deprivation of Liberty in Nursing Homes.



Evaluation of this approach for Future use by the Observatory

- This approach is considered a sustainable and effective way of synthesizing information and working collaboratively with similar organisations for shared objectives.

Key issues found

Areas of autonomy and recognition of and support for decision making and legal capacity

Deprivation of liberty

The right to participation and social inclusion

The right to family and private life

Access to justice and safeguarding

Recommendations for the Future Observatory

- These issues could possibly be addressed within a framework that can effectively monitor the human rights situation for those availing of long-term care and support services in Ireland. The Donabedian model has been used to conceptualise quality assurance in healthcare settings for many years. This structure-process outcome model of quality evaluation theorises that changes to structural conditions with effective enabling processes will improve outcomes.

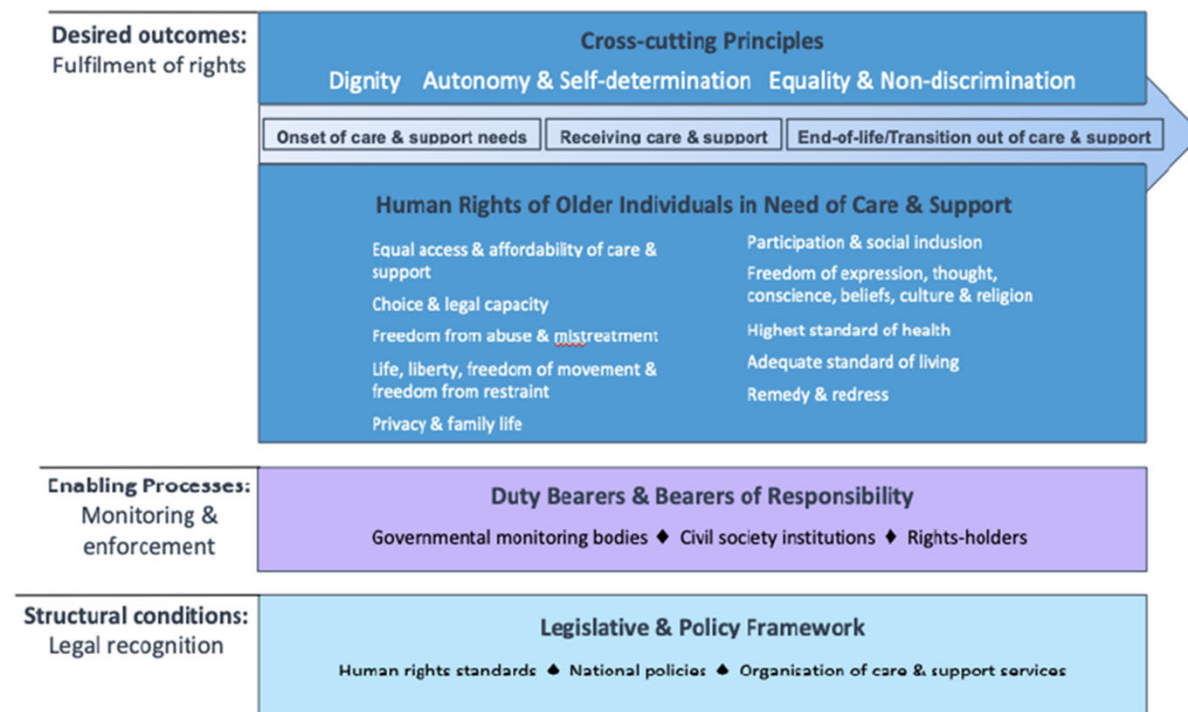
'Avedis Donabedian, Explorations in Quality Assessment and Monitoring: The Definition of Quality and Approaches to Its Assessment - PhilPapers'.



Recommendations for the Future Observatory

- The use of this model has been applied to research in relation human rights in health care provision. European centre for social welfare policy and research have developed a conceptual framework of a human rights based approach to care and support for older persons in Europe using this model. Please see figure below.
- *'Towards a Rights-Based Approach in Long-Term Care- Projects - European Centre for Social Welfare Policy and Research'*.

Figure 1: Conceptual framework of a rights-based approach to care and support for older persons



*DESIRED
OUTCOME*
**FREEDOM FROM
ABUSE AND
NEGLECT**

- Safeguarding is a key area of concern for Human Rights and Long-term care

Monitoring and enforcement

- There is no legislative provision for access by independent advocates to nursing homes (public or private).
- HIQA regulates services and 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 right of access to private nursing homes.

Monitoring and enforcement

- Currently, there is a lack of clarity and guidance as to what data can be shared and under what conditions between individuals and organisations where concerns of abuse, neglect and exploitation of an adult at risk are being investigated.



Monitoring and enforcement

- There is a need for clarity in this area in order to increase cooperation and ultimately protection for those at risk of abuse and neglect.

STRUCTURAL CONDITIONS

- There is a need for targeted safeguarding legislation that will improve awareness, reporting and access.
- Safeguarding measures require a legislative basis to ensure that they are fully implemented.
- The HSE National Policy & Procedures, MHC National Standards, and HIQA and Safeguarding Ireland Guidance do not have adequate legislative backing.

STRUCTURAL CONDITIONS

- The absence of a primary legislative basis focused on the Safeguarding of Adults in Ireland is a structural concern for the realisation of the right to freedom from abuse and neglect.
- There is consensus among stakeholders that primary safeguarding legislation is vital to achieve an adequate standard of safeguarding.
- The law reform commission has published a framework for this legislation. The need for this legislative basis been established since 2017.

POSSIBLE ENABLING PROCESSES;

The future Observatory may decide to focus on working towards enabling processes in the following ways;

AWARENESS

- As established by Safeguarding Ireland, the public awareness of reporting structures for adult abuse is poor. The Observatory may decide to develop activities that increase knowledge and awareness of these reporting structures.



**POSSIBLE
ENABLING
PROCESSES;**

PARTICIPATION AND DEVELOPMENT OF ADVOCACY

Involvement in and promotion of information and rights awareness training among those experiencing long-term care services.

POSSIBLE ENABLING PROCESSES;

MONITORING

- Conduct research on abuse and neglect pertinent to long term care settings.

PUBLICISE

- Publicise research findings

LOBBYING

- Lobby for a more effective interface between the HSE safeguarding and protection teams and HIQA. Including information sharing and coordinated activities.

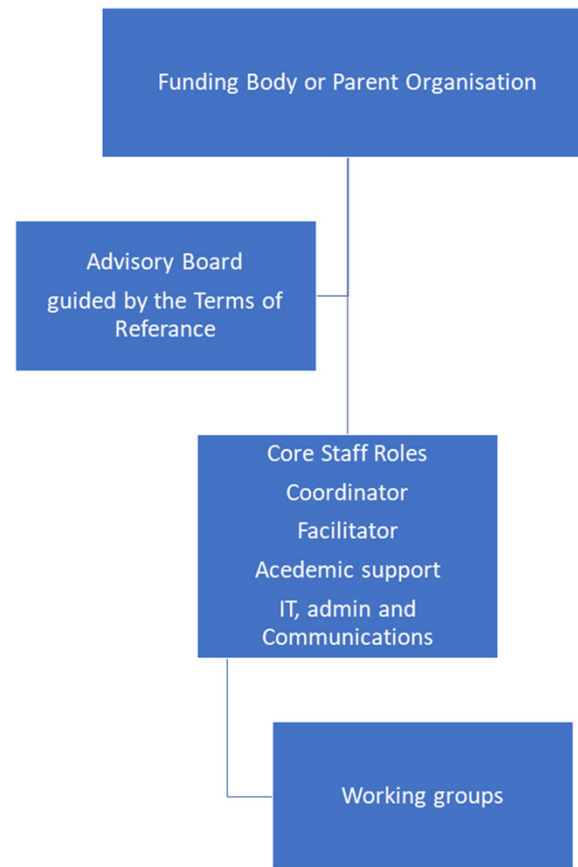
POSSIBLE ENABLING PROCESSES;

- **LOBBYING**
- Lobby for a primary legislative basis for Safeguarding Adults including mandatory reporting, access for independent advocates, access for HSE safeguarding and protection teams to have access to all long-term care facilities.

POSSIBLE ENABLING PROCESSES;

- **LOBBYING**
- Lobby for a more effective interface between the HSE safeguarding and protection teams and HIQA. Including information sharing and coordinated activities.
- Lobby for a primary legislative basis for Safeguarding Adults including mandatory reporting, access for independent advocates, access for HSE safeguarding and protection teams to have access to all long-term care facilities.

Proposed
structure for the
formation of a
Future
Observatory on
Human Rights in
Long-Term Care



Thank you!

sage advocacy

**Observatory on
Human Rights in
Long-Term Care**



To examine the key human rights issues for people
with experience of long-term care and support.