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Quality Standards for Support and Advocacy

Work with Older People



sage

Support & Advocacy Service
for Older People

third age

Sage is a Third Age programme in partnership with

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The Six Quality Standards

1.

Respect

Reflecting the right of every person to be treated with dignity and respect, including each individual's right to privacy, confidentiality and self-determination.

2.

Social Justice

Promoting equal treatment with other people in respect of access to basic goods, services and protections and a positive affirmation of social solidarity.

3.

Competence and Compassion

Demonstrating high levels of skill, competency, compassion and consistency on the part of advocates.

4.

Accessibility

Available in a manner that is convenient and easily accessible to people who require support.

5.

Independence

Structurally, operationally and psychologically independent from health and social care service providers and representing only the will and preferences of people receiving support.

6.

Accountability

Acting with integrity and responsibility and engaging with people who use the service and with other stakeholders in an honest and transparent manner.

Foreword



Over many years at the bench I have witnessed many of the challenges that ageing poses for people and the sometimes very complex issues that can end up in the courts and legal system. At a personal level I have been both witness to and participant in these challenges through care of a family member and as I age myself I increasingly wonder about some of the challenges that lie ahead for me.

Each of the six Quality Standards, set out in this document, are simply stated and clearly explained. They set out what is required of those who undertake support and advocacy work with older people. They also set out what is required of the service provider and the expected outcomes for those availing of support and advocacy services. They are a lodestar to guide people in what can sometimes be extremely challenging journeys and they are something to be practiced rather than preached. They suggest a need to match aspiration with perspiration. Former President Mary Robinson expressed it well in a wider context: "The aim is to push beyond standard-setting and asserting human rights to make those standards a living reality for people everywhere".

The mission statement of Sage is "To promote and protect the rights, freedoms and dignity of older people by developing support and advocacy services wherever ageing poses a challenge for individuals." Too often we see the issues facing older people as related solely to health and social care. In doing so we can sometimes forget the fundamental importance of values, standards and the law in determining the wellbeing of citizens. Given the emergence of legislation in respect of capacity, and the considerable consensus that has developed around it, I hope that these Quality Standards will be appreciated by all those whose role is to build the framework of provision for older people and within it fashion systems and services that give voice to the wishes and preferences of older people in Ireland.

Mary Laffoy
Judge of the Supreme Court
October 2015

What Support and Advocacy Work with Older Persons Is

- Safeguarding people's basic human rights
- Enabling people to tell other people what they want
- Helping people to know what choices they have and the likely consequences of these choices
- Enabling individuals and groups to have control over their lives

The Quality Standards: What They Contain

Structure of Quality Standards Document

- A vision for support and advocacy work based on sound principles;
- A value-based benchmark against which the functioning of advocacy providers and the practice of individual advocates can be measured;
- A focus on the need for greater engagement with older persons in terms of ensuring that their rights are protected;
- An emphasis on the fact that older persons have the same rights to autonomy and self-determination as all other citizens, including, in particular, those whose ability to exercise autonomy may be lessened because of a physical or cognitive impairment;
- The essential elements that need to be in place to ensure a consistent quality approach to support and advocacy work with older people;
- An outline of best practice in providing support and advocacy in different health and social care settings – in people's own homes, in primary care settings, in hospitals or in long-stay residential care facilities;
- An identification of best practice in respect of enabling individuals to exercise their will and preferences in accordance with people's basic right to self-determination;
- A menu of support actions to:
 - Empower people to articulate their needs and have their voices heard;
 - Safeguard the rights of individuals who are vulnerable for one reason or another;
- A reinforcement of the concept of 'independence' as central to the advocacy process¹ based on the principle 'nothing for/about you, without you'.

The Document contains four sections:

- (i) An Introductory Section
- (ii) The Six Quality Standards
- (iii) Guidance for Health and Social Care Providers on Working with a Support and Advocacy Service
- (iv) Five Case Scenarios

Section One (Introduction) sets out the purpose of the Quality Standards, the reasons why they are important, the process used for developing them, the definition and understanding of support and advocacy used, key underlying principles of support and advocacy work and a synthesis of critical issues.

Section Two (The Quality Standards) sets out six overarching standards: Respect; Social Justice; Competence and Compassion; Accessibility; Independence; and Accountability. The individual components for each of the six standards are outlined, what is required from advocates and advocacy providers as well as outcomes for people who use the support and advocacy service. A list of indicative evidence of compliance with each Standard is included.

Section Three, Working with an Advocacy Service: Guidance for Health and Social Care Service Providers sets out the main factors relevant to health and social care providers in integrating independent support and advocacy into their services.

Section Four provides five Case Scenarios which illustrate how the six standards can be applied in practice.

A Glossary of Terms is provided and a List of key Resource Documents.

¹ It is, of course, acknowledged that many people who are not 'independent', in the sense that they are the actual providers of services (nurses, doctors, social workers), engage in support and advocacy work by empowering people to act on their own behalf and enabling them to implement their will and preferences. Also, in many instances, people are enabled to manage their daily lives in accordance with their own preferences through the support of families, neighbours and friends. Family carers play a significant role in this regard.



Section One:

Background and Context

Why a Dedicated Support and Advocacy Service for Older People Is Important

There is general acknowledgement that some older persons need support in asserting their rights, in having their voice heard and in articulating their will and preferences. It is widely accepted that support and advocacy has an important role to play in helping services to meet the range of needs of individuals and groups who require additional support. Since the Mental Health Act 2001 there is statutory provision for legal advocacy for people with mental health difficulties. The Disability Act 2005 provides an entitlement to advocacy for persons with a disability while the Citizens Information Act 2007 provides for the establishment of a Personal Advocacy Service.² There are a number of references in HIQA Standards to the role of advocacy and the need to make provision for people to have access to independent advocates.³

More recently, the Ombudsman has noted that advocates can perform a very valuable function in hospitals by solving small problems before they become large ones and by helping people feel that they are being treated fairly and with respect by the hospital.⁴ The Ombudsman concludes that independent advocacy services should be sufficiently supported and signposted within each hospital so patients and their families know where to get support if they want to raise a concern or issue. The recent HIQA Report⁵ of the investigation into the safety, quality and standards of services provided by the HSE to patients in the Midland Regional Hospital, Portlaoise recommended the establishment of an advocacy service for hospital patients.

Advocacy has of course an important role in helping to address larger systemic issues. For example, the Ombudsman's 2014 Report, A Good Death,⁶ refers to complaints about end-of-life care in Irish hospitals and sets

out some pointers as to how shortfalls in such care might be addressed. It is also the case that the experiences of individuals and groups engaging with the health and social care delivery system as mediated through advocates can provide a rich data source for feedback to Government and related policy development.

'Older' Persons: A Question of Definition

While the term 'older persons', as commonly used, is age related, it refers to a widely diverse segment of the population which includes:

- People with good social support networks and those with little or no networks
- Those living in the community independently or with support and those in residential care facilities
- People with relatively good health and those with poor or failing health
- People with different levels of assets and disposable income
- People with reduced capacity because of dementia or other cognitive impairment
- People with physical/sensory/intellectual disabilities and/or mobility impairment
- People with mental health difficulties
- Those actively engaged and making a significant contribution to society

Experience of old age reflects lifelong inequalities and differences based on class, gender and career path. Some of the advantages or disadvantages accruing from a particular level of participation in the work force are likely to be sustained into old age. The position of older people depends not just on their income and health but also on their command over other assets such as property, savings which they can realise as appropriate. There are key social, cultural and economic processes which result in a lessening of citizenship for older people. While there is no inevitable process of disengagement from society with the passing of years, economic and social structures tend to foster disengagement, e.g., 'retirement'. The communications environment makes certain assumptions about people's capacity to hear, to see and to speak. The built environment and transport design impact on mobility.

The Benefits of Quality Standards

These Quality Standards are envisaged as contributing to a wider public debate in respect of quality of life issues for older people and addressing a related need to ensure that the highest standards prevail in health and social care settings. They are predicated on the belief that the availability of a continuum of support and advocacy in all health and social care settings can make a significant contribution to both enhancing the quality of life for people who need support, ensuring that their rights are upheld and, in the longer term, facilitating a more responsive and respectful support and care system.

Quality standards as a key component in the delivery of health and social care services have come very much to the fore in Ireland since the establishment of the Health Information and Quality Authority (HIQA). The National Economic and Social Council (NESC) has published a series of reports on quality and standards in human services, including an overview of concepts and practices, which examined international and Irish evidence of approaches to regulation and standards-setting in human services, along with the promotion of good practice.⁷ The Hospice Friendly Hospitals Programme has identified standards for end-of-life care and has supported and monitored progress in this regard.⁸

Quality standards have the potential to contribute significantly to the development of good practice in support and advocacy services, ensure consistency and bring clarity to the role of the independent advocate. They also provide a benchmark against which the functioning of advocacy providers in terms of underlying values, performance, governance and service delivery and the practice of individual advocates can be measured. Quality standards also provide safeguards for independent advocacy service providers and for people that use/receive their services and help advocacy providers to define and explain their role. Quality Standards help to ensure uniformity in practice.

The beneficiaries of Quality Standards for Support and Advocacy Work with Older People are:

- People using independent support and advocacy services
- Individual advocates
- Providers of independent support and advocacy services
- Health and social care service providers

- Commissioners and funders of independent support and advocacy services
- Other professions and disciplines supporting older persons (e.g., nurses, doctors, social workers, care workers)
- Relatives, carers and support networks

Development of the Quality Standards

The development of the Quality Standards was carried out by Sage⁹ in six inter-related phases:

Phase One:

Literature Review to scope the parameters of the Quality Standards – Draft Paper 1 considered by the Sage Practice and Guidance Working Group;

Phase Two:

Consultation with key informants – interviews and focus groups;

Phase Three:

Draft Paper 2 considered by the Sage Practice and Guidance Working Group

Phase Four:

Preliminary Draft Quality Standards compiled – considered by Sage and by other stakeholders and feedback provided;

Phase Five:

Public consultation on Draft Quality Standards

Phase Six:

Finalisation and publication of Quality Standards

All phases were co-ordinated and directed by the Sage Practice and Guidance Working Group.

² The Personal Advocacy Service was deferred by the Government in the light of budgetary circumstances and the service has not been established. The National Advocacy Service for People with Disabilities (NAS) has been established by the Citizens Information Board on a non-statutory basis.

³ See, for example, Draft National Standards for Residential Care Settings for Older People, <http://www.hiqa.ie/publications/draft-national-standards-residential-care-settings-older-people-ireland-2014> – it is noted that these Standards have not to date been finalised.

⁴ <http://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Learning-to-Get-Better/Learning-to-Get-Better.pdf>

⁵ <http://www.hiqa.ie/publications/report-investigation-safety-quality-and-standards-services-provided-health-service-exec>

⁶ <https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/A-Good-Death/A-Good-Death-Report.pdf>

⁷ <http://www.nesc.ie/en/publications/publications/nesc-reports/achieving-quality-in-irelands-human-services-a-synthesis-report/>

⁸ http://hospicefoundation.ie/wp-content/uploads/2013/04/Quality_Standards_for_End_of_Life_Care_in_Hospitals.pdf

⁹ Sage is an organisation operating under the governance of Third Age Ireland, with HSE and Atlantic Philanthropies funding. The mission of Sage is: "to promote and protect the rights, freedoms and dignity of older people by developing support and advocacy services wherever ageing poses a challenge for individuals". Its aim is to address both individual and systemic issues and respond effectively to the challenges that arise as older people's needs, abilities and places of care change.

Defining and Understanding Support and Advocacy

The Quality Standards are based on the following broad understanding of support and advocacy¹⁰:

- Representing and working with a person or group of people who may need support and encouragement to exercise their rights, in order to ensure that their rights are upheld;
- May involve speaking, acting or writing on behalf of another person or group;
- Differs from mediation or negotiation because these processes aim to reach a mutually acceptable outcome between parties;
- Will differ in different circumstances and according to the skills and needs of the individual or group;
- May involve working against established or entrenched values, structures and customs, and therefore needs to be independent of service providers and authorities.

Adapted from <http://www.agedrights.asn.au/rights/whatis.html>

The underlying principle of all independent support and advocacy is to facilitate people in speaking for themselves and in articulating their own needs. This includes supports at various points along a continuum which includes the provision of information, assistance with negotiating health and social care pathways and engaging in representative advocacy with or on behalf of people. “Advocacy is not about making decisions for people or telling or advising someone what you think they should do”.¹¹

Independent support and advocacy

While many service professionals and service delivery personnel have an advocacy role,¹² it is necessary to recognise that service providers may sometimes experience a conflict between advocacy and their role in the organisation and, for this reason, an independent advocacy service offers a different type of intervention and is usually seen as ‘the better option’ (Reed 2004:62)¹³.

¹⁰ <http://www.agedrights.asn.au/rights/whatis.html>

¹¹ The Scottish Independent Advocacy Alliance, Non-Instructed Advocacy Guidelines: A companion to the Code of Practice for Independent Advocacy ps. 16-17).

¹² O’Mahony-Browne Researchers (2005), Feasibility Study on the Use of Volunteers in an Advocacy Role for People Dying in Hospitals and Their families, Study for the Irish Hospice Foundation, Dublin: Irish Hospice Foundation.

¹³ Reed, J. (2004). “Involvement, Empowerment and Advocacy”, in Nies, H., and Berman, P., (Eds.), Integrating Services for Older People: A Resource Book for Managers, Dublin: European Health Management Association, p http://catalogue.iugm.qc.ca/GEIDFile/19367.PDF?Archive=196566891474&File=19367_PDF

It is also the case that 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 and support in daily living. This is particularly the case in relation to people who are full-time carers who frequently have to engage forcefully with health and social care services to get the services needed by their loved ones. While the role of families and relatives as advocates is crucially important, there is an additional and necessary perspective that independent support and advocacy can bring to ensure that the voice of the person is clearly articulated in all circumstances, and, particularly, where crucial decisions are being made in relation to medical interventions, place of living and care arrangements.

Empowerment as an underlying principle of support and advocacy

Empowerment refers to a process where, through the provision of information, support and advocacy, people are enabled to assert their rights, make choices and decisions and contribute to wider policy-making in the areas that affect their lives. The support and advocacy process is built on the presumption of capacity and geared towards maximising capacity and facilitating supported decision-making. At the core of advocacy support is the concept of ‘standing beside’ people and enabling them to make decisions and exercise choice. Indeed, the provision of basic information on an individual’s rights and entitlements can in itself be hugely empowering. An advocate can build up a person’s confidence simply by listening to and supporting him/her in expressing an opinion or working through options for him/herself.

- Empowerment means assisting people to be as autonomous as possible while acknowledging a person’s right to be mistaken, to change his/her mind, to take risks and to seek outcomes that may appear not to be the best options in the situation;
- The principle of empowerment ideally requires that existing and potential client groups should participate in shaping how the advocacy service is run and be represented in the planning, policy development and advocate recruitment processes.

Self-advocacy as an underlying goal

While a wide range of terms are used to distinguish different types of advocacy – self-advocacy, peer advocacy, citizen advocacy, patient advocacy, crisis advocacy, professional advocacy, political advocacy, group advocacy, individual advocacy – it is now established best practice that all advocacy should be done in a spirit of self-advocacy, including that where advocates carry out a safeguarding role in respect of people whose capacity may be diminished due to physical or mental disability, or infirmity associated with the ageing process (a non-instructed advocacy approach).

Individual, Group and Systemic Advocacy

One variation within the domain of advocacy is whether the focus is on the individual or the group and the distinction between ‘individual strategies’ and ‘group strategies’ and between these and systemic advocacy. Individual strategies provide information and personal support to enable a person to articulate his/her will and preferences. Group strategies aim to give people a voice in the services which they use and include mechanisms such as forums, user panels and other forms of consultation and participation. Related to group strategies, systemic advocacy seeks to introduce and influence longer term policy changes to ensure that people’s rights are attained.

Circles of Support¹⁴

A central component of support and advocacy for older persons is building Circles of Support to strengthen the natural support structures of family and community in partnership with relevant professionals and local community and development organisations. The concept Circle of Support broadly refers to a group of people who work together on a regular basis to help a person accomplish his/her personal goals in life. The Circle acts as a community around an individual (the ‘focus person’) who, for one reason or another, is unable to achieve what s/he wants in life on his/her own. One model of the Circle of Support developed in the UK¹⁵ and targeted at older persons expands the definition of ‘resources’ to combine public, private and voluntary resources and, secondly, focuses on all the different aspects of quality of life and well-being

¹⁴ The idea of a Circle of Support was developed in Canada, spread fairly quickly through North America and early Circles began in the UK in the mid-1980s.

¹⁵ See www.particible.net/projects

that are important to older people, including, in particular, social connections and relationships. The key feature of the Circle is the local mobilisation of public, private, voluntary and community resources to help all older people define and create quality of life and well-being for themselves. The Circle of Support concept envisages a panel of people with legal, technical or clinical expertise who would advise on matters as required either by an individual or a group of older persons.

Support and Advocacy Work with Older People: Principles and Practice

Support and advocacy work with older people is underpinned by a core set of values and principles, both among practitioners and within the projects and organisations in which they work. These can be summarised as follows:

- The fundamental human rights of people are non-negotiable – protecting people against infringement of basic human rights (e.g., right to freedom, privacy and bodily integrity) is thus central;
- Respect for individual personhood is at the core of engagement with people;
- Each person is innately deserving of recognition and viewed as a ‘valuable’ member of society;
- People are engaged with on the basis that their worth is equal to that of others;
- Each person throughout his/her life cycle has inherent capabilities which require an appropriate social support infrastructure in order to be realised;
- Each individual, while differing in capacity, character and intelligence, is equally enabled to maximise his/her potential and has something to contribute to humanity;
- Maintaining people’s engagement with life – their social networks and their community – is vital to quality of life and well-being;
- Risk for people who are vulnerable should be modulated by appropriate supports;
- Support and advocacy practice is ethically informed;
- The will and preferences of people constitute the primary terms of engagement – the concept of supporting informed decision-making thus shapes advocates’ interactions with people;
- Respect for people’s autonomy and independence requires involving individuals in all decisions that affect them directly or indirectly.

Broadly understood, six types of independent support and advocacy relevant to older persons can be identified:

- (i) With/for an individual (or a group of older people) in a residential care setting, acute hospital, in community care settings or in their own home;
- (ii) Enabling people in long-stay residential facilities and hospital patients to identify and raise issues arising out of their experiences through, for example, facilitating and supporting group forums;
- (iii) Working with older people to ensure that their experience of hospital care or primary care is communicated to and understood by health and social care professionals;
- (iv) 'Being there for' (accompany) older people in challenging care situations, e.g., acute hospitals;
- (v) Helping to build circles of support and advocacy around older people who require additional assistance;
- (vi) Working with older persons to strengthen natural support structures of family and community in partnership with relevant professionals.

Integrating Quality Standards with Other Measures

Independent support and advocacy services for older people do not work in isolation but rather need to be integrated with the broader legal, policy and service delivery infrastructure. Support and advocacy should thus be an integral part of health and social care services and Quality Standards for Support and Advocacy Work with Older People should seek to complement relevant strategies, policies and other service delivery standards. The following¹⁶ are particularly important in this regard:

- Safeguarding Vulnerable Persons at Risk of Abuse: National Policy & Procedures (HSE)
- The Irish National Dementia Strategy
- HIQA National Standards for Residential Care Services for Older Persons
- HSE National Consent Policy
- HIQA National Standards for Safer Better Healthcare
- National Guidelines & Procedures for Standardised Implementation of the
- Home Care Packages Scheme

¹⁶ This is not an exhaustive list.

- Quality Standards for End-of-Life Care in Hospitals (Hospice Friendly Hospitals Programme)
- HIQA Guidance for Designated Centres, Restrictive Procedures
- Judgment Framework for Designated Centres for Older People (HIQA)
- The Assisted Decision-making (Capacity) Bill which includes provision for advance healthcare directives¹⁷
- National Positive Ageing Strategy

Centrally relevant to support and advocacy work is the Assisted Decision-making (Capacity) Bill 2013 currently (October 2015) going through the Oireachtas. The provisions of the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003 are important in ensuring that the highest standards prevail in the matter of protecting people's right to privacy. The provisions of the European Convention on Human Rights, the UN Convention on the Rights of Persons with Disabilities, and the Council of Europe Statement on the Rights of Older Persons¹⁸ are key reference documents for support and advocacy work with older people.

Support and Advocacy Work with Older People: Critical Considerations

There are a number of critical considerations relevant to support and advocacy work with older persons:

- The importance of an ethical framework
- The right to self-determination
- Risk assessment and management in the context of a rights approach
- Support and advocacy in the context of safeguarding people who may be at risk
- Distinguishing between legal capacity and mental capacity
- Quality of life considerations

These critical considerations can only be referenced here and need to be explored in much greater detail both in the context of training for support and advocacy work and in policy discourse generally as it relates to older persons and the social supports infrastructure.

¹⁷ A Draft General Scheme of legislative provisions to Provide for the Making of Advance Healthcare Directives was published by the Department of Health in February 2014 and has now (October 2015) been incorporated into the Bill.

¹⁸ 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).

The importance of an Ethical Framework (see Glossary)

Ethics is concerned with questions about what is morally right in a particular situation. In many situations it may be clear what it is right to do. In other situations, however, there may be several options, none of which is unambiguously right. Deciding on which course to take involves judgment in deciding how much weight to give to different values.¹⁹

Components of an Ethical Framework²⁰

Component 1: A 'case-based' approach to ethical decisions: Ethical decisions can be approached in a three-stage process: identifying the relevant facts; interpreting and applying appropriate ethical values to those facts; and comparing the situation with other similar situations to find ethically relevant similarities or differences.

Component 2: A belief about the nature of dementia: Dementia arises as a result of a brain disorder, and is harmful to the individual.

Component 3: A belief about quality of life with dementia: With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.

Component 4: The importance of promoting the interests both of the person with dementia and of those who care for them: People with dementia have interests, both in their autonomy and their well-being. Promoting autonomy involves enabling and fostering relationships that are important to the person, and supporting them in maintaining their sense of self and expressing their values.²¹

Component 5: The requirement to act in accordance with solidarity: The need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole.

¹⁹ <http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf>

²⁰ This Framework has been developed by the Nuffield Council on Bioethics for application in the case of people with dementia <http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf> The framework is equally applicable to other groups of older persons who are vulnerable because of a cognitive or other impairment.

²¹ Autonomy is not simply to be equated with the ability to make rational decisions. A person's well-being includes both their moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level of cognitive functioning.

Component 6: *Recognising personhood, identity and value:* The person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions.

Source: Nuffield Council on Bioethics: Dementia: ethical issues²²

"Although there are many different approaches to health care ethics, the value placed on factors such as a person's wishes, values and general well-being, and on broader factors such as some sense of fairness or justice, are common to all" (Nuffield Council on Bioethics:21).²³

The Right to Self-Determination (see Glossary)

The provisions of the UN Convention on the Rights of Persons with Disabilities (CPRD) are centrally relevant to support and advocacy work with older people. The Convention sets out the legal standard of a presumption of capacity which should apply to people with disabilities and, by extension, to older persons who have a cognitive impairment. Its focus is clearly on empowerment and personal autonomy which is echoed in the The Council of Europe Statement on the Rights of Older Persons²⁴ which states that older persons are entitled to lead their lives independently, in a self-determined and autonomous manner (Principle 111(9)).

The following rights are enshrined in the UN Convention:

- To make decisions about healthcare, finances, relationships and where and with whom to live (Article 12)
- To enjoy full 'legal capacity on an equal basis with others' (Article 12(2))
- To be actively involved in decision-making processes in all matters concerning them (Preamble, Section 0)
- To have effective access to justice including procedural and age-appropriate accommodations (Article 13)
- To be protected, both within and outside the home, from all forms of exploitation, violence and abuse (Article 16)
- To live in the community, with choices equal to others (Article 19)

²² <http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf>

²³ Ibid.

²⁴ 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).

- To choose their place of residence and where and with whom they live on an equal basis with others and not obliged to live in a particular living arrangement (Article 19)
- To consent to the most effective and efficient healthcare treatment (Article 25)
- To have access to health services required specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons (Article 25)
- To have services provided as close as possible to people's own communities, including in rural areas (Article 25)
- To take part on an equal basis with others in cultural life and to enjoy access to cultural materials and activities (Article 30)

Risk assessment and management in the context of a rights approach

Risk assessment and management in the context of a rights approach is a matter of considerable importance and one which has not to date, perhaps, received adequate attention in the context of supporting older people with a cognitive impairment. The dilemmas faced by practitioners and service managers in risk assessment, particularly for people with dementia, are complex, and influence the nature of care available to people.²⁵

It has been found that very wide understandings of risk are identifiable, ranging from concern with avoidance of physical harm through to managed risk taking to improve quality of life, and to an appreciation of the impact of organisational and professional patterns of behaviour resulting in harm to the person with dementia.²⁶

The environmental context of vulnerability rather than the individual context has been emphasised in the context of people with disabilities. Dr. Hoong Sin²⁷ argues that risk is not simply due to disability or characteristics of the person, but that it is situational. i.e., it is related to the social and environmental context within which a person lives. Essentially, Hoong Sin suggests, the best response

to address vulnerability is the same as for any other citizen. People need to be informed; make decisions that help them feel in control and thereby increase their competence, confidence and safety. Promoting protection through empowerment in this way, ensures people are supported as much or as little as needed, and are seen as individuals in their own unique situation, capable, and with full rights and entitlements to citizenship. Hoong Sin advises against protectionist, (disabled people are vulnerable) or deficiency (disabled people are lacking) approaches and recommends rights based approaches with more structured and explicit processes for managing risk. He acknowledges that this is a balancing act, involving rights and risks that must involve people with disabilities themselves. Ultimately, rights promotion and protection from abuse are multifaceted in nature and require a complex response rather than the denial of rights. The focus should thus be more on the suitability or unsuitability of the environment in which a person lives and on the relationships in his/her life rather than on the individual characteristics and manifestations of a particular disability.

Reference has been made to positive and negative risk management cycles.²⁸ It has been suggested that the development of risk assessment frameworks that make explicit the perspectives of practitioners, people with dementia and family carers may assist staff to resolve some of the risk management issues.²⁹

Support and advocacy in the context of safeguarding people who may be at risk³⁰

In the case of people who may not be able to self-refer to a support and advocacy service or to fully comprehend what is involved, an advocate can legitimately take the role of exploring with those responsible for the care and support of an individual how his/her human rights are being protected – a safeguarding role. This approach is typically referred to as 'non-instructed' advocacy. However, this is a somewhat contested term in that it may not fully equate with the concept of supported decision-making (see *Glossary*).

Four distinct yet complementary approaches to support and advocacy work in a safeguarding role for people who may

be at risk have been identified as a guide to best practice in this area.³¹ Each has similarities and differences to the other approaches and they are not mutually exclusive.

Approach 1: Human Rights Approach

This approach begins with the premise that we all have certain fundamental human rights that can be clearly defined and explicitly measured. The role of the advocate is to ensure, using a variety of means, that the basic human rights of people are promoted and defended and to intervene and to challenge such violations and seek redress. This may be required where a person is being denied food or drink, is being restrained or is the victim of abuse.³²

Approach 2: Person-Centred Approach

This approach is based on a long-term, trusting and mutually respectful relationship between the advocate and an individual. In spending time with the person, the advocate builds up a picture of his/her lifestyle, preferences and needs which is aided by the advocate's independence from service systems. The advocate is in a unique position to describe and, where necessary, represent the person's views. In doing so the advocate is capturing the unique perspectives of the individual.

Approach 3: The Watching Brief Approach

This approach centres around quality of life domains and related questions that the advocate can put to the decision maker on behalf of an individual. Watching Brief provides a framework for challenging the decision maker in a non-confrontational way and encourages service providers to put the individual at the centre of the decision-making process.

Approach 4: Witness-Observer Approach

The advocate's role as an observer or witness to the ways in which services interact with an individual or group allow him/her to see or hear things that are unacceptable or which pose a threat to the person's well-being. The advocate may also pick up on people's preferences and pleasures, which can in turn be used to enhance positive relationships. The witness-observer approach does not require the advocate to make judgements or assumptions, merely to report on the facts of his/her observations and, in doing so, draw attention to matters not previously recognised or taken into account e.g., lack of stimulation; dislike of certain people, foods or activities; appropriateness of routines and systems; the communication function of key behaviours or actions.

Source: http://aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf

31 http://aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf

32 Clearly, matters involving suspected or alleged criminality should be reported to the Gardaí

Distinguishing between Legal Capacity and Mental Capacity

The notion of legal capacity is conceptually very different from the concept of mental capacity "The term 'mental capacity' refers to a set of psychological abilities (roughly: decision-making skills) that vary in the human population. 'Legal capacity,' by contrast, is not a psychological concept at all – it refers to a legal status or standing".³³ There is thus a crucial need to distinguish between legal capacity and mental capacity. While legal capacity is a central concept of the Convention on the Rights of Persons with Disabilities (CRPD), there is no definition of legal capacity in the Convention. However, the UN Committee on the CRPD (the UN Committee)³⁴, in its first General Comment made in 2014, defined legal capacity as follows:

Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors³⁵

Assisted Decision-Making Legislation

The Assisted Decision-Making (Capacity) Bill 2013 provides that a person has capacity unless the contrary is shown.³⁶ A basic premise of the proposed legislation is that people should be presumed to have the capability to make decisions and a person shall not be considered as unable to make a decision unless all practicable steps have been taken without success to help him or her to do so. The Law Reform Commission has noted that "a statutory statement of presumed capacity would have the advantage of dovetailing into the human rights disability model by embracing the concept that unless there is evidence to the contrary, an adult is to be taken as capable of autonomous decision-making."³⁷ The legislation will also recognise different levels of decision-making capability and therefore provides for different categories of interveners to assist a person in maximising his or her capacity.

33 Essex Autonomy Project (2014), Does the MCA recognise legal capacity on an equal basis? <http://autonomy.essex.ac.uk/wp-content/uploads/2014/06/3.-Briefing-Paper-Three-FINAL.pdf>

34 The UN Committee is the formal treaty body for the CRPD with powers and responsibilities established under the Convention.

35 Equal Recognition before the Law General Comment No1(2014) par12

36 Section 8(2) Assisted Decision-Making (Capacity) Bill 2013

37 Law Reform Commission Vulnerable Adults and the Law (LRC 83 2006) at 2.37

Important amendments made to the Bill at Committee Stage in the Oireachtas were:

- Replacing the term 'mental capacity' in the Bill with the term 'decision-making capacity'
- Provision for the guidance of persons acting as advocates on behalf of relevant persons
- Change of the name 'Office of Public Guardian' to the 'Decision Support Service'
- Change of the name 'Public Guardian' to the 'Director of the Decision Support Service'
- The removal of co-decision making agreements from the court process
- Provision for the making of Advance Healthcare Directives

The latter provision is particularly important in relation to support and advocacy in that it establishes a legal basis for the making of Advance Healthcare Directives by a persons in respect of their will and preferences concerning medical treatment should they subsequently lack capacity. The legislation will also provide for the appointment of Designated Healthcare Representatives with the power to, inter alia, ensure that the Advance Healthcare Directives concerned are complied with.

Quality of Life Considerations

Quality of life considerations are at the heart of the support and advocacy process. Quality of life is broadly-based and includes a range of domains including physical health, psychological and emotional well-being, degree of independence, social relationships and relationship to the environment in which people live. For example, quality of life domains for people with dementia include:³⁸

- The opportunity to perform activities of daily living (ADL)
- The opportunity to engage in meaningful use of time
- Social interactions
- Achieving a favourable balance between positive emotion and the absence of negative emotion
- Expression of the religious/spiritual dimension of life

Older people requiring additional support face the same daily stresses that affect people of any age. They may also

38 Suzanne Cahill and Ana Diaz (2010), Living in a Nursing Home, Quality of Life: The Priorities of Older People with a Cognitive Impairment, in association with Dementia Services Information and Development Centre, http://www.nhi.ie/zuploads/page_docs/living%20in%20a%20nursing%20home%20quality%20of%20life%20dr%20suzanne%20cahill.pdf

have the added concerns of age, illness, retirement, and other lifestyle changes, all of which may lead to difficulties with intimacy and sexuality.³⁹ Many people in later life must reconcile a sense of closeness with the experience of being alone.⁴⁰ In some long-term care settings, resident's attempts at sexual expression may be viewed as 'problem' behaviour. However, there is an increasing recognition that interest in, and the right to, sexual expression and intimacy exists throughout the life span and that healthy sexuality among older adults should be supported.⁴¹

Quality of life and the physical and sensory environment

The relationship between the physical and sensory environment, healthcare outcomes and quality of life has been recognised for some time. Internationally, there is a growing body of evidence reflecting a move away from congregated settings toward smaller or domestic style environments that encompass homeliness and more nurturing environments that encourage greater involvement with children, plants and animals.⁴² The role of the visual arts, music and entertainment in enhancing hospital environments is increasingly appreciated. Evidence based design (EBD) is a process-based approach to design that uses current best evidence from research and practice to create healthcare environments that improve patient and staff outcomes and operational performance.

The Hospice Friendly Hospitals Programme (HFH) Design and Dignity Guidelines⁴³ provide guidance for the design and planning of acute hospitals so that the buildings can support quality end-of-life care. These Guidelines have also been promoted as appropriate for community hospitals and for residential care settings for older people. The HIQA Draft National Standards for Residential Care Settings for Older People in Ireland⁴⁴ contain a number of references to the design

39 <http://retirement.berkeley.edu/pdf/Sexuality%20and%20Intimacy.pdf>

40 www.nia.nih.gov/health/publication/sexuality-later-life

41 [http://www.gnjournal.com/article/S0197-4572\(08\)00266-8/pdf](http://www.gnjournal.com/article/S0197-4572(08)00266-8/pdf)

42 Brownie, S. & Nancarrow, S. (2013), "Effects of person-centered care on residents and staff in aged-care facilities: a systematic review", *Clinical Interventions in Aging* 8, 1-10, <http://dx.doi.org/10.2147/CIA.S38589> Kane, R.A., Lum T.Y., Cutler, L.J., Degenholtz, H.B. and Tzy-Chyi Yu. (2007), "Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program", *Journal of the American Geriatrics Society* 55, 832-839. <http://www.beingblocked.com/wp/wp-content/uploads/2014/02/Resident-outcomes-in-small-house-nursing-homes-A-longitudinal-evaluation-of-the-initial-green-house-program.pdf>

43 <http://hospicefoundation.ie/wp-content/uploads/2013/04/Design-and-Dignity-Guidelines-for-Physical-Environments-of-Hospitals-Supporting-End-of-Life-Care-HFH-2008.pdf>

44 <http://hiqa.ie/publications/draft-national-standards-residential-care-settings-older-people-ireland-2014>

and physical environment aspects of the buildings. There is reference to the advantages of single rooms (1.6.2) and the importance of the sensory environment is also referenced (1.6.3) – access to gardens and views of the natural environment.

Another important quality of life consideration is the role of pets and the related sense of loss and bereavement people experience when, for example, they have to live in residential care facilities where there is no provision for keeping pets.

Mobility as a key determinant of quality of life

Mobility is another important consideration in determining quality of life in that it is an important component of independence. The ageing process and related disease can impact on a person's ability to maintain his/her independence. The UN Convention on the Rights of Persons with Disabilities refers to the importance of personal mobility in ensuring that people have the greatest possible independence (Article 20). Meeting the personal mobility needs of people should thus be a central factor in health and social care provision. The provision of mobility aids to those who need them, wheelchairs being the largest mobility assistive technology required by older persons,⁴⁵ is at the core of quality service delivery. Related easy access to occupational therapy, physiotherapy and speech and language therapy is of paramount importance.

45 O'Gorman, E. and Gowran, R.J. Invisible Policies: A Scoping Literature Review of Wheelchair and Seating Provision for Older People in Irish Nursing Home Settings. Poster, Irish Gerontological Society, 62nd Annual and Scientific Meeting, 1way 9th-11th October 2014.

Summary of Section One

This Section has set out the purpose of the Quality Standards for Support and Advocacy Work with Older People, the reasons why Quality Standards should be introduced; the process used for developing the Quality Standards, the definition and understanding of support and advocacy used; and key underlying principles of support and advocacy work. Critical considerations identified and synthesised were the importance of an ethical framework; the right to self-determination; risk management in the context of a rights approach; support and advocacy in a safeguarding context; distinguishing between legal capacity and mental capacity; and quality of life considerations.

Section Two:

Six Quality Standards for Support and Advocacy Work with Older People

This section sets out six overarching standards for support and advocacy work with older people, the components for each standard, what is expected from both advocates and advocacy providers in respect of each component and the expected outcomes for those availing of the service. Indicative evidence of compliance with each standard is also outlined.

Introduction

These Quality Standards (see *Glossary*) provide a benchmark against which the functioning of advocacy providers in terms of underlying values, performance, governance and service delivery and the practice of individual advocates can be measured. They have been developed by Sage on the basis of a review of the national and international literature on advocacy, consultation with key informants (practitioners, policy-makers and academics) and input from Sage staff and the Sage National Advisory Committee.

The Quality Standards are envisaged as applying to support and advocacy in different health and social care settings – in

people's own homes, in primary care settings, in hospitals or in long-stay residential care facilities.⁴⁶

Six overarching Quality Standards are set out, each with an identified set of components. The expectations arising from each component are identified in respect of both individual advocates and providers of advocacy services. The expected outcomes for people availing of support and advocacy services are also set out in respect of each component. A list of indicative evidence of compliance with each Quality Standard is included.

⁴⁶ Sage has developed policies and Operational Guidelines for Advocates in respect of each of these care settings – available on request from info@sage.thirdageireland.ie

Six Overarching Standards and Related Components

Standards	Components
1. Respect	<ul style="list-style-type: none"> • People treated with dignity and respect • Respect for people's autonomy and right to self-determination • All personal information, whether obtained directly or indirectly, treated in strict confidence • Empowerment of individuals as a core value
2. Social Justice	<ul style="list-style-type: none"> • An underpinning human rights perspective • A focus on social inclusion • Each person respected as having equal rights before the law • Recognising and respecting diversity
3. Competence and Compassion	<ul style="list-style-type: none"> • Advocates adequately trained, supported and supervised in their work • Adherence to agreed Codes of Practice • Advocates working consistently to high quality standards • Total clarity of advocacy role and boundaries
4. Accessibility	<ul style="list-style-type: none"> • Available in an equitable and timely manner for those who need it • Promoted so that potential users become aware of it • Proactive in seeking out hard-to-reach people and those who might have difficulty self-referring to the service • Information about the service fully accessible
5. Independence	<ul style="list-style-type: none"> • Structurally and operationally independent • Free from conflict of interest • Clear boundaries between advocates and health/social care services staff • Collaboration with other health/social care providers
6. Accountability	<ul style="list-style-type: none"> • Accountable to the people who use the service • Service effectively managed • Adherence to all legal requirements • Underpinned by human rights provisions and equality legislation



1. Respect

This refers to the right of every person to be treated with dignity and respect, including the person's right to privacy, confidentiality and self-determination limited only by law.

Why do we need this Standard?

We need this Standard to enshrine in our work practice the inalienable right of the human person to make decisions in accordance with his/her own will and preferences and without undue interference by others.

Core components of this Standard

- 1.1 The rights and dignity of each individual person are respected in conduct and practice;
- 1.2 People's right to autonomy and self-determination is respected;
- 1.3 All personal information, whether obtained directly or indirectly, is treated in strict confidence;
- 1.4 Empowerment of individuals is a core value.

1.1

The rights and dignity of each individual person are respected in conduct and practice

Advocates: What is Required

- The Advocate is respectful of people's needs, views and experiences and always operates in a non-judgemental manner
- The Advocate at all times fully respects and is directed by the will and preferences of the individual;
- Advocates represent the will and preferences of the person whether they agree with them or not except in situations where doing so would involve a significant risk of harm to the person or to another or infringement of the law;
- Advocates ensure that any information they receive concerning an individual is shared with the person involved;
- People using the service are kept fully informed by Advocates at all stages of the process;
- People's relationships with their families and other social networks are fully respected

Advocacy Provider: What is Required

- The Advocacy Provider values and respects the people who use its services;
- There are written policies and codes of practice on confidentiality and data protection which adhere to best practice standards and legal requirements;
- There is a Code of Conduct for Advocates;
- There are Ethics Standards in place;
- There is a policy and related Operational Guidelines on visiting people in their own homes;
- There are Data Recording and Data Management policies in place which enable:
 - Tracking
 - Accountability
 - Quality control
 - Identification of outcomes for individuals and groups

Expected outcomes for people who use the Support and Advocacy Service

- People feel respected and acknowledged;
- The advocacy service is directed by the needs, interests, views and wishes of the people who use it;
- People are enabled to have control over their lives and to be fully involved in decisions which affect them

1.2

People's right to autonomy and self-determination is respected

Advocates: What is Required

- Information about available choices and options available to individuals is provided and in a manner that the individual/group can understand;
- People are encouraged to carry out actions themselves where possible and facilitated accordingly;
- Advocates implement the Advocacy Provider's policies and guidelines on Rights Safeguarding (see *Glossary*);
- Advocates implement the organisation's policy on case management and data recording/ management;
- People are made aware that they can request a change of advocate (within the constraints of advocacy provider resources), or terminate contact with the advocate at any time;
- Advocates support people to develop skills in self-advocacy and assertiveness and in 'speaking up' for themselves;
- Where an individual so wishes, Advocates work in partnership with families and social/ friendship networks.

Advocacy Provider: What is Required

- The Advocacy Provider supports individual autonomy, self-determination and empowerment through its work;
- The Advocacy Provider has in place policies and operational guidelines on:
 - Consent
 - Protecting Vulnerable Adults
 - Carrying Out A Rights Safeguarding Role
 - Communication
 - Complaints
 - Stakeholder Consultation
- The Advocacy Provider takes a proactive approach to raising advocacy awareness among health and social care services personnel.

Expected outcomes for people who use the Support and Advocacy Service

- People understand the options and choices available to them and the consequences of their choices;
- Each individual has support to enable him/her to make decisions;
- Each person's rights, irrespective of his/her decision-making capacity, are fully protected.

1.3

All personal information, whether obtained directly or indirectly, is treated in strict confidence

Advocates: What is Required

- Advocates are fully conversant with the Advocacy Provider's Client Confidentiality Policy and are able to explain it in straightforward language;
- Advocates at all times observe and respect people's right to privacy taking into account the circumstances in which this may not be possible (e.g., harm to self or others, abuse);
- As a general principle advocates do not share personal information without the express permission of the individual involved;
- Advocates explain the fact that they may be required to disclose personal information to supervisors and line managers;
- Where required in order to address an issue, advocates share information with agencies* that have monitoring responsibilities for services;
- Where support and advocacy is provided on the basis of a rights safeguarding (non-instructed advocacy) role, information is shared only for the purposes of promoting the person's rights;
- Advocates inform each individual about all actions taken on his/her behalf;
- Advocates ensure that all written information kept on an individual is securely stored and routinely updated in accordance with the Advocacy Organisation's Confidential Data Storage Policy.

Advocacy Provider: What is Required

- The Advocacy Provider has in place policies and operational guidelines on Client Confidentiality and Data Protection and Confidential Data Storage;
- The Advocacy Provider complies with data protection legislation;
- Information is made available in accessible formats;⁴⁷
- Client information used for research or service promotion purposes is presented anonymously;
- Where case scenarios are used for research or systemic advocacy, the identity of individuals and groups is always protected;
- People's consent to use information about them in Case Scenarios is sought.

Expected outcomes for people who use the Support and Advocacy Service

- People are assured that any information they divulge to advocates is treated in strict confidence;
- Individuals have access to all information that is held about them (electronically or hard copy);
- People are provided with information in formats that are accessible to them.

* For example, HIQA, Office of the Ombudsman; the Office of the Inspector of Mental Health Services, HSE Complaint Officers, HSE Elder Abuse Case Workers.

⁴⁷ See, for example, National Disability Authority, <http://nda.ie/Good-practice/Codes-of-Practice/Irish-Code-of-Practice-on-Accessibility-of-Public-Services-and-Information-Provided-by-Public-Bodies-/> Citizens information Board http://www.citizensinformationboard.ie/publications/social/downloads/Accessible_Information_For_All.pdf; National Adult Learning Association (NALA), Plain English guidelines, https://www.nala.ie/sites/default/files/publications/Plain%20English%20guidelines%20at%20a%20glance_1.pdf. Information in Transition: The information, advice and advocacy needs of older people in the technology and information age (2013),

1.4

Empowerment of individuals is a core value

Advocates: What is Required

- Advocates take instructions from the individuals or groups whom they support;
- Advocates do not make decisions for people;
- The activities of Advocates are as far as possible on the basis of mutually agreed plans with the individuals/groups involved;
- Advocates are clear about the circumstances in which they can act without the expressed consent of people (a safeguarding of rights or non-instructed advocacy⁴⁸ approach);
- Where a person who is deemed unable to give instructions but is identified as requiring support, the Advocate uses an ethical framework and related Ethical Guidelines (see *Glossary*) to inform decisions about advocacy activities.

Advocacy Provider: What is Required

- The empowerment of people (individually and collectively) is a key goal of the support and advocacy service;
- Training and continuous professional development is provided for advocates in different and innovative ways of communicating with people who are not verbal;
- People are provided with information about how they can give feedback to the Advocacy Provider;
- People have opportunities to get involved in the wider activities of the Advocacy Provider organisation if they so wish;
- Ethical Guidelines are available to inform support and advocacy involvement where a person is unable to communicate his/her views.

Expected outcomes for people who use the Support and Advocacy Service

- People make and have control over all decisions that affect their lives;
- People understand the choices and options available to them, the actions being taken and the likely implications of different courses of action;
- People are supported to enhance their skills in assertiveness and speaking up for themselves;
- People who require support to execute their will and preferences have access to such support.

Standard 1: Respect

Indicative Evidence of Compliance

Supporting policies

- Accessibility
- Case Management
- Case Recording
- Complaints
- Confidentiality
- Conflict of Interest
- Consent
- Data Protection
- Dignity at Work
- Equality and Diversity
- Freedom of Information
- Referrals
- Rights Safeguarding (Non-instructed Advocacy)
- Service Users Charter
- Staff Induction and Training
- Support and Supervision
- Working Alone

Practical implementation

- Comprehensive and clear Operational Guidelines for Advocates in place
- Evidence of adherence to Operational Guidelines
- Operational Guidelines reviewed on an ongoing basis
- Record-keeping monitored and reviewed
- Training Plan Implemented
- Continuous Professional Development Plan Implemented
- User feedback mechanisms in place
- Case Management Group in place and meeting regularly
- Case Reviews taking place and recorded
- Users and potential users of the service participate in research, planning, delivery and evaluation



2. Social justice

Social justice means, on the one hand, equal treatment with other people in respect of access to basic goods, services and protections, and, on the other, a positive affirmation of social solidarity at all points of people's engagement with societal structures and institutions.

Why do we need this Standard?

We need this Standard to ensure that older persons are supported to share the full spectrum of human rights, are enabled to access all societal goods and services on an equal basis with others and receive equitable treatment with other sections of society in how their health and social care needs are met.

Core components of this Standard

- 2.1 The engagement with people is on the basis that we all have human rights and the right to be socially included;
- 2.2 The social inclusion of people is at the forefront of the support and advocacy engagement;
- 2.3 Each person is accorded respect as having equal rights before the law;
- 2.4 Diversity is recognised and respected.

2.1

The engagement with people is on the basis that we all have human rights and the right to be socially included

Advocates: What is Required

- The Advocate challenges negative discrimination and unjust policies and practices;
- The Advocate recognises and respects diversity;
- The Advocate demonstrates cross-cultural competence;
- The Advocate works at all times towards the goal of social inclusion for all individuals and groups;
- The engagement by Advocates is at all times informed by the following core principles:
 - Equality
 - Individual dignity
 - Privacy
 - Protection
 - Empowerment

Advocacy Provider: What is Required

- Advocates are supported to challenge negative discrimination and unjust policies and practices;
- There is an underlying principle in the organisation of working for the fair distribution of resources based on identified levels of risk/need;
- Training and continuous professional development for advocates includes modules on citizenship and human rights;
- There is a focus on collaborating with other agencies (statutory and NGO) working in the area of social inclusion;
- Systemic advocacy is carried out in respect of blockages to social inclusion relating to older persons identified;
- Feedback is provided to relevant statutory agencies and NGOs in order to promote ongoing discourse at national level on social inclusion issues.

Expected outcomes for people who use the Support and Advocacy Service

- People individually and collectively experience social solidarity on an equal basis with others;
- Discriminatory practices against older persons are identified;
- Ageist attitudes are challenged;
- People individually and collectively are able to assert their right to be treated equally and fairly.

2.2

The social inclusion of people is at the forefront of the support and advocacy engagement

Advocates: What is Required

- Advocates are cognisant of the fact that equality of status sometimes necessitates differential responses;
- The Advocate pays due attention to both people's basic needs and supporting their individual capacities;
- The Advocate links individuals with Circles of Support and supports their development as required;
- Promoting equality of access to health and social care services informs all support and advocacy engagement;
- Advocates establish appropriate structures/forums to provide a voice for older people within particular care settings (e.g., residential care facilities);
- Advocates highlight gaps in service provision for specific individuals and for groups;
- The Advocate pays particular attention to any specific instances where equality of status is not afforded to people (individually or collectively).

Advocacy Provider: What is Required

- Core social inclusion principles are reflected in policies, operational guidelines and training programmes;
- Organic links between the Advocacy Provider and local communities are fostered and developed;
- The Advocacy Provider engages in ongoing systemic advocacy in respect of gaps and unnecessary complexities in service provision;
- Representative structures and systems to provide a voice for older people within particular care settings (e.g., residential care facilities and hospitals) are developed and implemented;
- Factors which hinder the involvement of older persons in their local communities are highlighted;
- Differential supports for care in the community in comparison with supports for hospital-based or nursing home care are examined and become part of an open discourse on societal choices;
- Circles of Support are developed which can be drawn on by individuals or groups who require additional or specific assistance;
- Training for Advocates is built around the inter-related concepts of 'choice' and 'voice' for older persons.

Expected outcomes for people who use the Support and Advocacy Service

- People are enabled to explore all options in relation to their will and preferences in respect of place of residence;
- People have access to supports to enable them to maintain community connectedness at the optimum level;
- People are afforded every opportunity to pursue their interests;
- People are supported to engage in activities that are meaningful and socially significant.

2.3

Each person is accorded respect as having equal rights before the law

Advocates: What is Required

- The provision of support and advocacy is based on an agreement between free and equal individuals;
- Advocates at all times recognise that people have legal capacity irrespective of whether or not they are deemed to have a cognitive impairment;
- Each person's right to liberty and freedom of expression is enshrined in the support and advocacy process;
- Advocates facilitate supported decision-making and work towards maximising each individual's capacity;
- Advocates respect the right of people to make decisions for themselves;
- Advocates work towards achieving the optimum balance between risk-taking by individuals and carrying out a safeguarding role;
- Advocates recognise that risk-taking by a person may be necessary in some instances to enable him/her assert his/her basic rights.

Advocacy Provider: What is Required

- Policies and operational guidelines are in place to ensure that advocates comply with the law;
- Negative discrimination against groups or individuals is systematically identified and challenged;
- People's right to liberty and freedom of expression is enshrined in policies, operational guidelines and codes of practice;
- The provisions of the Assisted Decision-making (Capacity) Bill 2013 are applied in training programmes, policies and operational guidelines.

Expected outcomes for people who use the Support and Advocacy Service

- Each individual is regarded as having legal capacity and is treated accordingly;
- People have the supports that they need to make autonomous decisions;
- People with cognitive impairment have whatever supports they need to maximise their decision-making capacity;
- People are enabled and supported to take reasonable risks in accordance with their individual will and preferences.

2.4

Diversity is recognised and respected

Advocates: What is Required

- Advocates have an understanding of and respect for diversity, different cultures and values;
- Advocates do not condone, facilitate or collaborate with any form of discrimination;
- People's right to be 'different' is at all times respected by Advocates;
- Information is provided in a culturally sensitive manner and in a way that is easily understandable by each person involved;
- Advocates base their engagement around Individual Support/Care Plans where these are in existence and accessible to the Advocate.

Advocacy Provider: What is Required

- Policies and operational guidelines are in place to ensure that advocates comply with the law;
- Negative discrimination against groups or individuals is systematically identified and challenged;
- People's right to liberty and freedom of expression is enshrined in policies, operational guidelines and codes of practice;
- The provisions of the Assisted Decision-making (Capacity) Bill 2013 are applied in training programmes, policies and operational guidelines.

Expected outcomes for people who use the Support and Advocacy Service

- All individuals are enabled to exercise their civil, political and religious rights as enshrined in Irish law;
- People's cultural and religious preferences are reflected in the delivery of health and social care supports;
- Discriminatory practices in respect of individuals or groups are identified and challenged.

Indicative Evidence of Compliance

Supporting policies

- Equality and diversity policy
- Systemic advocacy procedures
- Promoting social inclusion for older persons
- Mechanisms for policy feedback to Government
- Mechanisms for public debate

Practical implementation

- Comprehensive and clear Operational Guidelines for Advocates in place
- Evidence of adherence to Operational Guidelines
- Operational Guidelines reviewed on an ongoing basis
- Record-keeping monitored and reviewed
- The systematic identification of the additional support needs of some groups of older persons
- Submissions to Government and policy papers
- Collaborative working with other agencies
- Open discussion forums
- Meetings held with statutory agencies
- Review meetings with people who use the service and their broader social networks.



3. Competence and Compassion

The support and advocacy practice at all times displays high levels of skill, competency, compassion and consistency and advocates work to achieve this at all times in their engagement with people using the service.

Why do we need this Standard?

This Standard is required in order to ensure that the support and advocacy provided and the engagement with people is of the highest quality possible in line with best standards and practices and that advocates are supported to achieve this consistently.

Core components of this Standard

- 3.1 Advocates are adequately trained, supported and supervised in their work;
- 3.2 There is strict adherence to agreed Codes of Practice;
- 3.3 Advocates work consistently to high quality standards;
- 3.4 There is total clarity of purpose, advocacy role and boundaries.

3.1

Advocates are adequately trained, supported and supervised in their work

Advocates: What is Required

- Advocates assume individual responsibility for carrying out their role in accordance with best practice and terms of engagement with individuals and groups;
- Advocates adhere strictly to the Advocacy Provider's policies, operational guidelines and codes of practice;
- Case management plans are implemented by Advocates in a timely and efficient manner;
- Advocates undertake ongoing training and continuous professional development as required;
- Advocates keep abreast of up-to-date information and research findings relating to older people and related policies that impact on older people generally and specifically those with dementia or other disability.

Advocacy Provider: What is Required

- The Advocacy Provider ensures that advocates are trained and supported in their role and are provided with opportunities for continuous professional development relating to the role;
- There is an Advocate's Support and Supervision Policy in place which provides for:
 - Supervision for advocates (individually and collectively)
 - External supervision
- Case management and record keeping systems are in place;
- There are systems in place for analysing case records to support decision-making, accountability and planning;
- Advocates are provided with accessible up to date information on relevant policy developments and research, e.g., through an online resource bank;
- There is on-line easy access for advocates to documentation, e.g., in the form of FAQs, covering all aspects of the delivery of support and advocacy.

Expected outcomes for people who use the Support and Advocacy Service

- People get the best possible support and advocacy in accordance with their needs;
- People have confidence that they will be dealt with confidentially and professionally;
- People are reassured that their voice is being heard.

3.2

There is strict adherence to agreed Codes of Practice (see Glossary)

Advocates: What is Required

- Advocates are fully familiar with and adhere to all the Advocacy Provider's policies and operational guidelines;
- Consent (written where possible) is always obtained prior to an Advocate's involvement with a person except where a rights safeguarding role (non-instructed advocacy approach) is deemed necessary;
- Where a rights safeguarding role (non-instructed advocacy) is deemed necessary, Advocates adhere to the Advocacy Provider's policy and operational guidelines on the matter;
- All users of the support and advocacy service and relevant others (health and social care personnel and relatives) are made aware by advocates of the Advocate's responsibility to report to his/her line manager/supervisor;
- Advocates make all those using the support and advocacy service aware of the organisation's Complaints Policy;
- Advocates report any instances to their supervisor/manager where there may have been an inadvertent breach of a policy or operational guidelines.

Advocacy Provider: What is Required

- There are easily understandable policies and operational guidelines in place;
- These policies and operational guidelines are based on best practice considerations derived from experience in Ireland and in other jurisdictions;
- All Advocates are provided with training in understanding the Advocacy Provider's policies and operational guidelines;
- There are mechanisms in place for monitoring and checking that Advocates implement policies and guidelines;
- There are protocols in place for dealing with any breaches by Advocates of policy or operational guidelines;
- The implementation by Advocates of the organisation's Consent Policy is closely monitored;
- There is a Complaints Policy and related operational guidelines in place.

Expected outcomes for people who use the Support and Advocacy Service

- People are able to have confidence in advocates, individually and collectively;
- People know that advocates are accountable for what they do;
- People know that they can make a complaint if they are unhappy with any aspect of the work of an advocate.

3.3

Advocates work consistently to high quality standards

(see also Standard Component 3.1)

Advocates: What is Required

- Advocates are very familiar with the core components of a quality support and advocacy service;
- Advocates adhere strictly to the Advocacy Provider's policies and operational guidelines on referral, case management, confidentiality, data protection and complaints;
- Advocates maintain detailed records of all actions and engagements with or on behalf of individuals or groups;
- Advocates recognise when their work does not meet the quality they aspire to and take effective remedial action;
- Where it is necessary to talk to other people in order to establish a person's likely will and preferences (a rights safeguarding/non-instructed advocacy approach), Advocates do so with due regard for the person's dignity and privacy (see also Standard Component 1.4);
- Advocates seek support from their supervisor/line manager in addressing any shortfalls in the quality of service delivered.

Advocacy Provider: What is Required

- The core components of a quality support and advocacy service are identified and kept to the forefront of practice and training and continuous professional development;
- Support for frontline advocates is provided at a level commensurate with delivering the quality service to which the Advocacy Provider aspires;
- Appropriate instruments are put in place to monitor and assess the quality of the service delivered;
- Funding, governance and management structures are sufficiently strong to ensure continuity of service;
- An independent evaluation of the service is carried out periodically, e.g., every 2 years.

Expected outcomes for people who use the Support and Advocacy Service

- People consent to actions carried out by advocates with them or on their behalf;
- People are re-assured that any interventions on their behalf will be carried out properly and in accordance with agreed policies and guidelines;
- People using the service have confidence that everything is 'above board';
- People are aware of how to make a complaint about an individual advocate or about the service provided.

3.4

There is total clarity of purpose and advocacy role boundaries

Advocates: What is Required

- Advocates have a clear understanding of what support and advocacy is, what it is not and of the boundaries of their own role;
- Advocates are able to explain, in straightforward language, the nature of the role and are equipped to answer questions and deal with enquiries about support and advocacy;
- Advocates give clear information about the support and advocacy role in a format that is appropriate and accessible to each individual;
- Where appropriate, and with the person's consent, Advocates refer people to other services, taking into account the need to protect confidentiality;
- Advocates provide information to service providers, professionals and other relevant people concerning the role of the advocate.

Advocacy Provider: What is Required

- The Advocacy Provider has clearly stated aims and objectives that communicate to users and other stakeholders the scope and limitations of the service;
- The aims and objectives of the support and advocacy service are incorporated into governance documents;
- There is clarity about:
 - The population served
 - The geographical area covered
 - The support and advocacy approach used
 - The limitations of the service
 - The referral processes in place
 - Complaints procedures
- The Advocacy Provider develops effective liaison structures with other independent advocacy providers and puts in place cross-referral protocols accordingly.

Expected outcomes for people who use the Support and Advocacy Service

- People are able to distinguish between the role of advocates and the role of other health and social care personnel and agencies;
- Users and potential users of support and advocacy are aware of what it can do and what it cannot do;
- People understand that they will be referred to another service if that is more appropriate and if they so wish;
- People know that they will get the service most appropriate to their individual needs.

Indicative Evidence of Compliance

Supporting policies

- Supporting Policies
- Advocates' Support and Supervision
- Case Management
- Clarity of Purpose statement
- Client Charter
- Code of Conduct for Advocates
- Data Recording, Storage and Management
- Ethical Guidelines
- Induction and Training

Practical implementation

- Comprehensive and clear Operational Guidelines for Advocates in place
- Evidence of adherence to Operational Guidelines
- Operational Guidelines reviewed on an ongoing basis
- Record-keeping monitored and reviewed
- Staff Training and Induction Policy implemented on an ongoing basis
- Case Reviews held monthly and recorded
- Support and Supervision and self-care practices implemented
- Individual advocates' training and continuous professional development documented
- Systematic in-house support and supervision for advocates documented
- External supervision documented;
- Panel of experts (*see Glossary*) available to advocates and usage recorded
- Monthly meetings between advocates and supervisors/ managers recorded
- Annual review of advocates' performance recorded.



4. Accessibility

Accessibility implies convenience, openness, receptiveness and facilitates independence. It means that services are available in a manner which makes it easy for people to approach and use.

Why do we need this Standard?

We need this Standard so that support and advocacy services will be readily available to the greatest number of people within the chosen target group. This Standard is also key to a social inclusion approach.

Core components of this Standard

- 4.1 The support and advocacy service is available to those who need it in an equitable and timely manner;
- 4.2 The support and advocacy service is promoted so that those who could benefit are aware of it;
- 4.3 The support and advocacy service is proactive in seeking out 'people who are hard to reach' (see *Glossary*) and people who may have difficulty self-referring;
- 4.4 Information about the nature of the support and advocacy service is easily available and is fully accessible.

4.1

The support and advocacy service is available to those who need it in an equitable and timely manner

Advocates: What is Required

- Advocates work hours that are suitable to people who may wish to use the service;
- Advocates make arrangements for accessible meeting places which afford confidentiality and are acceptable to people using the service;
- Advocates have a transparent system for prioritising referrals and managing ongoing cases;
- Advocates make timely referrals in cases where other support/assistance is required;
- Advocates adhere to the Advocacy Provider's Case Management policy.

Advocacy Provider: What is Required

- Provision is made for a continuum of support and advocacy tailored as required towards the specific needs of individuals and groups;
- A Case Management system is in place which includes monitoring of individual advocates' caseloads;
- The Advocacy Provider has in place a Memorandum of Understanding (service agreement) with health and social care providers – residential care facilities, hospitals, GP practices, primary care services;⁴⁹
- The Advocacy Provider reaches out to the widest possible range of people who may require support;
- Those who are likely to be at risk and in need of support are proactively targeted;
- Regular reviews of uptake of services are carried out;
- The support and advocacy service is made well known to potential referring agencies;
- The Advocacy Provider works with other stakeholders to generate referrals in respect of people who cannot self-refer;
- There is a general policy of not charging people for services provided.⁵⁰

Expected outcomes for people who use the Support and Advocacy Service

- People understand what the support and advocacy service is;
- People are aware that they can access support and advocacy support if they so wish;
- People who may not be able to self-refer are identified;
- Specific groups of older persons who may need additional support (e.g., people in long-term residential care facilities, people with dementia, those with weak family and social networks) are proactively identified and offered support to have their voice heard.

⁴⁹ See Section Four, Guidance for Health and Social Care Service Providers

⁵⁰ An ongoing consideration for Advocacy Providers is how to deal with situations where some people may be in a position to pay for a service and may wish to do so

4.2

The support and advocacy service is promoted so that those who could benefit are aware of it

Advocates: What is Required

- Advocates use all opportunities to inform people who may need support about the nature of service being offered;
- Advocates seek out people who may need the service but who are unlikely to self-refer;
- Health and social care services personnel and relatives are informed by Advocates about the service as the occasion arises.

Advocacy Provider: What is Required

- There is provision for a range of publicity material appropriate to the population targeted;
- Regulatory Authorities, (e.g., HIQA, the Office of the Ombudsman, the Office of the Inspector of Mental Health Services, HSE Complaint Officers, HSE Elder Abuse Case Workers), are made aware of the service;
- The service is publicised in settings where older people are likely to be present – GP surgeries, hospital out-patient departments, residential care facilities, day centres and active retirement social clubs;
- Promotional materials are written in an accessible language style using Plain English guidelines (see also Standard Component 4.4);
- Information materials are available in alternative formats, e.g., Easy-to-Read, Braille;
- Media, including, national and local, are used to promote the service;
- Meetings with groups in specific settings (e.g., residential care facilities, day centres) are organised on a systematic basis.

Expected outcomes for people who use the Support and Advocacy Service

- People know that outside support is available should they need it;
- People who may feel that their voice is not being heard know where they can get help;
- People experiencing difficulty in accessing health and social care services are assured that there is a service to help them;
- People know that they can seek assistance in having their will and preferences implemented.

4.3

The support and advocacy service is proactive in seeking out ‘hard-to-reach’ people (see Glossary) and people who may have difficulty self-referring

Advocates: What is Required

- Advocates are skilled in identifying people who require additional support and in engaging in appropriate interventions with or on behalf of such people;
- Advocates follow the organisation’s Vulnerable Adults Policy (see Glossary) and operational guidelines in respect of rights safeguarding (non-instructed) advocacy;
- Advocates are knowledgeable in the current best practice approaches with regard to rights safeguarding (non-instructed) advocacy, i.e., Human Rights Approach, Person Centred Approach, Watching Brief Approach and/or Witness-Observer Approach (see Glossary);
- Advocates carry out an observation role in specific settings (e.g., hospitals, residential care facilities) in accordance with agreed protocols and report to the Advocacy Provider and to the relevant health/social care provider accordingly.

Advocacy Provider: What is Required

- There is a Code of Practice relating to a rights safeguarding (non-instructed) advocacy approach;
- Advocates trained and skilled in non-instructed advocacy are available where required;
- A Witness/Observer or Watching Brief Role (see Glossary) for advocates in specific settings is included as part of a Memorandum of Understanding between the Advocacy Provider and the health/social care provider involved;
- Specific issues identified through the Advocates’ Observation Role are highlighted to the relevant health/social care provider;
- Group advocacy work promoting self-advocacy and empowerment is included as part of the planned support and advocacy programme.

Expected outcomes for people who use the Support and Advocacy Service

- People who are vulnerable by reason of absence of social support networks are identified and offered support;
- People who need support and advocacy and who may not be able to self-refer become aware of the service;
- People in specific settings who require additional support are identified and provided with help as appropriate.

4.4

Information about the nature of the support and advocacy service is easily available and fully accessible.

Advocates: What is Required

- Information is communicated appropriately to each individual and made easily understandable;
- Advocates are approachable, friendly and easy to talk to;
- Advocates make every effort to ensure that information they have gathered on behalf of an individual is accessible and understandable to that individual;
- Advocates ensure that people have a choice of communication method – person to person, phone, letter, email, text.

Advocacy Provider: What is Required

- There is an inclusive Communications Policy and related operational guidelines;
- All publications and communication are accessible to people who may wish to use the service;
- All information relating to the service is produced in accessible language using Plain English guidelines;⁵¹
- Information is provided in alternative formats – Braille, digitally and Irish Sign Language – as required;
- Sign language interpretation is available on request;
- Interpretation and translation to other languages is available where there necessary.

Expected outcomes for people who use the Support and Advocacy Service

- People are able to communicate in the form that is easiest for them;
- People have a choice of communication method – person to person, phone, letter, email, text;
- People understand the nature and the limitations of the service being offered.

51 See Footnote 47 above

Indicative Evidence of Compliance

Supporting policies

- Accessibility
- Communications
- Equality and Diversity
- Home visits
- Information dissemination
- Involvement of service users
- Referrals

Practical implementation

- Comprehensive and clear Operational Guidelines for Advocates in place
- Evidence of adherence to Operational Guidelines
- Operational Guidelines reviewed on an ongoing basis
- Record-keeping monitored and reviewed
- Toolkit for working with people with communication differences
- Training in alternative communication techniques documented
- Disability awareness training documented
- Equality and diversity training documented
- Promotional materials in Plain English
- Materials available in alternative formats
- Promotion of the availability of alternative communications formats
- Web Accessibility Initiative (WAI) compliance
- Protocol for assessing Sign Language and other language interpreting services
- Free nature of the service promoted
- Service delivered at outreach locations
- Service provided where the person requiring the service lives
- Suitability of meeting spaces reviewed and documented
- Availability and use of assistive technology as required
- Information delivered by various media, e.g., phone, email, local radio slots, online media, television, one-to-one sessions, and public sessions



5. Independence

Support and advocacy is provided in a manner that is structurally, operationally, financially and psychologically independent from other services for the target group and Advocates are free from any conflict of interest.

Why do we need this Standard?

We need this Standard to ensure that both the support and advocacy service and individual advocates represent only the will and preferences of the individuals or groups receiving support and to ensure that the independent role of advocates is generally understood and acknowledged.

Core components of this Standard

- 5.1 Advocates work in a manner that is structurally, operationally and psychologically independent;
- 5.2 The support and advocacy service is as free from conflict of interest as possible both in design and operation;
- 5.3 Advocates operate independently from health and social care personnel;
- 5.4 Advocates work in collaboration with health/social care professionals.

5.1

Advocates work in a manner that is structurally, operationally and psychologically independent

Advocates: What is Required

- Advocates comply with the Advocacy Provider's conflict of interest policy and related operational guidelines;
- Advocates operate independently from any programme providing direct health or social care services to the target group;
- Advocates explain to the people being supported and to relevant other people involved what independent support and advocacy means;
- Advocates adhere to protocols for resolving any issues affecting the advocate's ability to function independently;
- Any communication with third parties (relatives or health and social care service personnel) only takes place with the express permission of the person involved.

Advocacy Provider: What is Required

- Structural and operational independence is reflected in the culture, ethos, management and governance of the advocacy service;
- The advocacy service is operationally separate from general health and social care services provided to the target group;
- The support and advocacy service is managed independently;
- Structural and operational independence of the support and advocacy service is an integral feature of all funding agreements;
- Representatives from funding bodies are not involved in the day-to-day management of the support and advocacy service;
- Funding that in any way may compromise the ethos of independence is not sought or accepted.

Expected outcomes for people who use the Support and Advocacy Service

- People receiving support and advocacy understand its nature and role and how it differs from supports provided by others;
- People are aware that the advocate takes direction only from them and not from any third party (relative or health/social care service provider) – within the confines of being legally compliant;
- People who require support are reassured that there is a service available to ensure that their voice is heard.

5.2

The support and advocacy service is as free from conflict of interest (see Glossary) as possible both in design and operation

Advocates: What is Required

- Advocates take all appropriate steps to avoid conflicts of interest occurring in their engagement with individuals or groups;
- Where a conflict of interest does arise, it is declared and dealt with in accordance with the Advocacy Provider's protocols on the matter;
- Advocates are aware of their own opinions, prejudices and discriminatory practices and actively work to eliminate these in their work;
- The engagement of Advocates with individuals or groups is never compromised by pressures from outside sources, e.g., health and social care providers or relatives.

Advocacy Provider: What is Required

- The Advocacy Provider ensures that ongoing training and support in managing conflict of interest situations is provided to advocates;
- The concept of independence is reflected in all relevant organisational policy documents and codes of practice;
- The principle of advocates not accepting money or gifts is enshrined in a Code of Practice for Advocates.

Expected outcomes for people who use the Support and Advocacy Service

- People are aware that their own will and preferences will be promoted by the advocate even when these may not be supported by other people involved in their lives, e.g., relatives;
- People are aware that they will not be expected to pay for the service;
- People are aware that advocates are prohibited from accepting money or gifts;
- People are aware that relatives will only be involved if the person him/herself so wishes – except in cases where a rights safeguarding (non-instructed advocacy) approach (see Glossary) is being adopted.

5.3

Advocates operate independently from health and social care personnel

Advocates: What is Required

- Advocates ensure that, as far as possible, all living, support, care and treatment options relating to an individual are explored with relevant professionals taking into account the individual's will and preferences;
- Advocates respect the opinions of health and social care professionals, e.g., clinical judgements;
- Advocates make health and social care personnel aware that the Advocate takes instruction only from the individual or group with whom s/he is working;
- Where involvement is on the basis of a rights safeguarding role (a non-instructed advocacy approach) (see *Glossary*), Advocates involve all other key informants in establishing as far as possible the likely will and preferences of the individual;
- Health and social care personnel and relatives (where they are involved) are given clear information about how support and advocacy works.

Advocacy Provider: What is Required

- The Advocacy Provider has a written policy and related operational guidelines in place in respect of ensuring the independence of advocates;
- There are agreed mechanisms with health and social care service providers for an advocate working with an individual to be consulted in any multi-disciplinary assessment of that person's needs;
- There are protocols in place for the involvement of advocates in any cases where there is an assessment of individual risk component relating to an individual asserting his/her will and preferences.

Expected outcomes for people who use the Support and Advocacy Service

- People are aware that the advocate carries out a different role from other health/social care personnel;
- People have confidence that their voice will be heard in any discussions about their living options, their care arrangements and their well-being (e.g., discussions between health professionals and relatives).

5.4

Advocates work in collaboration with health/social care professionals

Advocates: What is Required

- While always acting for an individual or group, advocates develop and maintain good relations with other personnel involved in a person's care, treatment and support;
- Advocates have a clear understanding of other people's roles and responsibilities (individually and collectively) in health and social care delivery;
- Advocates at all times respect the roles and responsibilities of health and social care personnel;
- Advocates build working relationships with health and social care service delivery personnel;
- Advocates identify specialists in different fields who are available to provide help and advice in complex cases;
- Advocates adopt an overall approach of collaborating and negotiating where possible with health and social care personnel on behalf of individuals and groups and challenging policy and practice where deemed necessary.

Advocacy Provider: What is Required

- The Advocacy Provider develops and implements operational guidelines on collaborative working in the context of delivering independent support and advocacy;
- There is internal management of collaborative working with other relevant parties and support for advocates is provided accordingly;
- Relationships and joint working arrangements are cultivated and developed with other support and advocacy services, including, in particular, those working in the areas of disability and mental health;
- Circles of Support are organised at local level which can be drawn on by advocates as required.

Expected outcomes for people who use the Support and Advocacy Service

- People have someone to assist them in having an overview of their situation;
- People know that they have someone to help them to liaise with service providers/professionals;
- People have assistance in negotiating the health and social care pathways;
- People unable to give consent have someone to ensure that they are safeguarded and that their rights are protected.

Indicative Evidence of Compliance

Supporting policies

- Advocacy Handbook with Statement of Independence
- Conflict of interest
- Consent
- Complaints
- Good practice case studies
- Governance documents (Constitution, Memorandum and Articles of Association)
- Job descriptions for advocates
- Transparent funding agreements publicly accessible

Practical implementation

- Comprehensive and clear Operational Guidelines for Advocates in place
- Evidence of adherence to Operational Guidelines
- Operational Guidelines reviewed on an ongoing basis
- Systematic in-house support and supervision for advocates implemented
- External supervision engaged in by advocates documented
- Record-keeping monitored and reviewed
- The open disclosure of potential areas of conflict
- Memorandum of Understanding and related Service Agreement with each health/social care agency involved
- Independent monitoring, advisory, steering structures established as appropriate for the service
- Target group facilitated to participate in the research, planning, delivery and evaluation of the advocacy service
- Mechanism for evaluation of the service every 2 years



6. Accountability

Accountability involves taking responsibility for actions and for the effectiveness of an organisation. It requires that both the Advocacy Provider and individual advocates act with integrity and responsibility in their dealings with people who use the service and with other stakeholders.

Why do we need this Standard?

We need this Standard to ensure that both individual advocates and the Advocacy Provider are clear about their respective responsibilities and that structures are in place to allow them to demonstrate how these responsibilities are fulfilled.

Core components of this Standard

- 6.1 The support and advocacy service is accountable to the people who use it;
- 6.2 The support and advocacy service is effectively managed;
- 6.3 The support and advocacy service adheres to all legal requirements;
- 6.4 The support and advocacy service offered is underpinned by relevant human rights provisions and equality legislation.

6.1

The support and advocacy service is accountable to the people who use it

Advocates: What is Required

- Advocates take directions from the people who use the service;
- The Advocate explains clearly to each individual in a manner suited to his/her communication methods what the support and advocacy being offered entails;
- The independent role of the Advocate vis a vis the support role of health and social care personnel is made clear at all stages of the engagement;
- Advocates engage in a regular checking process to verify that interventions and actions being taken are in accordance with the will and preferences of the individuals involved.

Advocacy Provider: What is Required

- There is a transparent Consent Policy in place;
- There is robust Complaints Policy;
- There is a comprehensive and transparent information dissemination policy in place;
- There are transparent service access and eligibility criteria;
- There is a clear policy on referrals and prioritisation;
- There are protocols in place for disclosure to the individual concerned of all actions and interventions on his/her behalf;
- There are opportunities for people using the support and advocacy service to be involved in the management and development of the service.

Expected outcomes for people who use the Support and Advocacy Service

- People have a clear understanding of how what the support and advocacy service does and how it works;
- People know clearly what actions and interventions are being undertaken by advocates on their behalf and consent to those actions;
- People are aware that they can make a complaint if they are dissatisfied with any aspect of the service and that they will be assisted in making a complaint;
- People have opportunities to influence the way the support and advocacy service is managed and delivered.

6.2

The support and advocacy service is effectively managed

Advocates: What is Required

- Advocates are fully aware of and implements the Advocacy provider's policies and operational guidelines;
- The Advocate is guided by his/her line manager/supervisor in matters concerning governance;
- The Advocate informs his/her manager of any conflict of interest in a particular case;
- Advocates highlight any operational issues arising from their work and report these to their manager.

Advocacy Provider: What is Required

- The Advocacy Provider has in place funding, governance and management structures that ensure the sustainability of the service;
- There are transparent governance systems in place;
- There are policies on employment, equal opportunity and financial management based on best practice;
- There are systems in place for the effective monitoring and evaluation of the work of advocates and of the programme as a whole;
- There is a process in place to identify unmet need;
- Usage and take-up patterns are analysed systematically to identify individuals and areas of greatest need.

Expected outcomes for people who use the Support and Advocacy Service

- People who may need support and advocacy are systematically identified and targeted;
- People have confidence that they will receive a high quality service based on best practice;
- People are confident that they will be helped to engage with the health and social care system in accordance with their needs.

6.3

The support and advocacy service adheres to all legal requirements

Advocates: What is Required

- Consent is always obtained by Advocates unless a rights safeguarding role (non-instructed advocacy approach) is identified as necessary;
- Advocates inform people – orally and with written material – of the type of support and advocacy service to be provided and its limits;
- Advocates are familiar with the Advocacy Providers governance structure;
- Advocates are familiar with and implement the Advocacy Provider's
 - Consent Policy
 - Health and Safety Policy
 - Vulnerable Adults Policy
 - Complaints Policy
 - Data Protection Policy
- Advocates assist people in accessing complaints mechanisms;
- The advocate informs his/her manager of any conflict of interest in a particular case;
- Advocates observe existing legal requirements and regulations in relation to instances of alleged or suspected abuse.

Advocacy Provider: What is Required

- The following policies are in place and reviewed annually:
 - Consent
 - Complaints
 - Health and Safety
 - Data Protection and Storage
 - Advocates' Support and Supervision
 - Vulnerable Adults
 - Rights Safeguarding (Non-instructed Advocacy)
- The Advocacy Provider is insured against employers and public liability;
- The Advocacy Provider complies with the Data Protection legislation.

Expected outcomes for people who use the Support and Advocacy Service

- People are aware that they are required to give consent to involvement by an advocate on their behalf;
- People have confidence that advocates will act appropriately at all times;
- People requiring support are reassured that any interventions by advocates adhere to best health and safety practices;
- People using the service are aware of how to make a complaint and, where required, are assisted to do so.

6.4

The support and advocacy service offered is underpinned by relevant human rights provisions and equality legislation (*see also Standard 2 Social Justice*)

Advocates: What is Required

- A human rights (*see Glossary*) ethos permeates the way advocates carry out their role;
- Advocates are familiar with the provisions of international human rights conventions and protocols, in particular,
 - The European Convention on Human Rights
 - the UN Convention on the Rights of Persons with Disabilities
 - The Council of Europe Statement on the Rights of Older Persons;
- Advocates are familiar with key relevant Irish legislation – Assisted Decision-making (Capacity) Bill 2013, the Equal Status Acts and the Mental Health Act 2001.

Advocacy Provider: What is Required

- The Advocacy Provider includes a human rights approach as a key underpinning working principle;
- An Equality Policy is in place;
- Training programmes include core modules on human rights;
- Training programmes include information about all relevant Irish legislation.

Expected outcomes for people who use the Support and Advocacy Service

- People have confidence that they will be assisted to deal with any infringements of their basic rights;
- People have confidence that their human rights will be protected;
- People are aware that they will be helped to have their voice heard;
- People are supported to exercise their will and preferences to the maximum extent possible.

Indicative Evidence of Compliance

Supporting policies

- Advocates' Support and Supervision
- Complaints
- Confidentiality
- Conflict of Interest
- Consent
- Data Protection
- Equality
- Financial Management and Control
- Information Dissemination
- Referrals
- Statement of Service

Practical implementation

- Comprehensive and clear Operational Guidelines for Advocates in place
- Evidence of adherence to Operational Guidelines
- Operational Guidelines reviewed on an ongoing basis
- Record-keeping monitored and reviewed
- Forums for service user feedback held regularly and outcomes documented
- Clear governance and management structures
- Access, eligibility and prioritisation criteria publicly available
- Forums for service user feedback held regularly and outcomes documented
- Mechanisms for feedback to people who use the service established and implemented
- Governance structures and accounts easily accessible to general public
- Designated person within the service to implement information provision policy and related data protection legal requirements
- Designated person within the service with responsibility for processing complaints



Section Three:

Working with a Support and Advocacy Service: Guidance for Health and Social Care Providers

This section provides guidance as to what would be required from health and social care services to facilitate support and advocacy work for people requiring assistance. It identifies the requirements for health and social care service providers in order to integrate support and advocacy, as provided for in the Standards (Section Two).

Introduction

This section looks at the Quality Standards from the perspective of health and social care services where support and advocacy would be provided independently to people requiring assistance. It sets out the rationale for the Quality Standards, provides a brief description of the role and nature of support and advocacy, identifies the requirements for health and social care services in order to integrate independent support and advocacy, as provided for in the Quality Standards (Section Two), into their service delivery systems.

Rationale for Integrating Advocacy into Health and Social Care Settings and Developing Standards Accordingly

It is now widely accepted that support and advocacy has an important role to play in helping services to meet the needs of individuals who, for one reason or another, are unable to assert their will and preferences and/or navigate the health and social care services pathway. For example, there are a number of references in HIQA Standards to the role of advocacy and the need to make provision for service users to have access to support and advocacy. The Ombudsman has recently noted that patient advocates can perform a very valuable function for both patients and hospitals by solving small problems before they become large ones and by helping patients feel that they are being treated fairly and with respect by the hospital.⁵² The Ombudsman concludes that independent advocacy services should be sufficiently supported and signposted within each hospital so patients and their families know where to get support if they want to raise a concern or issue.

The Quality Standards are envisaged as informing the development and provision of an independent and impartial support and advocacy service for older people in all care settings – in their own homes; GP services, primary care services, long-stay residential facilities; hospital; hostel; hospice, and in the process of transition between these settings. The provision of support and advocacy is seen as helping to ensure that the motto of ‘Nothing for or about you/without you’ is applied throughout the health and social care system.

The development of these Quality Standards is predicated on the belief that the availability of a continuum of support and advocacy in all health and social care settings can

⁵² <http://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Learning-to-Get-Better/Learning-to-Get-Better.pdf>

make a significant contribution to both enhancing the quality of life for older persons who need additional support and ensuring that their rights are upheld. It is envisaged that the Quality Standards will contribute to a more responsive and respectful care and support system for older persons by triggering a national conversation in Ireland in respect of quality of life issues for older people who have become vulnerable and a related need to ensure that the highest standards prevail in different health and social care settings.

It is envisaged that the Quality Standards will contribute significantly to the development of good practice in support and advocacy services by:

- Highlighting the role and contribution of support and advocacy
- Ensuring consistency and uniformity in the approach of advocates
- Bringing clarity to the role of independent support and advocacy (what it is/what it is not)
- Providing a benchmark against which the functioning of advocacy providers and the practice of individual advocates can be measured
- Providing safeguards for independent support and advocacy service providers and for people that use/ receive their services

Defining and Understanding Support and Advocacy

Many people have a support and advocacy role – health and social care professionals, relatives, friends and mutual support groups. While this is vitally important in ensuring that people have access to health and social care appropriate to their needs, it is necessary to recognise that service providers may sometimes experience a conflict between advocacy and their role in the organisation and, for this reason, support and advocacy provided independently from service providers offers a different type of intervention.

While six types of support and advocacy relevant to older persons can be identified (see Section One of document), the underlying principle of all independent support and advocacy is to facilitate people in speaking for themselves and in articulating their own needs. This includes the provision of supports at various points along a continuum which includes the provision of information, assistance with negotiating health and social care pathways and engaging in representative advocacy with or on behalf of people. Advocacy is not about making decisions for people or

telling or advising someone what you think they should do.⁵³ Advocates do not have an inspection role per se but rather an observation or witness role from the perspective of service users, e.g., people seeking admission to hospital, people seeking home supports, people in residential care facilities.

Statutory Provisions Relevant to Independent Support and Advocacy

There are a number of statutory provisions which provide a context for and inform independent support and advocacy work, including, in particular:

- The Assisted Decision-making (Capacity) Bill 2013
- Data Protection Act 1988 and Data Protection (Amendment) Act 2003
- HIQA Standards (in particular, National Standards for Residential Care Services for Older Persons and HIQA Guidance for Designated Centres, Restrictive Procedures)
- Section 9 of Health Act 2004 (which refers to Complaints)
- The Ombudsman Amendment Act 2012 (which brought over 180 additional public bodies under the remit of the Ombudsman with effect from 1 May 2013)
- Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2010 (SI 36/2010)
- Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013 (SI 415/ 2013)

What can be expected from Advocates

Core outcomes of support and advocacy envisaged in the Quality Standards are that:

- People have someone to assist them in having an overview of their situation and their options;
 - People know that they have someone to help them to liaise with service providers/professionals and to navigate the pathway to health and social services;
- People unable to give consent have someone to ensure that they are safeguarded and that their rights are protected. The following are identified in the Quality Standards as

⁵³ The Scottish Independent Advocacy Alliance, Non-Instructioned Advocacy Guidelines: A companion to the Code of Practice for Independent Advocacy ps. 16-17)

what is required from advocates working in health and social care settings.

- Adopt an overall approach of collaborating and negotiating where possible and challenging policy or practice where necessary in whatever health and social care settings they work;
- Have a clear understanding of other people’s roles and responsibilities (individually and collectively) in health and social care delivery;
- At all times respect other people’s roles and responsibilities;
- Build working relationships with health and social care service delivery personnel;
- Identify specialists in different fields who are available to provide help and advice in complex cases.

The Quality Standards: Requirements for Health and Social Care Providers

The Standards are based on the concept of collaborative working with health and social care professionals. It is envisaged that relationships and joint working arrangements would be cultivated and developed with service providers and professionals to ensure that the complementary role of independent support and advocacy is both understood and acknowledged. The Quality Standards envisage that health and social care providers (hospitals, GPs, nursing homes, primary care services) would include independent support and advocacy as an integral part of their service delivery infrastructure. This will require health and social care providers to:

- Have in place policies and related practice that respects the rights of older people individually and collectively to:
 - Exercise choice in accordance with their will and preferences
 - Exercise autonomy
 - Access health and social care services commensurate with need on an equal basis with others
 - Have their voice heard
 - Have the supports they need to make decisions for themselves
- Acknowledge the potential contribution to quality service delivery of having easily accessible independent support and advocacy;

- Acknowledge and understand the importance of the rights safeguarding role (non-instructed advocacy) where people may not be able to self-refer or to give instructions to an advocate;
- Facilitate the integration of an ethos of independent support and advocacy within the health/social care setting;
- Formally acknowledge the independent role of advocates and their responsibility to collaborate and negotiate where possible and to challenge practice and policies where necessary;
- Understand the multiple roles of advocates –support, representation, witness/observer, facilitator of group discussions (e.g., in residential care settings);
- Acknowledge and support the principle that the primary role of advocates is to enable people to exercise their will and preferences;
- Acknowledge that the advocate is accountable in the first instance to the person/s who are availing of the support and advocacy service;
- Understand and acknowledge the systemic nature of some issues that are identified by advocates and work with the Advocacy Provider to address such issues;
- Familiarize themselves with the Six Standards for Support and Advocacy Work with Older People, their related components and indicative evidence of compliance (Section Two);
- Enter into a Service Agreement/Memo of Understanding (MoU) (to be reviewed annually) with an appropriately constituted Advocacy Provider;
- Facilitate the involvement of advocates in accordance with the provisions of this Service Agreement/MoU;
- Develop a knowledge of and familiarity with the Policies and Operational Guidelines for Advocates put in place by the Advocacy Provider;
- Nominate a Designated Link Person/s who will have responsibility for liaising with the Advocacy Provider and for ensuring that advocates are facilitated in carrying out their role in accordance with the Service Agreement;
- Ensure that all users of health and social care services have easy access to independent support and advocacy services in accordance with HIQA Standards;
- Facilitate arrangements for people wishing to meet with advocates;
- Have a particular focus on people who may not be able to self-refer and facilitate the involvement of advocates in respect of such people;
- Communicate and document any changes to services that may have an impact on the provision of support and advocacy;
- Address, as far as possible, issues identified by advocates (where these are relevant to the health/social care provider involved)
 - Service access issues affecting individuals or groups
 - Quality of life issues
 - Rights infringements
 - Alleged or suspected abuse
 - Systemic issues which impact on older people's social inclusion and/or equality of access to services and supports
- Engage in awareness raising among all staff about the role of advocates and their potential contribution to enabling people to:
 - Get services and supports commensurate with need
 - Exercise choice in accordance with their will and preferences
 - Engage in autonomous decision-making
- Work collaboratively with the Advocacy Provider to achieve the highest standards of support and care for individuals and groups;
- Support people's right to self-determination and to take reasonable risks in accordance with their will and preferences;
- Support advocates in engaging in a human rights safeguarding role (witness/observer and watching brief roles) and related non-instructed advocacy (see *Glossary*);
- Facilitate in a timely manner the processing of complaints by individuals or groups;
- Proactively promote and publicise the advocacy service within their own health/social care facility;
- Collaborate with the Advocacy Provider in reviewing on an ongoing basis support and advocacy practice within the health/social care setting.

The Quality Standards: Requirements for Advocacy Providers

The Quality Standards for Support and Advocacy Work with Older People are being promoted as a benchmark against which all organisations which provide independent support and advocacy (either as a stand-alone service or as part

of a broader range of support services) can assess the quality of the support and advocacy provided. The detailed requirements for both Advocacy Providers and individual advocates contained in Section Two of the document can be summarised as:

- The obligation to have in place well-structured and transparent governance and management systems and accountability protocols in place;
- Highest professional standards guided by the values of collaboration, transparency, mutual responsibility and respect;
- The best quality service and best possible outcomes for people who avail of the support and advocacy service;
- Policies and Operational Guidelines based on best practice considerations, including, in particular, consent, confidentiality, complaints and referrals;
- Transparent and robust advocate recruitment policies;
- Advocates trained to a high standard with appropriate accreditation;
- Advocates well supported and supervised in their work;
- The availability of the following support/interventions as required:
 - Information
 - A rapid response service where a matter is considered urgent
 - Facilitation of service user groups, e.g. nursing home residents or primary care clients
 - Specialist advocacy supports for people with complex issues, e.g. people with dementia
 - Representative advocacy (including access to legal representation)
 - A witness/observer role (as clearly distinct from an inspection role) in respect of best practice standards
- Consistency and continuity regarding the level and quality of service;
- Access by advocates to effective and secure data recording systems in accordance with policies on confidentiality, data protection, support and supervision;
- Designated link persons with health and social care settings where support and advocacy is provided;
- Protocols for introducing advocates into health and social care settings;
- Collaboration with health and social care providers in addressing issues of concern to people using the support and advocacy service.



Section Four:

Quality Standards for Support and Advocacy Work: Five Case Scenarios

This section provides five Case Scenarios which illustrate how the Six Standards might apply in different contexts and provide an overview of the practical application of the standards in different situations.*

* While reflecting good practice in support and advocacy, these case scenarios are not based on a Best Practice review. The names of the individuals used in each of the Case Scenarios are fictitious.



Discharge from an Acute Hospital

Case Scenario 1

Helen is a patient in an acute hospital. Helen fell at home a number of months previously after a minor stroke. The stroke resulted in Helen having some communication difficulties and gave rise to questions about her cognitive functioning. Helen is medically fit for discharge and indicated her desire to return home. Her niece and other family members are concerned about her ability to manage at home and the perceived risks involved. The family expressed their opinion that Helen should consider nursing home care.

Helen's medical social worker contacted the advocacy service on the basis that Helen would be likely to benefit from the support of an independent advocate to help her to look at her post-discharge options.

What the advocate did:

The Advocate visited with Helen and introduced himself and his role. The Advocate informed Helen that this was a free service, which was led and instructed by her and that the aim was to ensure that her will and preference was upheld. Through further discussion, Helen agreed to talk with the Advocate regarding her long term care options and this led to her discussing her desire to return home.

The Advocate visited with Helen twice and on both occasions Helen displayed insight into her situation and the risks of returning home. Helen stated that she could fall again and not be found until the morning but she 'would rather die at home than go to a nursing home'. Helen gave her consent for the Advocate to work on her behalf, and in doing so to discuss her needs with other professionals. She signed a Consent/Authority to Act Form (see Glossary). Helen was open to a home care package, attending a local day care centre a few times a week and agreed to engage with her local public health nurse.

Helen requested that the Advocate attend on her behalf an upcoming Multi-Disciplinary Team (MDT) meeting regarding her discharge and articulate her will and preference in this regard. The MDT was eager to hear Helen's preferences, but Helen did not want to attend the meeting herself as she was nervous regarding her speech and the number of professionals that would be present. At the MDT meeting, the Advocate, taking a functional (time and issue specific) approach to Helen's capacity, confirmed that Helen could understand, retain, weigh and communicate her desire to return home and displayed insights into the risks involved.

The Advocate met with Helen after the MDT meeting to inform her of what happened and the outcomes which would take time to implement.⁵⁴ As the process was a long drawn out one, the Advocate regularly engaged in support and supervision sessions with his supervisor. This ensured the Advocate received support and provided a platform to raise and explore systemic issues, e.g., delay in accessing home care packages.

⁵⁴ There was a question of Helen being asked to move to a step-down facility/transitional care bed while the logistics of her Home Care package were being worked out. However, as the matter transpired, this did not happen.

Outcome for Helen:

After considerable effort from the MDT team and many conversations with Helen's family and the Advocate, a discharge plan was put in place. This was a discharge home with a home care package. Helen was happy with the outcome. However, her family remained apprehensive regarding the decision. By agreement, the Advocate, therefore, responded by supporting Helen and her family during the transition and Helen agreed that she would like the Advocate to remain involved. The Advocate has visited Helen at home to follow up and is available in the future to work with Helen if she requires further support.

Practical Application of Standards

Standard 1: Respect

Helen's will and preferences in terms of returning to live at home were upheld. Helen was enabled to exercise autonomy which included some risk-taking on her part.

Standard 2: Social Justice

The concept of supported decision-making was applied using a functional approach to capacity in accordance with the provisions of the Assisted Decision-Making (Capacity) Bill 2013. Helen received a Home Care Package which she felt was her right.⁵⁵

Standard 3: Competence and Compassion

The advocate demonstrated a high level of competency and compassion in engaging with Helen, with health care personnel and with relatives.

Standard 4: Accessibility

The service was available in a timely manner in response to the referral from the social worker and was available on an ongoing basis.

Standard 5: Independence

The advocate worked independently, taking instructions only from Helen but working collaboratively with health care professionals and with Helen's relatives.

Standard 6: Accountability

The advocate acted responsibly and with integrity and received support and supervision as required.

⁵⁵ While it is stated policy to support people to remain in their own homes for as long as possible and while under Section 61 of the Health Act 1970, home help services may be provided for this purpose, there is no legal entitlement to a Home Care Package.



Person in a Nursing Home

Case Scenario 2

Paul has recently moved from a Congregated Setting for people with an intellectual disability to a Nursing Home. Paul has limited communication skills. Paul has had no access to his Disability Allowance for some time. This has resulted in Paul being unable to participate in social outings outside of the nursing home, as there is an extra charge for this. The Director of Nursing contacted the advocacy service as he believed Paul could benefit from the support of an advocate.

What the Advocate did:

The Advocate met with Paul and they engaged and interacted well. Over a number of visits, the Advocate spent time with Paul, getting to know him and building up a picture of his lifestyle and preferences. The advocate learned that Paul routinely participated and enjoyed social outings in his previous home.

The Advocate was unable to get Paul's explicit consent to act on his behalf and follow up on his disability payment. The Advocate took affirmative action on Paul's behalf without his explicit consent on the basis that his right to his disability payment was being infringed. The Advocate used a rights safeguarding (non-instructed) advocacy approach in order to uphold Paul's right to his Disability Allowance.

The Advocate was informed that Paul's family had been receiving his Disability Allowance in full for many years but that this was not being transferred to Paul. Paul's case was discussed with the Advocate's supervisor and monitored by the Advocacy Provider's internal Designated Officer for the Safeguarding of Vulnerable Adults and the case management team. The Director of Nursing in the nursing home retained an interest in the case. As it is not the role of an Advocate to investigate abuse and there is a duty to report, a referral was made to the local Social Worker for the Protection of Vulnerable Adults on the basis of a concern about possible financial abuse perpetrated by Paul's family. The referral and subsequent follow up was recorded and monitored by the Advocate, the supervisor and through the internal case management system.

After further discussions with the Director of Nursing and the Social Worker for the Protection of Vulnerable Adults, the Advocate identified the issue as systemic in that, historically, in some cases, Disability Allowance was seen by some families as a 'family payment' rather than a payment to an individual.

A series of meetings followed with key professionals, Paul and his Advocate and Paul's family. With input from the local Social Worker for the Protection of Vulnerable Adults and the Director of Nursing, Paul's Disability Allowance was secured and a new Personal Property Account was opened in Paul's name by the Nursing Home.

This was a complex case which involved difficult family circumstances and thus meetings were often tense. Paul's family were anxious to support him but required support in understanding the best manner to do so. The Advocate also required and received ongoing informal and formal support and supervision, throughout the process and self-care was encouraged. These support and supervision meetings were documented and recorded by the Advocate's supervisor. Throughout these meetings, the family became more open and agreed to work with the Advocate and other professionals in determining the best manner to support Paul.

An important outcome of this case was that a need for ongoing training for advocates regarding rights safeguarding (non-instructed) advocacy was identified and is planned as part of the Advocacy Provider's continuous professional development (CPD) programme for advocates.

Outcome for Paul:

Paul's right to have full access to his Disability Allowance was upheld. The independent support and advocacy provided to Paul was almost certainly a key factor in having the matter dealt with. Paul's quality of life has greatly improved. Although this case has been closed, ongoing support is available to Paul, his family and the nursing home should it be required.

Practical Application of Standards

Standard 1: Respect

Paul's wish to participate in social outings was clearly established by the Advocate. The need for him to have access to his Disability Allowance to enable him to do this was acknowledged and acted upon.

Standard 2: Social Justice

Paul received his Disability Allowance to which he was rightly entitled.

Standard 3: Competence and Compassion

The Advocate demonstrated a high level of competency and compassion in engaging with Paul and with his family in what was a difficult and complex situation.

Standard 4: Accessibility

The service was available in a timely manner in response to the referral from the Director of Nursing in the nursing home where Paul now lives. The Advocate is available to work with Paul and his family on an ongoing basis if required.

Standard 5: Independence

The Advocate worked independently using a rights safeguarding (non-instructed) advocacy approach and worked in collaboration with Paul's family and nursing home staff in this regard.

Standard 6: Accountability

The Advocate acted responsibly and with integrity and received support and supervision as required. A need for ongoing training for advocates in rights safeguarding (non-instructed) advocacy was identified and a plan put in place by the Advocacy Provider for this purpose.



Person living in the community

Seán is a single man residing alone in the community. Seán has a challenging relationship with some of his siblings, who believe he is having cognitive difficulties and plan to make an application to have Seán made a Ward of Court. Seán contacted an Advocacy Provider as he requires legal support regarding the Ward of Court procedure and support in challenging his family's proposed action.

Case Scenario 3

What the Advocate did:

The Advocate spoke with Seán by telephone, introduced the support and advocacy service, explained the role of the Advocate and discussed Sean's desired outcome. The Advocate obtained Sean's consent to work with him on this matter and discuss legal and other matters with the wider team, including obtaining legal advice. As Seán had some mobility issues, the Advocate arranged a follow up visit in Seán's home. As this was a visit alone to Seán's home, the Advocate followed the Advocacy Provider's Home Visit policies and procedures, informing colleagues of the time and location of the visit and documenting and recording the visit and outcomes.

The Advocate took time to develop a relationship with Seán and fully reflect his wishes and preferences in a mutually agreed advocacy support plan. Seán had made arrangements to create an enduring power of attorney (EPA) with a solicitor (who was satisfied that Seán understood the effect of creating the power of attorney and that Sean was not under undue pressure to create the power) but confirmed to Seán that it was also necessary to have a doctor confirm that he had the capacity to understand the effect of creating the power. Seán, therefore, arranged to visit a consultant in geriatric medicine to have a full capacity assessment. Seán was aware that, with the emotional support of an Advocate in these meetings, he would feel less stressed and thus be better able to accurately present for an assessment of his decision-making ability. Seán was very capable of self-advocating and required additional support and information only in some areas.

Seán's support and advocacy plan was discussed, monitored and reviewed at regular case meetings and legal advice was sought by the Advocate as required. These were recorded, monitored and reviewed. The Advocate consistently made Seán aware of this process and of the fact that his information was protected in line with Data Protection Guidelines.

Sean's siblings regularly made contact with the Advocacy Provider and were informed that the role and duty of the Advocate was to follow Sean's direction at all times and take the lead solely from him. Thus, information was only shared with Seán's siblings at Seán's direction and request. Seán's siblings were made aware of the Advocacy Provider's Complaints Policy when they highlighted their concerns. This complaint was managed, reviewed and responded to by the Advocacy Provider's designated complaints person.

The Advocacy Provider has approached Sean requesting feedback and comment on the service provided to date. These comments and outcome will feed into the internal evaluation process.

Outcome for Sean:

Seán and his Advocate attended meetings with his solicitor and consultant. Sean was able to create his enduring power of attorney, which, his solicitor pointed out, would only come into effect when he reached the stage when he was unable to make decisions for himself and the enduring power of attorney was registered. The solicitor also pointed out that as Seán had given a general authority to the two people he appointed his attorneys, any Ward of Court application would be unnecessary. Seán was more confident in navigating many legal and clinical meetings with the support of the Advocate and thus felt fully supported and empowered in this process. However, Sean still has a challenging family dynamic and thus the Advocate is continuing to provide support.

Practical Application of Standards

Standard 1: Respect

The Advocate fully respected Seán's right to self-determine and supported him in so doing. Seán was empowered to carry out his will and preference through the support of the Advocate.

Standard 2: Social Justice

Sean received the support he needed to protect his right to retain control over his affairs and to challenge the proposed Ward of Court application being considered by his siblings. The appropriate (least restrictive) mechanism for Seán to exercise his will and preference (an enduring power of attorney) was put in place.

Standard 3: Competence and Compassion

The Advocate demonstrated an ability to relate to Seán in a competent and skilled manner and in a way that showed an understanding of his potentially vulnerable position.

Standard 4: Accessibility

The service was available in a timely manner in response to a self-referral. The Advocate ensured accessibility of the service by arranging a follow up visit to Sean's home.

Standard 5: Independence

The Advocate worked independently, taking instructions only from Seán. Attempted interference by Seán's siblings in the advocacy process was dealt with appropriately.

Standard 6: Accountability

The Advocate acted responsibly and with integrity and received support and supervision as required. Sean was asked to provide feedback on his experience of the service.



Person transferring from a Nursing Home to an Acute Hospital

Case Scenario 4

Mary who was a frail 85-year old had been a resident in a Nursing Home for about 2 years having found that she could not manage by herself at home because of severe arthritis, hearing loss and she also had a cardiac problem.

What the Advocate did:

At Mary's request, the Advocate met with Mary on a number of occasions. Mary confirmed that she had no family and so wished to discuss her approaching end of life with the Advocate. Mary's concern was that she wished to have a happy death and if it was possible to receive palliative care at the end of her life. She said that her particular wish was to be kept in comfort but that she did not want to 'be put on any machines to keep her alive if she was in fact dying'. She said that she had read a lot about end-of-life issues and was happy to die when 'God called her'. Mary also confirmed

that she was very happy living in the nursing home and was very well looked after by the staff who were very kind to her.

The Advocate explained to Mary that if she wished she could set out in writing what her end-of-life wishes were as this would assist to ensure that her wishes were carried out. The Advocate also suggested that Mary might discuss her wishes with her GP and she could also ask her GP any questions to explain how her wishes might be carried out. Mary subsequently asked the Advocate to prepare the note of her wishes and the Advocate received Mary's consent to give the note to the Director of Nursing who agreed to put Mary's wishes on her file.

A few weeks after the Advocate's last conversation with Mary, the Advocate received a call from a nurse at the Nursing Home to say that Mary had taken ill. A doctor had been called to attend to her and had stated that Mary had pneumonia. The doctor had arranged for Mary to be admitted to hospital and arrangements had been made to transfer Mary by ambulance to the hospital. When the ambulance collected Mary at the nursing home, the nurse confirmed that she gave an envelope to the paramedic and explained that it contained Mary's specific end-of-life wishes. The paramedic's reply, as reported by the nurse, was: 'Don't worry about such things, there is no time for that, this lady will be treated in hospital in accordance with what the doctors decide'.

The nurse confirmed to the Advocate that Mary had repeatedly talked about the fact that she was no longer concerned about dying as she was happy that the Nursing Home knew her wishes. The nurse asked the Advocate could he do anything to ensure that Mary's wishes were carried out as Mary had left the Nursing Home in the last half-hour.

The Advocate contacted his supervisor and the Advocacy Provider arranged for a Support Person to go to the hospital immediately and to talk to the doctor treating Mary and to ensure that Mary's end-of-life wishes were known in the hospital and that arrangements would be made to carry out her wishes. The Advocacy Provider's Support Person met with the doctor treating Mary who confirmed that Mary was indeed at the end of life. It was arranged that palliative care would be provided for Mary. Mary died in the hospital 2 days later.

Outcome for Mary and others:

Mary's end-of-life wishes were understood by the Advocate and the Nursing Home and she did ultimately receive treatment in accordance with her wishes. (There is a prima facie question as to whether it was in fact necessary to transfer Mary to hospital or would it have been possible for Mary to receive palliative care in the Nursing Home where she would have been happy to die).

Following Mary's death, the Advocacy Provider was asked by the Nursing Home to arrange for one of its representatives to facilitate a meeting of the residents in the Nursing Home who wished to discuss how they could plan and ensure that their end-of-life care wishes were respected. This was arranged.

The outcome of the meeting was that the residents confirmed to the Director of Nursing that many of them would be preparing individual end-of-life care wishes to be recorded on each of their files. The residents also asked that the Nursing Home undertake to ensure that any GP coming to the Nursing Home was made aware of such wishes and that in the event of any suggested transfer to a hospital that the GP refer to the resident's wishes in the referral note to the hospital. The Nursing Home itself also undertook to train staff in good end-of-life care for residents and compassionate treatment of their families.

Practical Application of Standards

Standard 1: Respect

The Advocate fully acknowledged and understood Mary's end-of-life wishes. Mary was empowered to state her will and preference through the support of the Advocate.

Standard 2: Social Justice

Mary received the supports that she needed to set out in writing her end-of-life wishes and to have her rights in this regard upheld. Other nursing home residents became aware of the importance of having their end-of-life wishes recorded.

Standard 3: Competence and Compassion

The Advocate demonstrated an ability to relate to Mary in a competent and skilled manner and to engage Nursing Home staff in understanding and acting on Mary's wishes.

Standard 4: Accessibility

The service was available in a timely manner in response to a self-referral. The Advocate met with Mary on a number of occasions to ensure that the matter was dealt with fully and efficiently. Contact was made by the Advocacy Provider with the hospital immediately to ensure that hospital staff were aware of Mary's wishes.

Standard 5: Independence

The Advocate worked independently, taking instructions only from Mary and, with her permission, communicated these to the Director of Nursing who included them on Mary's file.

Standard 6: Accountability

The Advocacy Provider acted quickly to ensure that Mary's end-of-life wishes were communicated in a timely manner to the hospital to which she had been admitted.



Person living at home

Case Scenario 5

John lived at home with his adult son Bill. John had dementia and did not have the capacity to make any decisions without support. John's daughter Liz lived some distance away but called as often as he could to visit her father. As Liz's husband had been made redundant, Liz was working full time to support her family. Liz had two children one of whom had special needs. However, Liz made the effort once a month to bring her father to her home for Sunday lunch and she knew he enjoyed this outing.

John owned the farm where he was living with his son Bill. Bill worked on the farm and, in fact, John had entered into a partnership with Bill to run the farm about 10 years ago and a joint farm account was opened at that time. When John was diagnosed with dementia three years previously, Bill suggested that he, Bill, be added as a joint signatory on John's Bank accounts (which included John's savings account) and, also, that he be appointed agent to collect John's State pension. Bill in practice controlled all of John's money and spent the money as he wished. In fact, when livestock or crops were sold on the farm, Bill lodged the proceeds to Bill's own account and not to the joint farm account.

John was no longer in a position to understand any of his own affairs or indeed to look after himself personally. He was becoming more frail and Liz became concerned about him. Liz had raised with Bill the possibility of getting some home help but Bill dismissed this and said that it would be too expensive and in any case stated that he was looking after his father. John and Bill did have someone come to the house one day a week to clean and she also did some cooking. Liz knew that her father could afford to pay for home help if it was needed. Liz contacted the Advocacy Provider and stated that she was concerned for her father but did not know where to turn or if there was any help that Bill could get in looking after their father.

What the Advocate did:

The Advocacy Provider arranged for an Advocate and the Advocate's supervisor to visit John at his home on a day that Liz was visiting and when Bill would be at home also.

The Advocate and supervisor spoke to John at the beginning and explained who they were. They told him that they were there to ensure that he would get any help he needed to manage his affairs and to talk to Bill and Liz about this. The Advocate and Advocate's supervisor confirmed to Bill and Liz that the Advocate's role was to ensure that John would get the service or assistance that he required and to liaise with the HSE on John's behalf in having his care/support needs assessed. The Advocate stated that if home help was needed this could be arranged with the HSE but this may be limited to a few hours in a week. She asked about the possibility of John being able to afford to pay for extended home care if this was needed. At first, Bill was reluctant to accept that further help may be needed for his father and stated that he, Bill, would not consent to it. He then agreed that his father's needs should be assessed when the Advocate stated that, regardless of whether Bill consented or not, her role was to support John

even though John was not in a position to seek assistance or make decisions for himself. Bill and Liz confirmed that John had not created an enduring power of attorney. In fact, neither of them had heard of such an arrangement. Bill stated, however, that there was no problem as he had access to all John's accounts. The Advocate asked had John ever spoken to them about his general wishes if he reached the stage where he lacked capacity to make decision for himself. Bill and Liz confirmed that he had not but they always assumed that they could make any decision for their father if that situation arose. Both the Advocate and the Advocate's supervisor agreed that the Advocate would return for a further meeting the following week when they had considered what assistance could be arranged for John.

The matter was discussed with the Advocacy Provider's Designated Officer for the Safeguarding of Vulnerable Adults, the wider case management team and the Advocacy Provider's internal legal and financial co-ordinator. It was arranged that the local Primary Care team (GP and Public Health Nurse) be asked to visit John and ascertain what care plan should be put in place for John and also to assess his decision-making capability. It was confirmed to the PC team that there was no indication of what John's wishes were for long term care but that he had lived all his life on the farm, still wandered in his fields every day and clearly loved the animals. Liz's view was that her father would wish to be at home but recognised that this may not be possible. The report back from the assessments was that while John did not have any particular debilitating illness he was at an advanced stage of dementia and was not in a position to make decisions without support. Because he appeared very happy in his surroundings it was suggested that arrangements should be made for home help to assist John to get up in the mornings, to shower and to have breakfast and to arrange for the laundering of his clothes which would greatly enhance his wellbeing. It was confirmed that the arrangements for the food (the main meal of the day) appeared to be working out but this should be kept under review. It was agreed with Bill and Liz that home help arrangements would be put in place.

On a return visit, the Advocate and the Advocate's supervisor explained to Bill and Liz in a very sympathetic way that family members did not have authority to make decisions on behalf of another adult family member unless appointed by the latter to do so. They confirmed that since John had not created an enduring power of attorney (which would give such authority) and since their father did not have the capacity to make decisions for himself then normally in such circumstances an application would be made to the court to have a person who lacked capacity made a Ward of Court. They explained that the current

legal process of wardship was very out of date and new legislation was about to be enacted which placed an emphasis on the respect of a person's rights and wishes. They pointed out that the proposed legislation will provide that any intervention in respect of a person who lacked decision-making capacity must be made in a manner that minimises the restriction on the person's rights and freedom of action and even provided that there should be no intervention unless it is necessary to do so having regard to the individual circumstances of the person in question. The Advocate suggested that perhaps the route of minimal intervention should be tried first for John.

They pointed out that neither Bill nor Liz had authority to manage John's bank accounts and that John's affairs would have to be regularised to ensure that John's property was protected and used for his benefit. Bill and Liz agreed to obtain professional advice on a number of issues that needed to be addressed and discussed at the meeting.

- The accounts to which Bill's name was added 3 years ago could not now be operated by Bill as John lacked the capacity to give instructions with regard to such accounts. The bank needed to be informed of this fact. These accounts were John's sole property and the only manner to which access to these accounts could be made was if John was made a Ward of Court. However, it was felt that monies in these accounts were not required immediately.
- It was confirmed that the account into which John's State pension was lodged could be operated for John's benefit if the correct procedures for the account were now followed – that the Department of Social Protection be informed that John no longer had capacity to make decisions, the GP had confirmed that having assessed John she was in a position to so certify on the Department's relevant agency form (the earlier authorisation had come to an end as the account was opened when John had capacity). If these procedures were followed and Bill was still to be the agent for John, these monies could be used to pay for home help for John. The Advocate in fact handed Bill and Liz a copy of the agency form and pointed out that an agent must sign that he or she understands the obligations placed on an agent that are set out on the form which included an undertaking to use the money for the benefit of the pensioner.
- The Joint Farm Bank Account could still be accessed by Bill as it was the intention when the account was opened that it would be owned jointly and operated jointly by John and Bill. In fact the farm partnership agreement set out that whoever was the survivor would be entitled to the proceeds. However, the Advocate did

raise with Bill the fact that he had confirmed that he had been lodging proceeds from recent farm sales to his own account. It was pointed out to Bill that this needed to be regularised and that John's share of the account should be used for John's needs if that was necessary.

Outcome for John:

John clearly did require some assistance with daily living and this was arranged for him.

The Advocate and the Primary Care Team who attended John took time to understand that it would be best for John to remain on his farm even though he had not expressed any wish about this or any alternative.

Thankfully, for John it was not necessary to have him made a Ward of Court immediately as it was possible to arrange his affairs where monies would be available to pay for his home care. It was agreed that this matter be kept under review as if John did need nursing home care in the future, a court application may be necessary to access further funds.

Bill and Liz became aware that, even though their father was in an advanced stage of dementia, he had rights which needed to be protected. They were not aware that they were in fact doing anything wrong in managing John's affairs and both were very grateful to avail of the Advocacy service provided.

Practical Application of Standards

Standard 1: Respect

The Advocate fully respected John's right to have control over his own money even if John did not fully understand that this right was being infringed.

Standard 2: Social Justice

John received the support he needed to protect his right not to have control over his money taken from him and to get the help that he needed to enable him to continue living at home in accordance with what could be regarded as his clear will and preference. In accordance with new thinking and the provisions of the Assisted Decision-making (Capacity) Bill 2013, the least restrictive option was adopted in protecting John's rights.

Standard 3: Competence and Compassion

The Advocate demonstrated an ability to relate to John in a manner that showed an understanding of his potentially vulnerable position and to his son and daughter in a manner that ensured that they retained a responsibility for facilitating their father in remaining in his own home.

Standard 4: Accessibility

The service was available in a timely manner in response to a referral. The Advocate ensured accessibility of the service by arranging meetings in John's own home at a time that suited John and his son and daughter.

Standard 5: Independence

The Advocate worked independently, taking on a rights safeguarding role in relation to John and in working with his son and daughter to ensure that John's money was protected for his own use as required and that he got access to the supports that he needed to remain living in his own home.

Standard 6: Accountability

The Advocate and Advocacy Provider adopted an approach to this case that was thorough and carried out with diligence. The Advocate's role and responsibility to ensure that John's rights were fully protected were adhered to throughout. John's son and daughter, during the course of their engagement with the Advocate, came to understand and appreciate that and acted accordingly.



Glossary of Terms

This Glossary provides a brief description of the meaning of some of the key terms used in the context of this document.

Abuse

The physical, psychological, emotional, financial or sexual maltreatment, or neglect of a vulnerable adult by another person. The abuse may be a single act or repeated over a period of time. It may take one form or multiple forms, including inappropriate restraint or use of medication. Abuse can occur both in a relationship where there is an expectation of trust and outside such a relationship.

Acute Hospital

This refers to regular hospitals which provide active short-term treatment and care for an acute illness, injury or medical condition.

Advance Care Planning

Advance Care Planning refers to a process which enables people to have their preferences for their care documented in the event of them losing the ability to express their own wishes in the future. Advanced care planning usually takes place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. Such planning can be facilitated by use of the Think Ahead Framework Document (see Think Ahead).

Advance Healthcare Directive

An Advance Healthcare Directive means an advance expression of will and preferences made by a person with capacity concerning treatment decisions that may arise in the event that the person subsequently loses capacity.⁵⁶

Advocacy

A process of empowerment of individuals or groups which includes taking action to help people say what they want, secure their rights, represent their interests or obtain the services they need. Advocacy can be undertaken by individuals themselves, by their friends and relations, by peers and those who have had similar experiences, and/or by trained volunteers and professionals (see also Empowerment; Non-instructed Advocacy).

Advocacy Provider

This refers to any organisation providing support and advocacy either in conjunction with other health and social care services or as a stand-alone service.

Advocate

An advocate is a person who acts on behalf of and in the interests of a person or group. The advocate facilitates a person or group to express their wishes and preferences

and to state their views on matters affecting their lives and well-being. In some instances, an Advocate may also speak and negotiate on behalf of a person who may feel unable to do so or who may have reduced capacity.

A Rights-Based Approach

A rights-based approach focuses on the right of each individual in society to be equally included in all aspects of society, to have access on an equal basis with others to services and supports and to self-determine. The rights of people with disabilities are stated in the UN Convention on the Rights of Persons with Disabilities and the rights of older people are stated in the Council of Europe Statement on the Rights of Older People (see also Human Rights and Rights Safeguarding).

Assessment of Need

This is a process by which a person's support and health and social care needs are identified so that they can be addressed through appropriate services and interventions. Engaging the individual in identifying his/her needs and in determining appropriate responses is an important feature of needs assessment.

Assisted Decision-Making (Capacity) Bill, 2013

The Assisted Decision-making (Capacity) Bill 2013 aims to provide a modern statutory framework that assists and supports decision-making by adults and enables them to retain the greatest amount of autonomy possible in situations where they lack or may shortly lack capacity. The Bill provides a statutory framework enabling formal agreements to be made by persons who consider that their capacity is in question, or may shortly be in question, to appoint a trusted person to act as their decision-making assistant to assist them in making decisions or as a co-decision-maker who will make decisions jointly with them. The Bill provides for the updating of the legal framework for Enduring Powers of Attorney and Advance Healthcare Directives. The Bill is expected to be passed into law before the end of 2015 (see also Supported Decision-making).

Authority to Act

A written agreement between an individual or his/her representative and the Advocacy Provider that sets out the terms and conditions of the advocacy support to be provided, and the rights and responsibilities of both parties.

Autonomy

The perceived ability to control, cope with and make personal decisions about how one lives on a day-to-day basis, according to one's own preferences. Some people making autonomous decisions may need support in executing these decisions.

Capacity (Decision-Making)

The ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is being made. Each individual should be presumed to have capacity to give or withhold consent unless the contrary is established. A person lacks the capacity to make a decision if s/he is unable to understand the information relevant to the decision, is unable to retain that information, is unable to use or weigh that information as part of the process of making the decision or is unable to communicate the decision by any means even with the assistance of a third party (see also Legal Capacity and Mental Capacity).

Circle of Support

The concept Circle of Support broadly refers to a group of people who work together on a regular basis to help a person accomplish his/her personal goals in life. The Circle acts as a community around an individual (the 'focus person') who, for one reason or another, is unable to achieve what s/he wants in life on his/her own.

Client

The term refers to any person who uses avails of the service. (Some advocacy organisations use the term 'service user' or 'advocacy partner').

Code of Practice

A Code of Practice is understood in the context of this document as any principles, policies, procedures or operational guidelines adopted by an organisation relating to the support and advocacy role.

Community Care

Personal and social care services delivered in the community. Community care services include home helps, home care packages, respite care, day care and supports for independent living (see also Primary Care).

Confidentiality

Confidentiality refers to protection of the right to privacy and the right of individuals to keep personal information from being disclosed to others without their consent. The right to privacy is not absolute and is balanced against other factors such as the need to protect people from harm. Data Protection legislation supplements the right to confidentiality by protecting personal information and providing safeguards against disclosure (see also Data Protection).

Conflict of Interest

Conflict of interest refers to a situation in which someone in a position of trust has competing professional and/or personal interests which may make it difficult for the person to fulfil his/her duties fairly. In the context of support and

advocacy, a conflict of interest is anything that could get in the way of an advocate being completely loyal to people who use the service and at all times giving absolute priority to the will and preferences of the users above other matters. Factors that could give rise to a conflict of interest include personal relationships/friendships and financial interests.

Consent

Consent is agreement by a person who has capacity, voluntarily given, without any element of duress and based on the person having the requisite information, in a form and language that s/he understands (see also Non-instructed Advocacy; Informed Consent). Consent would also include directions given in an Enduring Power of Attorney or an Advance Healthcare Directive that has come into effect, i.e. was made by a person when they had capacity setting out their will and preference on matters in advance.

Data Protection

Data Protection legislation requires that any information recorded and held about people must be kept secure and available only to those who have a right to access such information, for example, those with a duty of care to an individual or those who have a safeguarding role in relation to alleged abuse or, the Gardaí, where criminality is alleged or suspected (see also Confidentiality).

Dementia

Dementia describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. Dementia is the loss (usually gradual) of mental abilities such as thinking, remembering, and reasoning. It is not a disease, but a group of symptoms that may accompany some diseases or conditions affecting the brain. The fact that a person has been diagnosed with dementia does not mean that person lacks decision-making capacity.

Designated Link Person

The Designated Link Person is the member of the staff in a nursing home or hospital who has been assigned particular responsibility for liaising with the Advocacy Provider and through whom formal communication between the Advocacy Provider and the nursing home/hospital is normally channelled.

Disability

Disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment (Disability Act 2005).

⁵⁶ http://health.gov.ie/wp-content/uploads/2014/04/Draft_General_Scheme_AHDs.pdf

Empowerment

Empowerment is the process, based on a trusting relationship, of providing information and support to enable people to assert their rights, make choices and decisions and contribute to wider policy making in the areas that affect their lives. Provision of basic information on an individual's rights and entitlements can in itself be hugely empowering.

End-of-Life Care

This refers to the care that a person with a terminal illness gets at the final stage of life. Quality Standards for End-of-Life Care in Hospitals can be accessed at www.hospicefoundation.ie

Enduring Power of Attorney (EPA)

An Enduring Power of Attorney is a legal device that enables a person to choose a person (called an "attorney") to manage his/her property and affairs in the event of him/her lacking capacity to do so. The Assisted Decision-Making (Capacity) Bill 2013 will extend the authority of an EPA to include healthcare decisions. A person may choose one attorney or more than one.⁵⁷ An Enduring Power only comes into effect when the person lacks decision-making capacity and the EPA is registered in the High Court.

Equality

Equality is the prevention, elimination or regulation of discrimination between people on the grounds of, for example, gender, marital status, race, disability, age, sexual orientation, language, social origin or other personal attributes, including, but not limited to, religious beliefs or political opinions.

Ethics

Ethics is concerned with questions about what is morally right in a particular situation. In many situations it may be clear what it is right to do. In other situations, however, there may be several options, none of which is unambiguously right. Deciding on which course to take involves judgment in deciding how much weight to give to different values and requires an ethical framework accordingly (see Rights Safeguarding and Non-instructed Advocacy).

Facilitator

This is a person who enables nursing home residents/hospital patients to identify and raise issues arising out of their experiences. The role may involve facilitating Residents' Groups in care settings to articulate and represent residents' issues and interests as well as working with people to ensure that their experience of hospital/primary care is communicated to and understood by healthcare professionals.

Governance

Governance refers to the function of determining an organisation's direction, setting objectives and developing policy to guide the organisation in achieving its objectives and stated purpose. Effective governance integrates different aspects of an organisation to deliver safe and effective services.

Hard-to-Reach

This refers to people whose needs, for reasons of social isolation/weak social networks or for reasons of dementia or other cognitive impairment, remain hidden or inadequately identified. People who are 'hard-to-reach' may live in the community or in a residential care facility.

Health Information and Quality Authority (HIQA)

An independent Authority established in May 2007 to drive continuous improvement in Ireland's health and social care services. HIQA is the regulatory, standard-setting and inspection body for residential care settings.

Human Rights

Human rights are rights held by individuals because they are part of the human race. They are rights shared equally by everyone regardless of gender or nationality. They are universal in content (see also A Rights-based Approach and Rights Safeguarding).

Independent Support and Advocacy

Support and advocacy provided by an organisation that is structurally, financially and psychologically separate from the services that deliver health and social care.

Individual Plan

An individual plan is a formally agreed statement which is based on information gathered with and from a person requiring support and those responsible for his/her care. It identifies a person's individual care and support needs and states how these needs will be met. It must be reviewed on a regular basis and, where appropriate, modified or changed in accordance with the needs of the individual. An individual care plan should cover all aspects of health and personal care, and show how these are to be met in terms of daily living and longer term outcomes. The format of the plan may be guided by specific policies and procedures, protocols and practice guidelines in specific services.

Informed Consent

Voluntary authorisation by a person who has full comprehension of the risks and benefits involved in the application of any medical treatment or intervention, the provision of personal care and supports, participation in research projects or provision of the person's personalised

information to a third party. Informed consent is required for the making of an Enduring Power of Attorney and an Advance Healthcare Directive.

Legal Capacity

Legal Capacity means the capacity to have rights and the power to exercise those rights. Article 12 of the UN Convention on the Rights of Persons with Disabilities 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 a disability have the same legal rights as persons who have no disability). (See also Capacity; Mental Capacity; Supported Decision-making).

Long-stay residential care

Public, private and voluntary services providing care to people usually on a permanent basis outside of their own home in an institutional setting. Long-stay residential care in Ireland tends to be synonymous with nursing home care.

Memorandum of Understanding (MoU)

This describes a bilateral or multilateral agreement between two or more parties. It expresses a convergence of will between the parties, in this case between an Advocacy Provider and a health/social care provider, indicating an intended common and agreed line of action (see also Service Agreement).

Mental Capacity

The term mental capacity refers to a set of psychological abilities (decision-making skills) that vary in the human population. It differs from legal capacity (see also Capacity; Legal Capacity and Supported Decision-making).

Non-Instructed Advocacy

This refers to a situation where a person is not in a position to instruct an advocate or to give consent. An advocate can legitimately take the role of exploring with those responsible for the care of the individual how their human rights are being protected – a safeguarding role. A decision to act for a person who is not capable of giving instructions or consent to representation should only be made following significant efforts to communicate with the person and taking into account the risks to the person if s/he does not have an advocate as well as the likely benefits to the person of having an advocate (see also Rights Safeguarding; Witness/Observer; Watching Brief).

Observation

This refers to the process of gathering information in a nursing home, in the community or in a hospital and tracking patterns and changes over time. It has a twofold purpose –

it can contribute both to individual care and support plans and to the systematic collation of data in order to improve the quality and safety of health and social care. Records of observations should be factual and evidence-based.

Older Persons

The term 'older persons', as used in this document, refers generally to people in their later years. While it is evident that the ageing process is a biological reality which has its own dynamic, it is also subject to social construction and age is sometimes defined by the social roles a person occupies, by a person's level of physical or cognitive ability as well as by chronological years (see also Vulnerable Adult).

Operational Guidelines

A written set of instructions that describe the actions that should be taken to implement the organisational policies and Codes of Practice (see Codes of Practice).

Policy

This is the written operational statement of intended outcomes to guide staff actions on particular aspects of the service and in particular circumstances.

Person Centred

Person-centred is an approach to the provision of care and support based on individual right to self-determination, mutual respect and understanding. When services and supports are person-centred, the service provider ensures that the person is involved, participates and is truly listened to. The choices that the individual makes are respected and services and supports are tailored around those choices. A person-centred approach also involves helping the individual to manage challenges and risk (see also Individual Plan).

Primary Care

This refers to the first point of contact that people have with health and personal social services. In Ireland, this contact is usually with GPs. The services and resources available within the primary care setting have the potential to prevent the development of conditions which might later require hospitalisation or the need for long-term residential care (see also Community Care).

Protected Disclosure

A protected disclosure provides legal safeguards for people who want to report serious concerns they have about standards of safety or quality in Irish health and social care services. If a reported concern qualifies as a protected disclosure, the person making the protected disclosure is afforded certain legal protections under the Health Act 2007 and in the case of an employee may come within the provisions of the Protected Disclosure Act 2014.

⁵⁷ See www.citizensinformation.ie

Protection

Process of protecting individuals identified as either suffering, or likely to suffer, significant harm as a result of abuse or neglect (see also Rights Safeguarding; Significant Harm).

Record

A record includes any form in which data are held or stored – manually, mechanically or electronically and anything that is a part or a copy, in any form, of any of the foregoing or is a combination of two or more of the foregoing.

Resident

A resident refers to a person living in a facility such as a nursing home and being provided with services by residential care staff.

Rights Safeguarding

This is ensuring that people's rights are protected in all cases but especially in cases where a person because of reduced capacity is unable to assert his/her rights and/or to give informed consent (see also Non-instructed Advocacy). Advocates in such instances act in a watching brief or witness/observer role in specific health and social care settings, e.g., a residential care facility.

Risk Assessment

Risk assessment refers to the process of identifying the chance of something happening or not happening that may have an impact on an individual or group and to identifying ways of eliminating or managing such risks. Risk assessment may be specific to a particular instance/situation, for example, the impact of going into residential care, family conflict, the potential impact of not providing advocacy support where it is unclear whether or not a person can give consent. Advocacy principles – user participation, respect, self-determination, encouraging independence – can all contribute to preventing and managing risk.

Self-determination

Self-determination refers to being able to make a personal decision to do something or think a certain way without external compulsion. It is similar to the concept of autonomous decision-making.

Service Agreement

An agreement between and Advocacy Provider and health and social care providers (nursing homes/ hospitals) which outlines the role of the Advocacy Provider and what is expected from both the Advocacy Provider and the health/ social care provider in respect of the support and advocacy being provided (see also Memorandum of Understanding).

Service Provider

Person(s) or organisations that provide services – this includes staff and management that are employed, self-employed, visiting, temporary, volunteers, contracted or anyone who is responsible or accountable to an organisation providing a service.

Significant Harm

Significant harm refers to ill-treatment (including sexual abuse and forms of ill-treatment which are not physical). It also includes the impairment of physical, intellectual, emotional, social or behavioural development. Significant harm can result from abuse (see Abuse).

Standard

The term Standard as used in this document refers to a statement based on underlying principles of, and best practice in, support and advocacy work. There are six standards delineated, each with four sub-components.

Support and Advocacy

This includes the provision of supports at various points along a continuum which includes the provision of information, assistance with negotiating health and social care pathways and engaging in representative advocacy with or on behalf of people (see Independent Support and Advocacy).

Supported Decision-making

Supported decision-making is a process in which adults who need assistance with decision-making, e.g., people with an intellectual disability or cognitive impairment, receive the help they need and want to understand the situations and choices they face, so they can make decisions for themselves. The concept of supported decision-making is based on Article 12 of the UN Convention on the Rights of Persons with Disabilities:

- Everyone has the right to make their own decisions – known as autonomous decision-making; and
- Everyone has the right to receive adequate support to do so – known as supported decision-making (see also Capacity, Legal Capacity and Mental Capacity).

Support Person

This refers to a number of roles:

- 'Being there for' (accompany) older people in challenging care situations, e.g., acute hospitals
- Visiting individual (or groups of) residents in care settings
- Helping build Circles of Support around older people who require assistance
- Strengthening natural support structures of family and community in partnership with relevant professionals

'Think Ahead'

This is an initiative which encourages people to plan for end of life by recording their wishes in the event of an emergency, serious illness or death. Developed by the Forum on End of Life in Ireland, a project of the Irish Hospice Foundation, (IHF), Think Ahead urges people to Think, Talk, Tell, and record and review their personal preferences for future medical, financial and personal care.

Third Party

A person or organisation not directly connected with the matter in hand.

Vulnerable Adults

The term refers to adults who, because of physical or mental impairment, are unable to take care of themselves without assistance or unable to protect themselves against abuse or exploitation. Some adults with physical, sensory and mental impairments which have been there since birth or have been acquired over the life-cycle who require support may be included in this category as may some people who require support because of chronic illness or advancing age.

Watching Brief

A support and advocacy approach that centres around quality of life domains for people receiving health and social care services and related questions that might be raised by an Advocate with health and social care providers (see also Non-instructed Advocacy, Rights Safeguarding and Witness/ Observer).

Witness/Observer

This refers to the Advocate's role as an observer or witness to the ways in which services interact with an individual or group. The role allows the Advocate to see or hear things that are unacceptable or which pose a threat to a person's well-being or indicate a failure to respect a person's will and preferences (see also Watching Brief).

Key Resource Documents Used

Advocacy Network Northern Ireland, ANNI Standards Framework, Email Communication;

Advocacy Network Northern Ireland, Code of Practice for Independent Advocates, http://www.hscboard.hscni.net/publications/2014/062014%20Code_of_Practice_for_Independent_Advocates_June_2014.pdf#search=

Age Concern (2013), An Advocate's Guide to Independent Non-instructed Advocacy, Older People and Dementia Principles, Practice and Guide to Further Resources <http://www.opaal.org.uk/Libraries/Local/1013/Docs/An%20Advocates%20Guide%20to%20Non%20Instructed%20Advocacy%202013.pdf>

Centre for Disability Law and Policy (NUIG), Equality, Dignity and Human Rights http://www.nuigalway.ie/cdlp/documents/principles_web.pdf

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Council of Europe Statement on the Rights of Older Persons, <https://wcd.coe.int/ViewDoc.jsp?id=2162283&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383>

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Our Mission

“To promote and protect the rights, freedoms and dignity of older people by developing support and advocacy services wherever ageing poses a challenge for individuals.”

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Support & Advocacy Service
for Older People