

Independent Advocacy in Ireland

Current Context & Future Challenge



Roundtable on Advocacy

17th October 2018

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Scoping Document

***Independent Advocacy in Ireland
Current Context and Future Challenge***

***An important and timely initiative by
Safeguarding Ireland***

Outline of Presentation

- Why a discussion on advocacy is important
- Defining and understanding advocacy
- Non-instructed Advocacy
- Independent advocacy
- Challenges to independent advocacy
- Linking advocacy with a human rights approach
- Development of policies and legislation in Ireland
- A National Framework for Independent Advocacy
- Overview and questions

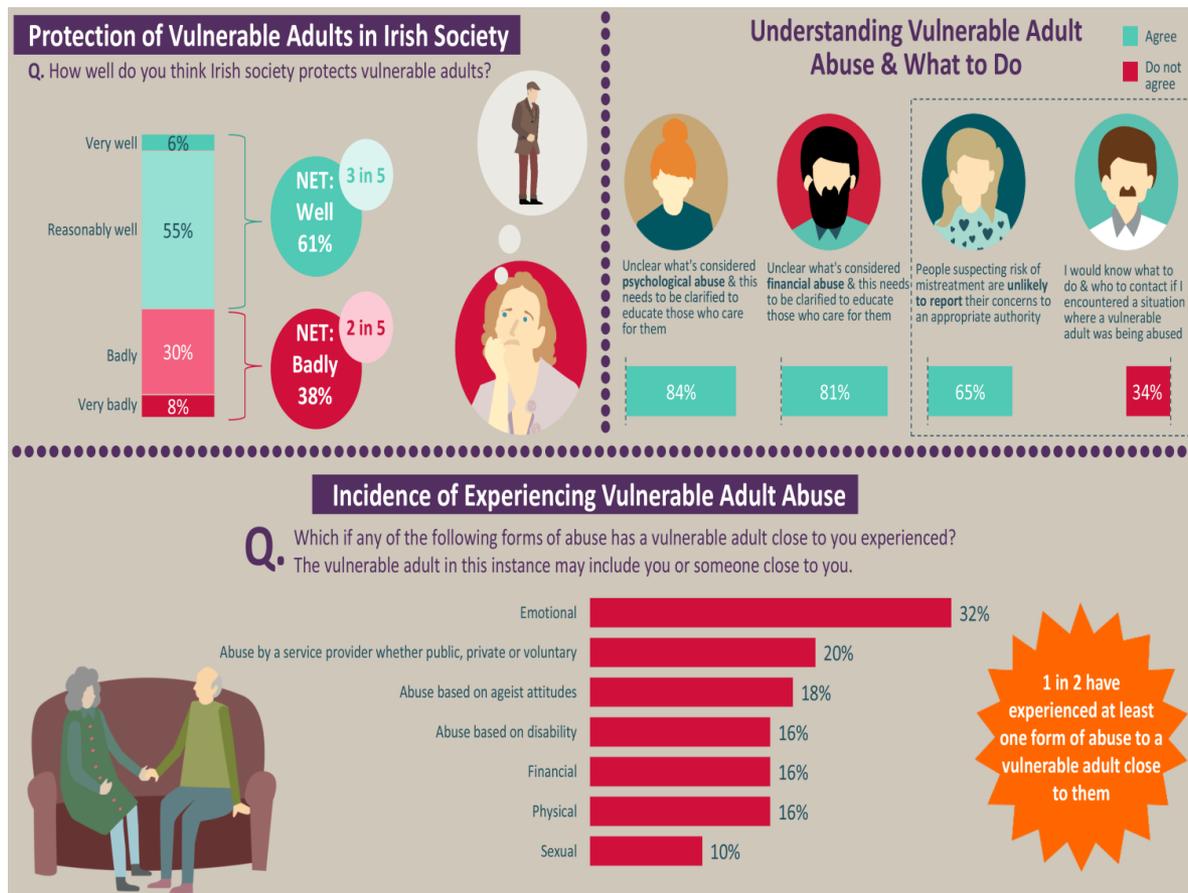
Why a Discussion on Advocacy is Necessary and Important

- To ensure that the goal of protecting people's rights, freedoms and dignity is not just aspirational
- Each individual needs to be able to exercise their own will and preferences on matters affecting their lives
- Many people face challenges in asserting their rights, due to:
 - Illness, disability, lack of social supports
 - Inadequate legislative and regulatory provisions
 - Lack of clear social and health services access pathways

Why Advocacy is Necessary and Important

- Some people, due to living circumstances, isolation, disability or cognitive impairment are unable on their own to defend their rights and interests.
- An ageing population in Ireland and inevitably an increase in numbers with reduced decision-making capacity
- A significant move towards supported decision-making (ADM Act 2015)
- Abuse of vulnerable adults endemic in society

Public Perspectives on Abuse of Vulnerable Adults in Ireland



Source: Safeguarding Ireland,

Abuse of Vulnerable Adults

- Half of all Irish adults have experienced at least one form of abuse to a vulnerable adult close to them.
- Two in 5 people think society protects vulnerable adults badly
- One in 3 believes vulnerable adult abuse to be widespread

Defining and Understanding Advocacy

Advocacy is a term which has tended in the past:

- To be used somewhat loosely and not always well understood*
- Sometimes confined to complaints and redress*
- Many professionals carry out an advocacy role
- Lawyers obviously engage in advocacy
- A professional dedicated advocate role has emerged more recently in Ireland
- A number of dedicated advocacy services in Ireland

Many Definitions and Types of Advocacy

Summarised in Figure 1/Page11 and following pages of the Scoping Document

Non-instructed advocacy crucially important in the context of safeguarding vulnerable adults

Non-instructed Advocacy

- Non-instructed advocacy is where the advocate acts in a safeguarding role where an individual may not be able to give consent;
- Capacity to instruct can be diminished for a number of reasons, for example, mental health difficulties, dementia, or other cognitive impairment
- The non-instructed advocate:
 - Seeks to uphold the person's rights (privacy, liberty, bodily integrity)
 - Ensure fair and equal treatment and access to services
 - Make certain that decisions are taken with due consideration for their unique will and preferences (in so far as these can be ascertained)

Non-instructed Advocacy

- Perhaps the most challenging form of advocacy
- May involve a witness/observer approach – in which the advocate observes or witnesses the way a person is and whether or not their voice is being heard
- Ascertaining a person's likely will and preferences can be difficult and challenging where the person has a cognitive impairment

Independent Advocacy

Support provided by an advocate working for an organisation that is:

- Structurally, financially and psychologically separate from the services that deliver health and social care
- Separate and independent from the family of the person to whom the advocacy service is being provided
- Advocates accountable only to the client/patient

Advocacy as an integral part of the role of many professions

Provision for advocacy Included in:

- The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives
- Code of Professional Conduct and Ethics for Social Workers
- Hospital Consultants' Contracts
- The Occupational Therapists Registration Board Code of Professional Conduct and Ethics

Legal advocacy is obviously provided by lawyers to clients as required

Important Advocacy Role of Families

- Families frequently carry out a significant support and advocacy role – parents in respect of their children with disabilities and people in respect of their parents or other relatives who require care
- Full-time family carers frequently have to engage forcefully with health and social care providers to get the services needed by their loved ones.
- Independent advocacy can bring a complementary and necessary perspective to family advocacy:
 - Ensuring that the voice of the person is clearly heard
 - Particularly, where crucial decisions are being made in relation to medical interventions, place of living and care arrangements.
- Will and preferences vs. best interests

Independent?

- Term ‘independent’ needs to be ‘unpacked’
- Some debate on the matter in the literature
- ‘Will and preference’ vs. ‘Best Interests’
- Questions:
 - Is ‘independence’ compromised by source of funding?
 - “Who better to advocate for the patients than an experienced professional who is looking after them?”

Providing Advocacy to 'Hard to Reach' Individuals and Groups

- Many potential beneficiaries of advocacy may not be in a position to know about what it means or that it may have relevance to them
- In many cases where abuse or violation of rights occur,
 - People are under the control of the perpetrator of the abuse or violation or
 - Do not have the capacity to voice their concerns or they may not be aware that abuse is taking place
- Other parties (e.g., family members) may be disinclined to allow or encourage access to independent advocacy

Advocacy and Human Rights

- Important relationship -- discussed in the Scoping Document p.18ff.
- Advocacy is both grounded in and reflects a rights-based approach which places the individual centre stage in all decisions affecting him/her.
- A rights-based approach views people as subjects and as equal citizens and stakeholders in society
- Challenges the social impulse to rank people in terms of their usefulness

Advocacy and Human Rights

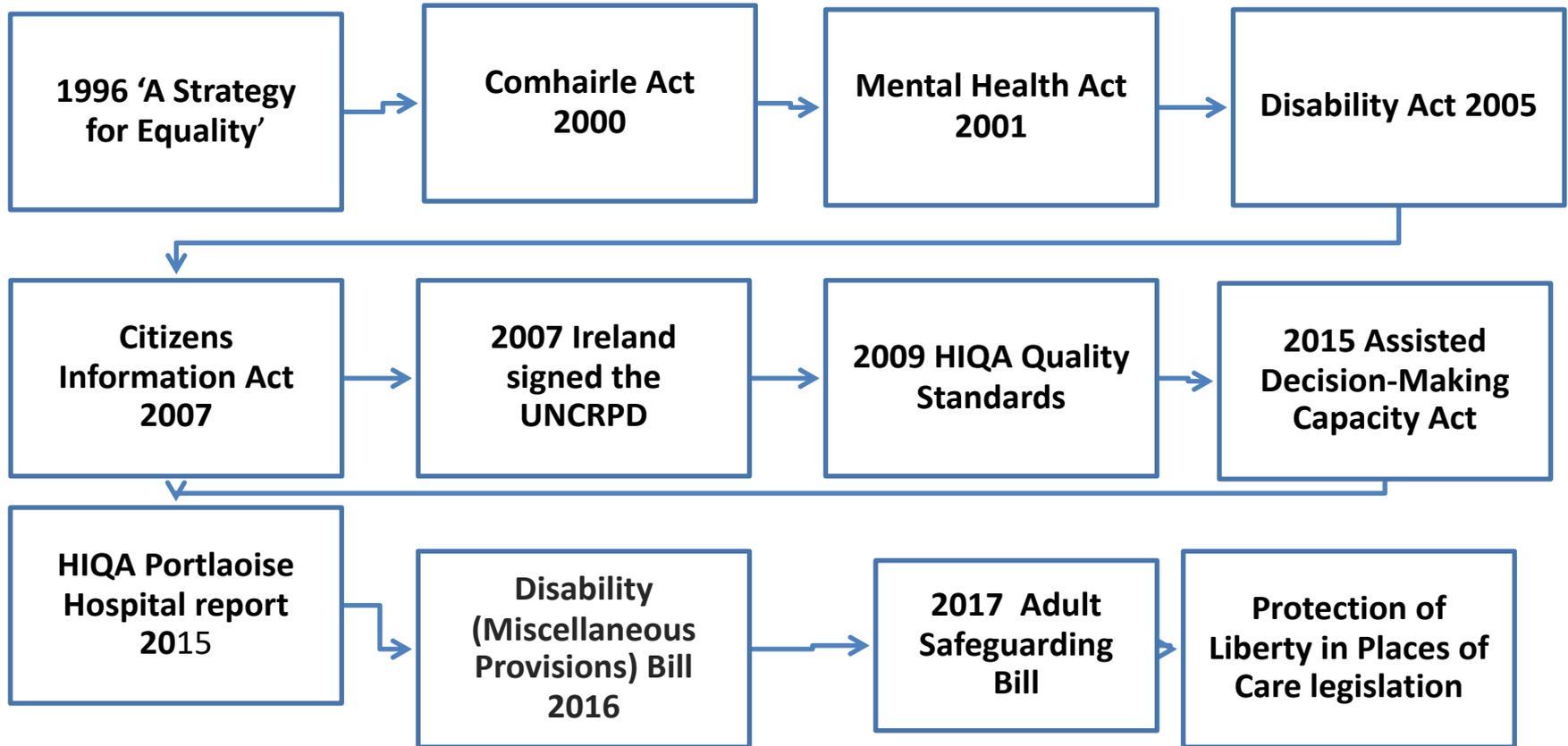
- Rights-based advocacy discourages *en bloc* compartmentalisation of identities (*viz.* older persons, people with disabilities);
- People are understood primarily in terms of individuals facing challenges and opportunities at different stage of the life-cycle rather than as members of ‘identity-groups’;
- A rights approach means abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights-bearers

Linking Advocacy with a Human Rights Approach

Principle Implied in:

- Universal Declaration of Human Rights 1948 (the focal point for subsequent international human rights)
- The European Convention on Human Rights (ECHR) 1953
- UN Convention on the Rights of the Child (1989)
- UN Convention on the Rights of Persons with Disabilities (2006)
- Council of Europe Statement on the Rights of Older Persons (2014)

Advocacy for Vulnerable Adults: A Slow 'Burn' in Ireland



Linking Advocacy with a Human Rights Approach in Ireland

- Commission on the Status of People with Disabilities - 1996
- Mental Health Act 2001
- Disability Act 2005
- Assisted Decision-making (Capacity) Act 2015
- Adult Safeguarding Bill 2017
- Deprivation of Liberty Bill

Mental Health Act 2001

- Provides for a person to be appointed independent legal representation in the review process of involuntary detention (Section 16(2)(b), .
- While the term advocacy is not used in the Act, effectively there is statutory provision for legal advocacy for people with mental health

Citizens Information Act 2007

- Includes a requirement for the CIB
- “ *...to support the provision of or, to provide directly, advocacy services to individuals, in particular those with a disability,*
- The National Advocacy Service for People with Disabilities (NAS) has been established by the CIB for this purpose
- Citizens Information Services also provide advocacy.

Provision for Advocacy in Assisted Decision-making (Capacity) Act 2015

The Assisted Decision-making (Capacity) Act 2015 makes provision for the Director of the Decision Support Service to:

- (a) prepare and publish a code of practice,
- (b) request another body to prepare a code of practice, or
- (c) approve of a code of practice prepared by another body,

for the guidance of persons acting as advocates on behalf of relevant persons 103(2)

Work is currently under way by the National Disability Authority in compiling such a Code of Practice.

The term 'independent advocate' seems likely to be used.

Adult Safeguarding Bill 2017

- The Safeguarding Authority (to be established) can arrange for a person who is independent (an “independent advocate”) to be available to represent and support an individual.

Condition for appointment of an independent advocate

Were an independent advocate not to be available, the individual would experience substantial difficulty in doing one or more of the following:

- (a) understanding relevant information
 - (b) retaining that information
 - (c) using or weighing that information as part of the process of being involved
 - (d) communicating the individual’s views, wishes or feelings (whether by talking, using sign language or any other means).
- 12(3)

Department of Health Initiative

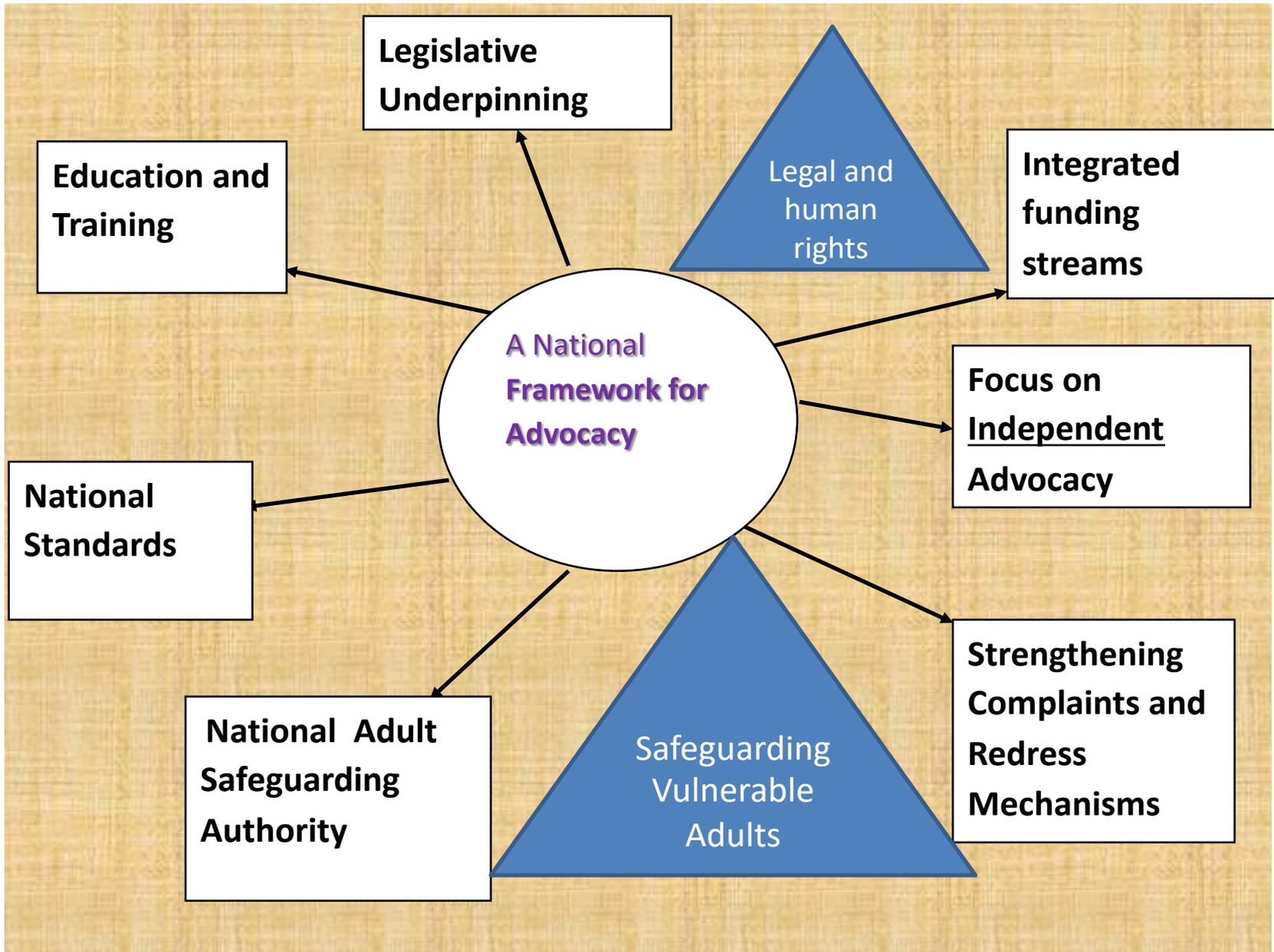
- National Patient Safety Office
- Development of a National Patient Safety Complaints and Advocacy Policy
- Recent publication of RFT for Patient Safety Advocacy Service
- The Development of a competency framework for healthcare/patient safety complaints advocacy and training course(s).

Progressing advocacy in Ireland

- Some legislative underpinning of advocacy is required to overcome current blockages, e.g., right to have access to an independent advocate
- Need to build a Framework for Advocacy

A National Framework for Advocacy

Core Components



A Shift in Focus Required

From

Assisting people with disabilities to obtain social services and to understand their entitlements

To

Enabling people to assert their will and preferences and to enforce their legal and human rights

Crucial and important distinction between decisional autonomy and the ability of a person on his/her own to execute those decisions;

Specific areas requiring attention

- Formal acknowledgement of the role of independent advocates
- Legislative underpinning
- Better coordination and oversight of existing advocacy services
- Agreed National Standards

The role of health and social care providers in facilitating advocacy

- Policies and practice that respect the rights of people to exercise their will and preferences
- Integrating an ethos of independent advocacy within service
- Acknowledging the importance of rights safeguarding in respect of people who may not, without support, be able to assert their rights
- Understanding the multiple roles of independent advocates –support, representation, witness/observer
- Availing of the growing interest in co-design / experience-based design to seek out the ‘voice’ of the service user

A National Advocacy Council ?

Purpose

Developing a national framework to create a context within which the practice, skills, development and coordination of advocacy can be effectively realized.

Modus Operandi

Engaging all appropriate government departments such as Justice, Employment and Social Protection, and Health, agencies of state such as the Office of the Ombudsman, Mental Health Commission, Decision Support Service, HSE and HIQA as well as inter-sectoral entities such as the Safeguarding Ireland.

Potential Areas of Responsibility

- Access to Advocacy
- Funding
- Standards
- Qualifications, Education and Training
- Codes of Practice
- Role of Volunteers
- Practice Guidelines
- Research & Evaluation
- Information Systems and Data Protection
- Impact & Outcomes

Some Suggested Roles of Council

- Drawing up an overarching National Advocacy Plan and overseeing its implementation
- Developing Codes of Practice and National Quality Standards in conjunction with other agencies
- Developing standardised training and accreditation for advocates
- Identifying delivery models appropriate in the Irish context
- Identifying integrated funding streams
- Ensuring equality of access to independent advocacy for all potentially vulnerable groups
- Exploring how independent advocates and other professionals with an advocacy role can work to optimum effect in specific care settings

Advocacy – a practice needing power

Time now opportune

- Code of practice for advocates being developed by the Decision Support Service
- Commissioning by the Department of Health of the Patient Safety Advocacy Service
- Proposed establishment of a National Adult Safeguarding Authority (Adult Safeguarding Bill 2017)
 - Provision for the appointment of independent advocates
- Ongoing work of Safeguarding Ireland
- Deprivation of Liberty Legislation

Advocacy not a Stand-Alone Intervention

- Advocacy alone is clearly not the answer to safeguarding vulnerable adults but it is a necessary component
- Also required are:
 - Rights-based structures, context and legislative frameworks
 - An open dialogue about where advocacy best fits in a continuum of services, supports and safeguarding

Guiding Principles of the Adult Safeguarding Bill 2017

- The promotion of individual physical, mental and emotional well-being
- The right to assistance, support and an independent advocate
- The right to protection from abuse and neglect
- The need for interventions in people's lives to be necessary and proportionate
- Respect for people's autonomy in decisions and interventions affecting them

THANK YOU