



Sage Advocacy: Forty Shades of Grey

Responding to the challenges and opportunities of an ageing society and economy

Legal issues that need to be addressed

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29 February 2024

Overview

- Home Care
- Social Care
- Adult Safeguarding
- Protection of Liberty
- Data Sharing & Protection of Privacy
- Social Enterprise
- International developments
- Conclusion



Home Care



Regulations for Home Care

- Legal Aspects of Professional Home Care – *Law Reform Commission 2011*
- Sláintecare Report - *Committee on the Future of Healthcare 2017*
- Regulation of Homecare Services: Research Report – *HIQA 2021*
- Regulation of Homecare: A Position Paper – *HIQA Dec. 2021*

- Draft Regulations for Providers of Home Support Services – Public Consultation Document – *Department of Health June 2022*

- Draft Regulations for Providers of Home Support Services – An Overview of the Findings – *A Report by the Institute of Public Health January 2023*

- *Health (Amendment) (Licensing of Professional Home Support Providers) Bill – Government Legislation Programme Spring 2024 – Heads in preparation*
 - A regulatory framework comprising of **primary legislation for the licensing of home support providers**, secondary legislation in the form of regulations, and HIQA national standards with the aim of ensuring that all service users are provided with high quality care. This is in line with Programme for Government and Sláintecare commitments.



Scope

- Draft Regulations 2022

- “Home-support” includes all forms of enabling **personal care and [other] practical assistance** provided [to] [for] an individual who by reason of illness, frailty or disability is in need of such care and assistance.

This may include, but is not limited to:

- a. physical assistance with mobility, personal hygiene, nutrition, hydration and toileting or prompting or supervising such activities where a person is unable to perform them effectively without such prompting or supervision;
- b. prompting and supervising the taking of medication;
- c. assistance with Instrumental Activities of Daily Living (IADLs) where outside assistance is necessary to enable a person to engage in these activities;
- d. exercise and social engagement within and outside the home;
- e. care for the emotional welfare of the service user;
- f. personal assistance.

Comment: Limited provision based on outdated landscape



General Duties concerning professional home care services - LRC

- The assessment of needs shall include
 - an assessment of companionship needs,
 - care needs and
 - the advanced home care needs of the care recipient
- ‘advanced home care’ involves the highest level of care and may involve some health care and may include personal care, respite care, dementia care, early Alzheimer’s care, assistance with continence and toileting and palliative care.

Legislation:

Home care provision must include some health care and regulation needs to address *the intersection of health and social care services*

Definition of ‘home care’ must include palliative care



Exclusions – Draft Regulation 2022

- The following exemptions apply:
 - (a) services for persons less than 18 years of age
 - (b) support provided in the context of a family or personal relationship
 - (c) services that do not involve an exchange of payment
 - (d) a paid employment relationship between an individual home support worker and one service-user
 - (e) services provided exclusively by registered healthcare professionals

What if any exemptions should apply –

Unregulated economy

Full regulation of home care services no matter who provides them

? Family exemption - but must have robust safeguarding provisions

LRC: Regulations and Standards must apply to any independent contractor providing home services in a person's own home.



Contractual Arrangement/Funding care

Principle of Equality of Care -

- Integrated system – why different arrangements for residential care and home care
 - need for integration with NHSS to allow for a single integrated system of care
- Interim measure - allow anyone qualifying for NHSS support the option of an equal amount of funding for home care

Law Reform Commission recommended that *a person who wishes to pay for professional home care services should have the choice to contract directly with a private sector care provider for to do so through the Health Service Executive.*

Care recipient as an 'employer'



Legislative Provision

Equality of Care – fundamental principle

Regulations:

HIQA's key areas –

- A 'root and branch' review
- Identify scope and parameters of home care
- Need for home care to be integrated and needs led
- Quality is central to homecare
- A national standardised assessment is required
- Investment in homecare workers required
- Funding for homecare should be a statutory right
- A universal methodology for commissioning disability homecare services should be developed
- Homecare must be inclusive, continual and consistent
- Need to focus on information sharing using integrated ICT systems
- Regulation should only be viewed as one component of broader reform and should not be burdensome
- Need to focus on maintaining a standard across the homecare sector before driving quality improvement



Care Legislation



Care Legislation

- Need for Care legislation
 - Currently there is no clear obligation on the State, state agencies or organisations to prevent harm or generally to protect adults at risk
 - No clear obligation on the State to assess care needs
 - No clear obligation on the State to provide care when it is required
- Purpose of legislation
 - promote well being and the prevention of abuse,
 - preventing the need for care and support,
 - promoting integration of care and support with health services,
 - providing information and advice,
 - promoting diversity and quality in provision of services



What should Care legislation provide for?

- Provide a legal basis for assessment of need and assessment of risk
- Duty and power to meet care needs
- Accountability of practical measures taken to address care needs in differing situations and taking account of individual circumstances not based on general criteria of age, disability...
- Mandatory provision for a Care Plan
- Periodic review of care plan and of measures taken
- Legal entitlement to Home Care services not based on ability to pay but on need
- Need to cover personalization of services, e.g. care vouchers, self-hire of care services.
- **Scotland:** For those aged over 65 assessed as needing personal care, the local authority has a duty to provide care and is not allowed to charge for it, even if the client could afford to pay. The care may be provided directly, commissioned from a private company, or the person may be given a cash sum to pay for 'Self-Directed Support'.
- Care Act could also provide basis for greater integration of section 38 (public sector organisations)/section 39 (non public sector) service providers into the wider framework of health and social care provision in line with Sláintecare.



Adult Safeguarding



Adult Safeguarding Legislation

- Adult Safeguarding Bill 2017
 - Introduced Private Members Bill Seanad February 2017
 - Received all party support
 - Main Provisions
 - National Adult Safeguarding Authority
 - Functions
 - Investigations by Authority
 - Determining if adult needs support and assistance
 - Provision of Independent Advocate
 - Right of entry and inspection
 - Reporting
- Oireachtas Joint Committee on Health **2017**
 - *There is an urgent need for the enactment of Adult Safeguarding legislation and this legislation is crucial in providing protection to adults at risk*
 - *There should be no unnecessary delay in implementing adult safeguarding legislation*



Identifying RISKS

Sharing RESPONSIBILITIES

The Case for a Comprehensive Approach
to Safeguarding Vulnerable Adults

Figure 9.1 Safeguarding adults at risk: nine key components



Required Legal Framework (SI's view)

- National Adult Safeguarding Authority to provide overarching governance to
 - ✓ National Safeguarding Service (independent of service provider)
 - ✓ Mental Health Commission
 - ✓ Decision Support Service
 - ✓ National Council for Advocacy (yet to be established)

The National Adult Safeguarding Authority (independent of all services) will have **multi-agency/multi-disciplinary representation** which will include the Policing Authority, legal and financial regulatory bodies, HIQA, HSE, Local Authorities, NGO's and others

Clear statutory duties and powers



A National Adult Safeguarding Authority

An **independent National Adult Safeguarding Authority** with overarching responsibility of safeguarding. Functions would include:

- Promote standards
- Undertake investigations
- Receive reports from mandated persons
- Promote education, training and public awareness regarding matters concerning adults at risk
- Provide information to adults at risk in respect of abuse and harm they may be experiencing
- Supervise compliance with the duties imposed by or under legislation
- Provide information and guidance to service providers, organisations and bodies in the State in relation to their interaction with adults at risk, including the carrying out of risk assessments and safety statements
- Determine if an adult needs support or assistance
- Make provision, where appropriate, for independent advocacy to an adult at risk and specifically if he or she is the subject of an investigation
- **Provide overarching governance to a number of bodies who have a 'safeguarding' remit....**



Emerging legislation

- Department of Health's Public Consultation on Policy Proposals on Adult Safeguarding in the Health and Social Care Sector (submissions by 13 March 2024)
 - Establishing a new independent statutory body or transferring the existing HSE's responsibilities to an existing sectoral body (e.g. MHC or HIQA) where it would be independent of service **OR**
 - Retain functions and structures within HSE, while expanding them as part of new Government approved national policy
- Report on the External Review on HSE Safeguarding policy, procedures and structures and advice on the possible options for the future of safeguarding (awaiting publication)
 - Need to see multi-disciplinary approach
 - A duty to co-operate across agencies
- Law Reform Commission's Report on the Regulatory Framework on Adult Safeguarding (publication Q1?)
 - Principles to underpin adult safeguarding legislation
 - ? What body should have responsibility for adult safeguarding - ? Independent Adult Safeguarding Authority
 - ? Multi-Agency Collaboration
 - ? Preferred Reporting model
 - ? Access to Sensitive Data and Data Sharing
 - ? Safeguarding Investigative Powers
 - ? Power of Entry/Inspection and No Contact orders
 - ? Statutory provision for Independent Advocacy



Legislative provisions – must have

- A National Safeguarding Authority
- Need for multi-disciplinary safeguarding teams resourced and skilled to work across all sectors not just health and social care
- Interim measure: oversight system for current HSE safeguarding work



Deprivation of Liberty



Procedure required by law

Constitution – Article 40.4.1

- No citizen shall be deprived of his personal liberty **save in accordance with law**

European Convention on Human Rights – Article 5

- Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save**in accordance with a procedure prescribed by law** – exceptions (Article 5.1)
- Everyone who is deprived of his liberty by arrest or detention shall be entitled to **take proceedings by which the lawfulness of his detention** shall be decided speedily by a court ... (Article 5.4)

UNCRPD – Article 14

- State Parties shall 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



AC v Cork UH and HSE [2018] IECA

- Application Article 40.4.1 and 40.4.2 of the Constitution
 - **Raises legal and constitutional issues of far reaching importance regarding the personal liberty...not least in so far as the care and welfare of the infirm and elderly are concerned**
 - *Right under the Constitution-cannot be swept away by Victorian wardship legislation*
 - **Legal issue not a medical one** – (Art 40.4.1 provides that all detention must be in accordance with law. The reasons and motives of the detainer are not relevant to any consideration of this issue of law).
- Whether detention lawful?
 - *The power [to detain] claimed by the hospital amounts to a **paternalistic entitlement to act in the best interests** of the patients whose capacity is impaired and, in effect, to restrain their personal liberty and freedom of movement and if necessary, to do at the expense of close family members. But ever, before the Constitution the common law has always rejected the claim that personal liberty could be compromised on such a basis.*
- Legislation required
 - *Those who contend that it would be appropriate that those caring for the elderly should have this power [depriving a person of his/her personal liberty] should not come to this Court requesting that we should create it,If the law is considered to be unsatisfactory, then any changes is exclusively a matter for the Oireachtas to determine.*



AC & others v Cork UH and HSE [2019] IESC 73

-*deprivation of liberty must in all cases be in accordance with law.*
- *To hold that persons cannot be found to be ‘detained’ if they are not capable of making a valid decision to leave for themselves, or if they are not aware of or able to object to their situation, would not simply permit restrictions on their freedom of movement for their own protection. **It would also have far-reaching consequences of denying to vulnerable persons...the benefit of the constitutional guarantee that they will not be deprived of their liberty otherwise in accordance with law.** It is possible for a person of full capacity to be detained without necessarily being conscious of that situation, and, equally, it is possible in the case of a person with impaired capacity. Both are entitled to legal protection. (Para 334)*



Deprivation of Liberty

- No Deprivation of Liberty Safeguards legislation
- Deprivation of Liberty – abusive practices imbedded in culture and practice
 - Greatest impact on older people
 - Disregard for the rights of persons
 - Will and preference of person not ascertained
 - Decision made, person not consulted even when person has capacity

 - To date: Wards of Court has been used inappropriately (High Court decisions)
 - Circuit Court does not have jurisdiction



DoLs Roadmap to date

- Consultation: Draft heads of Bill published in Dec 2017 by Department of Health (DofH)
- DofH set up Advisory Group in early 2018 to consider submissions (over 50)
 - Aim was to publish detailed Bill by end 2018 (not achieved)
- AC case Court of Appeal 2018 and Supreme Court 2019
 - AC case – scope not limited (original recommendation to limit to persons in a designated centre)
- Supreme Court:
 - Must start with the factual question, did the person wish to leave, was she deprived of her liberty
 - This question should be answered first, before the consequences of any doubts over capacity are considered
 - **Analysis must start with the express constitutional provision in Article 40.1 that *no person shall be deprived of his or her personal liberty save in accordance with law.***
 - It emphasised that the constitutional guarantee of the right to liberty protects persons who lack decision-making capacity to the same extent as everyone else.



Why we need the Deprivation of Liberty legislation

- Procedure required by law – Constitution, ECHR and UNCRPD
- AC case – constitutional right – requires clear legislative provision
- Not covered by ‘personal care’ decisions (where a person shall live) in ADMC Act – all decisions in ADMC Act must be in accordance with past or present ‘will or preferences’
- ADMC Act does not contain any legislative provisions with regard to Deprivation of Liberty,
- Delayed discharges – need in some case to make an application to the court if the person’s past and/or present ‘will and preferences’ is that they do not wish to be transferred to a long term residential care facility – hence the need for adequate home care support
- Legislative gap needs to be addressed urgently – interim measure provided in:

Assisted Decision-Making (Capacity) (Amendment) Act 2022

- *Nothing in this Act shall affect the inherent jurisdiction of the High Court to make orders for the care, treatment or detention of persons who lack capacity.*
- *KK [2023] IEHC 565...it is necessary to consider the safeguards that a court is required to put in place when exercising this jurisdiction both by reference to the Constitution and the ECHR*



DoLs Roadmap/Timetable

- Department of Health set up further Advisory Group in January 2023 – priority area of work
- Issues
 - Scope, (acute hospitals, all residential care facilities, homes) ?
 - Those who lack capacity, those who have capacity (constitutional right to access to the High Court if a person is detained)
 - Using the scaffolds of the ADMC Act and UNCRPD
 - What decisions for detention (care, treatment, detention)?
 - Authorisation process – court, tribunal or other
 - Place of Care Decisions – setting out will and preference in advance
- Legislative Programme Spring 2024 – states that work is underway
- **Legislation:**
 - Important that there is no limitation in the scope of the legislation (a person is in their own home)
 - Right to access to an independent advocate
 - Right to legal representation free of charge
 - Equality of Care - No limits on the adequate provision of home care service



Data Sharing & Protection of Privacy



Obligations to share information - legal basis

National Vetting Bureau (Children and Vulnerable Persons) Act 2012

- Legal obligation to share information relevant to safeguarding
- HIQA, HSE and MHC to notify specified information
- Limited to sharing only with the NVB

Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Persons) Act 2012

- Legal obligation to share information relevant to safeguarding
- A person will be guilty of an offence if he/she does not disclose relevant information to An Garda Síochána in relation to specified offences
 - Limitations of this Act not understood
 - Awareness of implications of non-disclosure not understood/documentated
- ***Criminal Justice Act 2011***
 - Legal obligation to share information that might be of material assistance in preventing, prosecuting or convicting the commission of offences relating to financial crime, company law offences and theft and fraud offences
- ***Assisted Decision-Making (Capacity) Act 2015 (as amended) Section 95A***
 - Provides for Regulations – disclosure by the Director of the DSS of information lawfully obtained...to a public authority or a public body....to protect the vital interests.....
 - Regulations for the sharing of special categories of personal data...substantial public interest...



Data Protection Legislation

- General Data Protection Regulation – GDPR
- *Data Protection Act 2018* (gives further effect to GDPR)
- *Data Sharing and Governance Act 2019* – sharing between public bodies (does not include sensitive personal data)

GDPR / Data Protection Legislation is not a barrier to sharing information.

It provides a framework to ensure that personal information about living persons is shared appropriately.

Legal Basis for sharing: (Safeguarding lens required)

- Consent
- Contractual necessity
- Compliance with a legal obligation – may be set out in primary or secondary legislation or court decision
 - ADMC Act obligation to get information....DSS v An Garda Síochána
- Necessary to protect the Vital interests – can be relied on directly (Art 6 and 9 GDPR)
- Task carried out in the public interest /substantial public interest – requires ministerial regulation
- Legitimate Interest – can be relied on directly (Art 6(1))



Data Sharing

ENGLAND

- Data Protection Act 2018 - Statutory Code for Data Sharing in relation Children + Vulnerable adults
- Data Sharing: Code of Practice (Information Commissioner's Office)

IRELAND

What we require:

- Safeguarding Legislation to provide a positive obligation to share data, when necessary and appropriately, is required
- Ministerial Regulations as provided for in the *Data Protection Act 2018* are required
- Data sharing Guidance from Data Protection Commission urgently required
 - Data Protection Commissioner has committed to preparing a Data Sharing Guidance Document

Multi-agency and multi-disciplinary approach to safeguarding is essential (across both public and private organisations) and the sharing of data is essential for this purpose



Privacy: Constitutional Right and a Right under International Conventions

- **Constitution of Ireland**

- Art 40.1 All citizens shall, as human persons, be equal before the law
- Art 40.3 The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen

Right to privacy an unenumerated right

- **European Convention on Human Rights**

- Art 2 Right to respect for private and family life
- European Convention on Human Rights Act 2003 – gave effect to Convention – Sec.3

- **UN Convention on the Rights of Persons with Disabilities (ratified 2018)**

- Art 22 Respect for privacy

Privacy is inextricably linked to the notion of consent

GDPR: Art 9.2(c) Processing is necessary to protect the vital interests of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent



Legislation – Right to privacy

- Garda Siochana Act 2005
- Freedom of Information Act 2014
 - To gain access ... to information in the possession of public bodies, consistent with the public interest and right to privacy
- **Assisted Decision-Making (Capacity) Act 2015**
 - Section 8 General Principles – applies to all interventions
 - Shall not attempt to obtain information that is not required for making a decision
 - Shall not use information for a purpose other than in relation to a decision
 - Shall take all reasonable steps to ensure that relevant information is kept secure from unauthorised access, use or disclosure and is safely disposed of when no longer required
- **Data Protection Act 2018 (1988-2003); GDPR**
 - Images captured by CCTV are personal data and subject to data protection legislation
- **Data Sharing and Governance Act 2019** (regulation of sharing information between public bodies – strict requirements)

What we need is a clear policy and guidance, particularly in the context of health and personal intimate care to ensure that the constitutional rights to bodily integrity, privacy and dignity are respected



Safeguarding
IRELAND



Social Enterprise

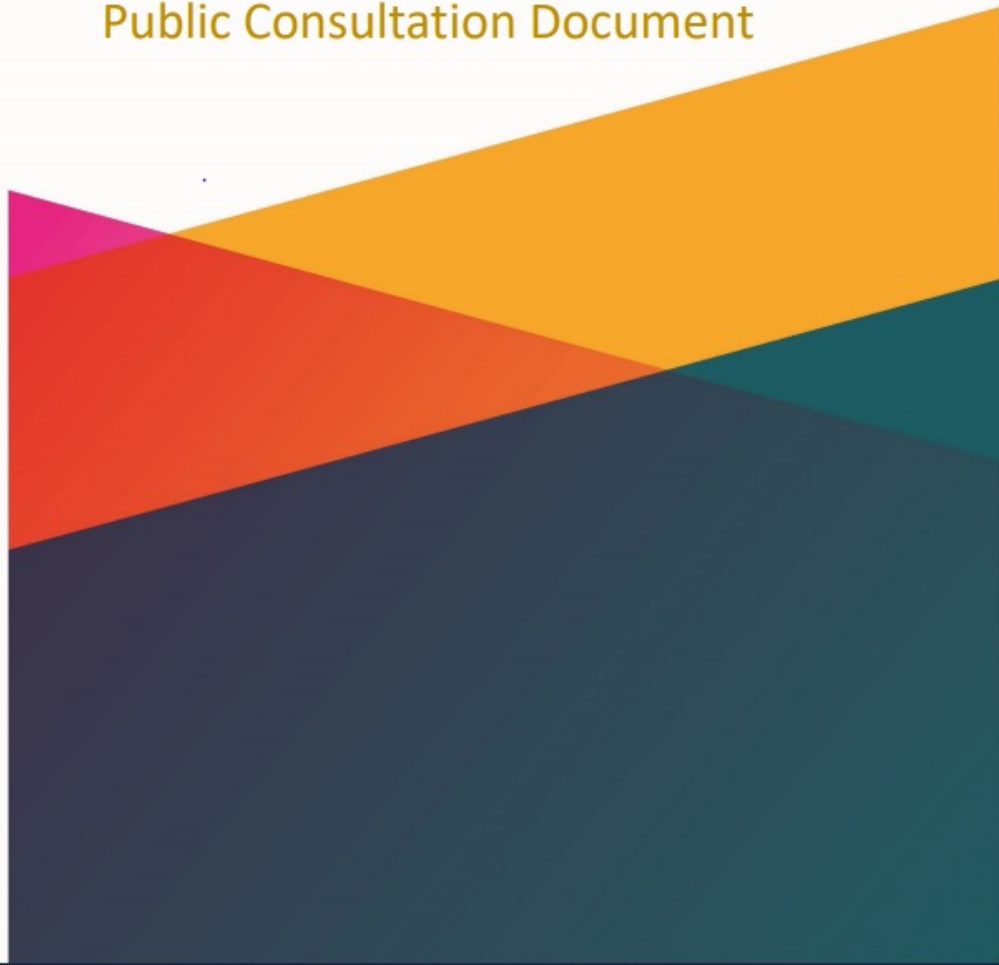




Rialtas na hÉireann
Government of Ireland

National Social Enterprise Policy for Ireland 2024-2027

Public Consultation Document



What is a Social Enterprise in Ireland?

Definition of a Social Enterprise

- *A business that, rather than maximising profit for its owners or shareholders, is an enterprise whose primary objective is to achieve ‘**profit for purpose**’ and a social, economic or environmental impact.*
- *A social enterprise pursues its objectives by trading on an ongoing basis through the provision of goods and/or services, and by reinvesting any surpluses into achieving its objectives.*
- *It is independent of the public sector and if dissolved, it should transfer its assets to another organisation with a similar mission.*

National Social Enterprise Policy for Ireland 2024-2027 Public Consultation Document

Closed for submissions 31 January 2024



Legal Form

- Currently no legal form provided under Irish law

Current legal forms that may be used include:

- Company limited by guarantee
- Company limited by guarantee with charitable status
- Designated activity company
- Industrial and Provident Society
- Unincorporated Association
- Trust



Issues for Consideration

- Identification of clear purpose
- Transparency
- Liability of members
- Regulation
- Taxation
- Restrictions on member being Directors (as is the case clgs with charitable status)

Legislation:

Co-operatives Societies Bill 2022 - modernising existing legislation/ consolidation and clarity

Policy: During the term of the new policy and as the sector grows and matures further, the needs of social enterprises that arise from their selected legal forms (and their effective use of current legal forms) should be continually monitored and reviewed.

Specific legislative format required for Social Enterprise



International – older persons



Specific Articles in relation to Care

10 Articles:

Article 1: Right to dignity, physical and mental well-being, freedom and security to include

- protection against medical and pharmaceutical abuse
- Protection from neglect

Article 2: Right to Self Determination - Freedom of choice

Article 4: Right to high quality and tailored care

Article 8: Right to palliative care and support, and respect and dignity in dying and in death

European Charter
of the rights and
responsibilities
of older people
in need of long-term
care and assistance



JUNE 2010



Co-funded by
the European Union



**Human Rights of Older Persons
and Long-Term Care Project:
The Application of International
Human Rights Standards to
Older Persons in Long-Term
Care**

February 2017



UN Convention on the Rights of Older Persons

UNCROP

- An Open-Ended Working Group on Ageing, (OEWGA) was established by United Nations General Assembly in 2010
- The OEWGA has the mandate to consider the existing international framework of the human rights of older persons and identify possible gaps and how best to address them
- The OEWGA has had 13 sessions up to April 2023, next session May 2024
- Before each session the OEWGA invites member states, civil society organisations and national human rights institutions to contribute inputs to the session's themes
- An overview of the work of the OEWG-A up until April 2022 has been produced by BAGSO, the German National Association of Senior Citizens' Organisations
- Sage Advocacy has participated with BAGSO in debates on rights of older persons in the last number of years
- Criticism about the delay in the UN Convention on the Right of Older Persons



Conclusion



Message to the Commission on Care

The Commission on Care needs to carefully consider a legislative framework for the support and care of older persons.

Choice and individual circumstances must be accommodated.

The Government needs to receive clear recommendations from the Commission as to what is required to enable everyone to facilitate older people's access to their fundamental rights.

Health and long term care, including prevention and early intervention, should be considered not as a cost but as an investment that benefits all age groups. EU health care and long-term care services should be based on solidarity between generations, to reflect the provisions of the Lisbon Treaty which state that the EU "shall combat social exclusion and discrimination, and shall promote social justice and protection, equality between women and men, solidarity between generations and protection of the rights of the child". European Charter



THANK YOU

Discussion Document:

Identifying RISKS – Sharing RESPONSILILITIES: The Case for a Comprehensive Approach to Safeguarding Vulnerable Adults



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