



Promoting the rights of vulnerable adults

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

## **A Scoping Document**

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<b>Contents</b>	<b>Page</b>
Introduction	2
Why advocacy is important	4
Safeguarding vulnerable adults	5
An ageing population	6
Population categories who may need advocacy	7
A diverse vulnerable adult population	7
Defining and Understanding Advocacy	8
Different types of advocacy	9
Patient advocacy	9
Systemic advocacy	12
Instructed and Non-instructed advocacy	13
Independent advocacy	14
Advocacy and health and social care professionals	14
Role of families/relatives	15
The role of the independent advocate	16
Access to independent advocacy	17
Advocacy and human rights	18
What are human rights	18
Human rights charters and conventions	18
Human rights principles	19
Autonomy and the right to self-determination	20
Deprivation of liberty	22
Advocacy and supported decision-making	22
Advocacy and legislative provision in Ireland	24
Advocacy Practice: Quality standards, skills and competencies	26
Advocacy skills and competencies	29
Advocacy and vulnerable adults: the practice in other jurisdictions	29
Developing a National Framework for Advocacy in Ireland	32
Challenges to independent advocacy in the Irish context	35
A changed discourse	36
National Advocacy Council	36
Overview and Conclusion	38
Appendices	
<i>Appendix One: Public Perspectives on Abuse of Vulnerable Adults in Ireland</i>	40
<i>Appendix Two: Current and Projected Over 60 Population in Ireland</i>	41
<i>Appendix Three: Advocacy Competencies</i>	42

## *Introduction*

The purpose of this Scoping Document is to inform the deliberations of a National Roundtable on Advocacy Provision in Ireland to be held on 17th October 2018 which is being organised by Safeguarding Ireland. It sets out the key factors underpinning advocacy and describes the current position relating to advocacy services in Ireland as these apply to adults who may be vulnerable. In particular, the document aims to provide a context for developing an informed and common understanding around the language and concepts relating to advocacy. This is considered necessary in order to identify clear pathways for the development of independent advocacy services in Ireland.

While the term ‘advocacy’ is relatively new, historically, there have consistently been people willing to speak up for others and in order to ensure that their interests are represented. During the 20<sup>th</sup> century, out of a diverse range of movements concerned with human, civil, social and political rights for the individual citizen, there emerged concepts, practices and services which can be broadly described as advocacy.

Six points need to be highlighted at the outset:

- 1) It is critically important to have a clear understanding of what advocacy is, where it fits in the overall social supports infrastructure and who is likely to need and benefit from advocacy.
- 2) It is important that the underpinning principles of advocacy are identified and explored.
- 3) The social and legislative context within which advocacy is, or should be, provided needs to be understood.
- 4) Advocacy practice/services have a protective or safeguarding role as well as an empowering dimension.
- 5) While many health and social care professionals have an advocacy role, there is an important distinction between the advocacy role of such professionals and the role of independent advocates.<sup>1</sup>
- 6) The issue of legal recognition in Ireland for independent advocacy needs to be addressed with some urgency.

It should also be noted that the current advocacy landscape in Ireland is quite varied in terms of responsibilities, funding and independence. For example, the National Advocacy Service for People with Disabilities (NAS) is funded by the Department of Employment and

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<sup>1</sup> Independent advocacy refers, essentially, to advocacy support provided by an organisation that is structurally and financially autonomous and independent from the services that deliver health and social care, as well as from the family of the person to whom the advocacy service is being provided.

Social Protection through the Citizens Information Board while statutory funding for other independent advocacy services at national and local levels is provided by the HSE. The absence to date of a legislative remit for independent advocacy<sup>2</sup> other than under the Mental Health Act 2001 results in an advocacy environment that is somewhat unclear and within which there are multiple understandings of advocacy.

As will be outlined in the document, the legislative landscape as it applies to advocacy has begun to change fundamentally in recent years.

### **Structure of Scoping Document**

The Document deals with a number of aspects of advocacy provision under the following themes:

- Why advocacy is important
- Defining and understanding advocacy
- Independent advocacy
- Advocacy and a human rights approach
- Advocacy and legislation in Ireland
- Best advocacy practice in other jurisdictions
- Challenges to independent advocacy
- Need for a National Framework for Independent Advocacy
- Overview and conclusions

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<sup>2</sup> While the Citizens Information Act 2007 provides for the establishment by the Citizens Information Board of a Personal Advocacy Service (PAS), 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.

## Why advocacy is important

While advocacy has its origins in the legal context where lawyers act as advocates in court to represent the interests of their clients, it has extended to many other spheres and in a non-legal context. Areas in which advocacy has been to the fore include the promotion of rights and voice of people with disabilities and users of the mental health care system and, more recently, users of health care services generally.

Many political theorists have asserted that advocacy is an essential function in any democracy.<sup>3</sup> By representing the viewpoints of minorities and disempowered groups, and by critically monitoring and pushing for changes in public policies, advocacy organisations serve as vital intermediaries that help maintain the quality of a democratic government and its responsiveness to the needs of all its citizens. Advocacy also serves to ensure that people's basic legal and human rights are protected.

Advocacy processes can also include the following<sup>4</sup>

- Increasing civic participation and awareness raising of issues
- Providing opportunities for disempowered and marginalised groups to be heard by decision makers
- Public education and awareness raising campaigns that seek to influence public opinion
- Putting forward research to support an argument
- Using the media to support particular causes
- Sector coordination and networking and
- More activist strategies such as staging protests and sit-ins

Given the growing emphasis on decision-making capacity in Ireland and the provisions for supported decision-making in the Assisted Decision-making (Capacity) Act 2015 (ADM Act), advocacy is now a necessary mainstream activity and is an important safeguard in a democratic society which 'gives voice' to the wishes and preferences of vulnerable adults.<sup>5</sup>

While the ADM Act requires that people supporting the person make every effort to enable him/her to express 'will and preferences', importantly, the Act does not include any reference to a 'best interests' principle. This reflects a significant paradigm shift in the context for engaging with people

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<sup>3</sup> Kinlen, L. (2013), ADVOCACY & AGENDA SETTING

<http://www.childandfamilyresearch.ie/media/unescochildandfamilyresearchcentre/documentspdf/Full-report.pdf>

<sup>4</sup> *Ibid.*

<sup>5</sup> See <https://www.sageadvocacy.ie/media/1336/quality-standards-for-support-and-advocacy-work-with-older-people-final-061015.pdf>

with reduced decision-making capacity and one which has huge implications for the role of independent advocacy.

Many people face challenges to their independence due to illness, disability, lack of family and community supports or an inability to access public services that meet their needs. The latter may be due to various barriers, e.g. linguistic, psychological, physical, social and cultural. Some people face progressive decline in their ability to make and communicate decisions as a condition, such as dementia, develops over time.

Physical disability, dementia, intellectual disability, autism, or mental health difficulties do not come as discrete and separate challenges. Some individuals experience a range of these conditions and, in addition, can face even further challenges such as polypharmacy<sup>6</sup>, incontinence and behaviours which others find extremely challenging. People in such situations frequently need advocacy in order to ensure that their rights, freedoms and dignity are promoted and protected and that they are enabled to exercise their own will and preferences on matters affecting their lives.

It is also important to remember that an individual's capacity to be involved in decision-making or to instruct an advocate may fluctuate. This provides a further argument in favour of an integrated and whole-systems approach to advocacy, which maximises continuity of participation and support.

### Safeguarding of Vulnerable Adults

There is a growing awareness of the fact that a significant population of people – particularly those with disabilities and other vulnerable adults – are at risk of various types of abuse and exploitation. In December 2014, the HSE published its Safeguarding Policy “*Safeguarding Vulnerable Persons at Risk of Abuse – National Policy and Procedures*”.<sup>7</sup>

While acknowledging that the HSE Safeguarding Policy encompasses both elder abuse and abuse of people in disability services, it should be noted that vulnerability is not dictated by a person’s age or disability alone, and circumstances and the external environment can contribute to vulnerability. Vulnerability can be a transient or permanent state depending on many influences, including dependencies, family circumstances, and societal attitudes and behaviours.

A Red C poll (December 2016)<sup>8</sup> conducted for the National Safeguarding Committee (recently renamed as *Safeguarding Ireland*) highlighted the fact that half of all Irish adults say they have experienced the abuse of vulnerable adults either through being abused themselves or seeing somebody close to them abused. Two in 5 people think vulnerable adults are badly treated and 1 in 3 believes vulnerable adult abuse to be widespread (see Appendix 1). These research findings indicate a very worrying prevalence of vulnerable

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<sup>6</sup> Polypharmacy, is defined by the World Health Organisation as "the administration of many drugs at the same time or the administration of an excessive number of drugs", it is frequent among people of advanced years who often suffer from chronic diseases with concomitant pathologies. <http://www.irdes.fr/english/issues-in-health-economics/204-polypharmacy-definitions-measurement-and-stakes-involved.pdf>

<sup>7</sup> <https://www.hse.ie/eng/services/publications/corporate/personsatriskofabuse.pdf>

<sup>8</sup> <http://safeguardingcommittee.ie/wp-content/uploads/2017/04/Red-C-Survey-Vulnerable-Adults-in-Irish-Society-060417.pdf>

adult abuse, uncertainty over what constitutes psychological and financial abuse, and a lack of knowledge of what to do when someone becomes aware of the abuse of vulnerable adults. National Centre for the Protection of Older People (NCPOP) research<sup>9</sup> shows that financial abuse is the most common type of abuse reported in relation to older persons.

In 2017 there were 10,118 safeguarding concerns managed by the HSE Safeguarding and Protection Teams, representing a 28% increase in alleged concerns reported from 2016. HSE figures also indicate that the rate almost triples for males and doubles for females in the over 80 age category.<sup>10</sup>

It is clear from other research that this is likely to be the tip of the iceberg as many safeguarding incidents go unreported. It is also clear from the Red C poll that there is a lack of clarity regarding the point of contact for reporting.

### **An ageing population**

This data becomes all the more relevant when placed in the context of an ageing population. According to CSO population projections (Central Statistics Office 2018), the proportion of the population aged 60 and over is set to increase by over 51% between 2016 and 2031, to account for just under a quarter of the total population in 2031. Those aged 70 and over will increase by over 70% between 2016 and 2031, and the number of people aged over 80 will increase by almost 91% during this period (see Appendix 2).

A key factor that needs to be taken into account in exploring why advocacy is necessary is that the population of Ireland is ageing and that, while more and more people are living longer and better lives, a growing number will require some form of support. ESRI analysis of population data<sup>11</sup> shows that expansion will be required in most forms of care to meet the needs of a rapidly growing and ageing population:

- The numbers of people aged 85 and over are projected to almost double – this will almost certainly result in a significant increase in the number of people with dementia
- Demand for in-home care and for residential and intermediate care places in nursing homes and other settings is projected to increase by up to 54 per cent
- An increasing number of adults either born with a disability or who have an early onset disability are surviving to older age.

These trends in the nation's population structure will result in a growing number of people being in categories and situations where there may be a significant risk of being vulnerable, of being deprived of the right to fully participate in the making of decisions that affect them, of being socially isolated, and of being subjected to exploitation and abuse.

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<sup>9</sup> See [https://www.ncpop.ie/userfiles/file/ncpop%20reports/599\\_NCPOP\\_proof5%20Final.pdf](https://www.ncpop.ie/userfiles/file/ncpop%20reports/599_NCPOP_proof5%20Final.pdf)

<sup>10</sup> <https://www.hse.ie/eng/services/publications/the-national-safeguarding-office-report-2017.pdf>

<sup>11</sup> <https://www.esri.ie/pubs/RS67.pdf>

There is, therefore, a real and urgent need to ensure that this vulnerable population has access to effective and independent support and advocacy services.

### **Population categories who may need advocacy**

While people with disabilities, vulnerable older people and people experiencing mental health difficulties frequently need advocacy services, there are clearly other groups who require advocacy support, including, in particular, health service patients, children and young people at risk and asylum seekers. Other adults that could be considered to be at risk or vulnerable include: victims of domestic abuse and family dysfunction, victims of crime, migrants, refugees, ex-prisoners, homeless people. It is possible that some vulnerable adults will fit into several 'at risk' categories.

While it is reasonable to argue that all adults are potentially vulnerable at some stage of their lives or in particular circumstances, this Scoping Document refers primarily people in the following categories.<sup>12</sup>

- People with mental health difficulties
- People with disabilities who are victims of abuse or of anti-social behaviour
- People with reduced decision-making capacity who are alleged perpetrators of anti-social behavior
- People being assessed or reviewed or wishing to appeal under the Mental Health Act 2001
- People who come under the provisions of the Assisted Decision-making (Capacity) Act 2015
- People in residential care settings, including people in nursing homes
- People where entry to residential care is a possibility
- People with dementia
- People with disabilities who are parents of children subject to safeguarding procedures
- People with physical disabilities in both residential and community settings
- People with disabilities where entry to residential care is a possibility
- Hospital patients
- Older people, particularly the 'older old' and
- Vulnerable adults at transition points between home/care/hospital settings

### **A diverse vulnerable adult population**

The vulnerable adult population is widely diverse in terms of assets, disposable income and access to the legal protection system. For example, some people will have relatively easy access to lawyers while others will not. Also, the experience of ageing invariably reflects lifelong inequalities and differences based on socio-economic factors such as social class, career path and income. The position of older can very much depend on their social capital,

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<sup>12</sup> This list is not exhaustive but rather indicative of situations where a need for advocacy is more likely to exist.



i.e., their ability to negotiate the system. There are key social, cultural and economic processes which result in some people having less social capital than others and this is where independent advocacy can play a crucial role.

It is also the case that many older people will never have had to engage regularly with the health and social care system or will not have had to avail of supports from disability services (e.g., in the form of a key support worker). Thus, people who have to engage for the first time with services and supports at a very vulnerable stage of their lives, e.g., where they have become cognitively impaired as a result of dementia or stroke, are likely to face additional challenges. Support from an independent advocate to enable such people to express their will and preferences in negotiating the health and social care system will almost certainly be of benefit to them.

### Defining and Understanding Advocacy

Areas in which advocacy has been to the fore in recent years include the promotion of rights and voice of people with disabilities and users of the mental health care system. There are multiple definitions and types of advocacy. Two definitions are quoted here which succinctly sum up what advocacy is about:

- (i) *“...the process of pleading the cause and/or acting on behalf of another person (or persons) to secure services they require and/or rights to which they and their advocate believe them to be entitled. Advocates owe those they represent a duty of loyalty, confidentiality, and a commitment to be zealous in the promotion of their cause”.*<sup>13</sup>
- (ii) *“Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf. Advocacy can often be undertaken by people themselves, by their friends and relations, or by persons who have had similar experiences. Delivering a professional advocacy service means providing a trained person who, on the basis of an understanding of a client’s needs and wishes, will advise and support that client to make a decision or claim an entitlement and who will, if appropriate, go on to negotiate or make a case for him/her.”*<sup>14</sup>

Advocacy has been described in terms of the approach used, such as casework advocacy and personal advocacy; instructed or non-instructed advocacy; condition (such as dementia) advocacy; and issue/complaints advocacy<sup>15</sup>. Within this kaleidoscopic range of ‘advocacies’, it is essential to be aware that people may need to draw on different types of advocacy for different needs and it may be necessary to integrate different types simultaneously to provide effective support.<sup>16</sup>

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<sup>13</sup> See Kerr, L. and Kerr, V. (2003) Older People Doing it for Themselves: Accessing Information, Advice and Advocacy. York: Joseph Rowntree Foundation (p.11) <https://www.jrf.org.uk/report/older-people-doing-it-themselves-accessing-information-advice-and-advocacy>

<sup>14</sup> *Advocacy Guidelines*, Citizens Information Board

<sup>15</sup> Dunning, A. (2005) Information, Advice and Advocacy for Older People: Defining and Developing Services, York: Joseph Rowntree Foundation.

<sup>16</sup> *Ibid.* p.11

Advocacy can be said to be underpinned by a core set of values, principles and standards, both among practitioners and within the projects and organisations that employ them.

- Promoting the wellbeing of individuals, based on an understanding of their personal and social context
- Promoting and respecting people's autonomy and independence
- Involving individuals in all decisions that affect them directly or indirectly
- Recognising that what is going on in one part of an individual's life can affect other areas of his/her life
- Working in partnership with families and friendship networks, where an individual so wishes
- A holistic perspective of influences in a person's life -- needs, risks and positive aspects
- Achieving a balance between vulnerability and resilience
- Capacity-building to improve outcomes
- The avoidance of harm
- Compliance with law, regulation and best practice standards

### **Different types of advocacy**

The range and types of advocacy available are extensive. A summary description of different types of advocacy is provided in Figure 1 below. The Scoping Document then provides brief descriptions of patient advocacy and systemic advocacy. The distinction between 'instructed' and non-instructed' advocacy is outlined. The concept of independent advocacy, which, it is suggested, is the single most important aspect of advocacy provision in Ireland at this juncture, is then explored.

### **Patient Advocacy**

The HIQA 2015 Report<sup>17</sup> of the investigation into the safety, quality and standards of services provided by the HSE to patients in the Midland Regional Hospital, Portlaoise makes reference to the role of a patient advocate and recommended that a patient advocacy service be established for health services in Ireland which would ensure that patients' reported experiences are recorded, listened to and learned from..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.<sup>18</sup> The Ombudsman's report further noted that many users of hospital services (whether patients or relatives/carers) do not know how to make a complaint about a hospital service and are not aware of the support available to help them to do so. It recommended that independent advocacy services should be sufficiently supported and signposted within each hospital so that patients and their families know where to get support if they want to raise a concern.

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<sup>17</sup> <http://www.hiqa.ie/publications/report-investigation-safety-quality-and-standards-services-provided-health-service-exec>

<sup>18</sup> <http://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Learning-to-Get-Better/Learning-to-Get-Better.pdf>

The Programme for Partnership Government (2016) includes a commitment in relation to the establishment of a national patient advocacy service. In parallel with the establishment of the patient advocacy service, the Department of Health has commissioned the development of a competency framework and a training programme in patient advocacy. It is expected that this training programme will also be made available to independent advocates involved in patient safety complaints and support.<sup>19</sup> In addition, the Department intends to commission the development of a code of practice and standards which advocacy services will be expected to adhere to.

The Department of Health has carried out a public consultation on a Patient Safety Complaints and Advocacy Policy. While such a policy is both important and necessary, in developing a culture of openness and transparency within the health and social care system, it is of crucial importance that a clear distinction is made both conceptually and in practice between advocacy and complaints. Only some people will require advocacy support to make complaints.

### *Patient advocacy provisions in other jurisdictions*

A 2016 Working Paper<sup>20</sup> on models of patient advocacy in other jurisdictions, carried out by the Health Research Board for the Department of Health, looked at practice in three countries – New Zealand, England and Western Australia. Of these, New Zealand has the longest-established service (since 1996). Its complaints and advocacy services are provided by a single statutory service that is independent of the health service. The legislation underpinning the advocacy service sets out a legal requirement for the positions of Health & Disability Commissioner (Ombudsman) and Director of Advocacy, who are independent of each other. It also sets out a legal requirement for a patients' Code of Rights, and requires the Commissioner to review the Act and the Code periodically.

England also has a long-established independent patient advocacy service, although it has only had a statutory basis since 2006. Its complaints system is separate from the advocacy service and is embedded within the NHS. The system of commissioning advocacy services is fragmented and complex, having moved from a system where three advocacy providers were centrally contracted by the Department of Health to provide a national service to the current system whereby each of the 353 local authorities has responsibility for providing a local advocacy service. While individual advocacy providers and local authorities furnish some data on the advocacy they provide, this is not published on a national basis, making it extremely difficult to assess if a functioning advocacy service is provided or if service users are happy with this service. It also makes it difficult to assess the impact of advocacy services has on individuals or on policy.

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<sup>19</sup> Written Answers 24<sup>th</sup> July 2018, <https://www.oireachtas.ie/en/debates/question/2018-07-24/1422/?highlight%5B0%5D=32852&highlight%5B1%5D=18>

<sup>20</sup> <http://health.gov.ie/wp-content/uploads/2016/10/Final-Version-Patient-Advocacy-Services.pdf>

**Figure 1: Types of Advocacy<sup>21</sup>**

<i>Advocacy Type</i>	<i>Main Characteristics</i>	<i>Illustrative examples</i>
Representative Advocacy	Operates on a one to one basis where people are provided with information, advice/assistance and advocacy support as required. It is generally issue-based. Individual advocacy can also be carried out by a key worker or a case manager in relation to assisting people with disabilities with person-centred care planning and articulating their will and preferences.	Citizens Information Services; Sage Advocacy; NAS;
Citizen Advocacy	Ordinary members of the local community working on a voluntary basis with people who may be vulnerable to enable them to have a voice and to make decisions about the things that affect their lives. Citizen advocacy partnerships are long term, not time-limited, and last for as long as the citizen advocate and the individual want them to.	Sage Citizen Advocacy Project South-East;
Peer Advocacy	One-to-one advocacy support provided by people with a similar experience. Trained and supported volunteers provide support to people as their equals based on similar experiences of issues.	Irish Advocacy Network
Group Advocacy	People with shared experiences, positions or values coming together in groups to talk and listen to each other, and to speak up collectively about issues that are important to them.	Residents' committees in nursing homes and other residential care facilities.
Self-advocacy <sup>22</sup>	An individual supported to effectively communicate his/ her own interests, desires, needs and rights and to 'speak up' for themselves about the things that are important to them.	An underlying goal of all advocacy types.
Professional Advocacy	Uses paid independent advocates to support and enable people to speak up and represent their views, usually during times of major change or crisis and in respect of specific issues.	NAS (paid staff only); Sage Advocacy (paid staff and trained volunteers).
Patient Advocacy	An area of lay specialisation in healthcare concerned with advocacy for patients, survivors, and carers and related systemic health care issues.	Irish Patients Association; Survivors of Symphysiotomy Group.
Non-instructed Advocacy	Acting on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The advocate seeks to uphold the person's rights, will and preferences and ensure fair and equal treatment. <sup>23</sup> Capacity to instruct or understand can be diminished for different reasons, e.g., mental health problems, cognitive impairment.	NAS; Sage Advocacy.
Legal Advocacy	Seeks to defend the rights and interests of people on a one-to-one basis through the legal system, e.g. in the area of mental health, where people can be detained in hospital against their wishes.	Legal practitioners working with various independent advocacy organisations.
Systemic Advocacy	Seeks to address systemic inequalities and weaknesses that exist in legislation, policies, and practices and engages with policy makers, public representatives, budget holders, decision-makers and the media regarding systemic issues of concern.	Inclusion Ireland, Age Action; Alone; Alzheimer Society; DFI.

<sup>21</sup> <http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/inclusion-empowerment-human-rights/types.asp>

<sup>22</sup> In 2008, the CIB carried out a *Mapping Self-Advocacy Initiatives for People with Intellectual Disability in Ireland* project, <http://www.citizensinformationboard.ie/en/publications/advocacy/>

<sup>23</sup> Henderson, R. Non-instructed Advocacy in Focus [http://aqvx59.dsl.pipex.com/What\\_is\\_non\\_instructed\\_advocacy.pdf](http://aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf)

The Western Australian model differs from the other two, as it does not have a statutory basis. While its Health Consumers' Council is contracted by the Department of Health to provide advocacy services, it is unclear what type of service level agreement exists between the two bodies. The complaints system is independent of the advocacy service and is provided by a statutory agency. It also offers complainants an opportunity (at no cost) to meet with a lawyer who has expertise in medical negligence.

### **Systemic Advocacy**

Systemic advocacy<sup>24</sup> or 'lobbying' is aimed at influencing decisions made by the government or public bodies. It has an important role in helping to address larger systemic issues and includes all attempts to influence legislators and officials. Systemic advocacy developed as a key tool for change in the 1980s and was seen as playing a central role in adjusting the power relations between service users and service providers, and as a vital element in challenging inequality and oppression.<sup>25</sup> 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 to inform policy development. Advocacy in this sense is not just about achieving personal improvement but also aimed at bringing about political, legislative or economic change on behalf of a collective interest.

It is of course possible (or even likely) that there may be an inherent conflict when advocacy organisations make public interest claims either promoting or resisting social change, in that, if such changes were implemented, this would conflict with the social, cultural, political or economic interests or values of other constituencies and groups'.<sup>26</sup>

This may result in NGOs being unwilling to 'bite the hand that feeds them' when it comes to being critical of those that also fund them.<sup>27</sup> This reticence has been described as leading to 'advocacy with gloves on', which is non-confrontational and incremental rather than confrontational and demanding.<sup>28</sup> While the extent to which this is a factor in Ireland requires further consideration and related research, it may be that the balance between

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<sup>24</sup> The term *advocacy* as used in the US and in several other jurisdictions is most often used to mean *systemic advocacy*.

<sup>25</sup> Oliver, C. (2008) 'Setting the Scene: Funding, Patterns of Advocacy Provision and Children's Access to Advocacy Services' in Oliver, C. and Dalrymple, J., eds., *Developing Advocacy for Children and Young People: Current Issues in Research, Policy and Practice*, London: Jessica Kingsley Publishers.

<sup>26</sup> Andrews, K. and Edwards, B. (2004) 'Advocacy organisations in the US political process', *Annual Review of Sociology*, 30(1), 479-506.

<sup>27</sup> Kinlen, L. (2013), *Advocacy and Agenda Setting*, <http://www.childandfamilyresearch.ie/media/unescochildandfamilyresearchcentre/documentspdf/Full-report.pdf>

<sup>28</sup> Onyx, J., Armitage, L., Dalton, B., Melville, R., Casey, J. and Banks, R. (2010) 'Advocacy with Gloves on: The Manners of Strategy Used by some third sector organizations undertaking advocacy in NSW and Queensland', *International Society for Third Sector Research and the John Hopkins University*.

relying on government funding and the sometimes necessary criticism of the State presents difficulties for advocacy organisations.

It should be noted that placing an issue on the public policy agenda, while a first important and necessary step in the process of change, does not necessarily equate to widespread policy change. For example, while test cases based on international treaties and conventions, have potential to bring about policy change, sustained effort is frequently required to achieve the desired outcomes.

### *Instructed and Non-Instructed Advocacy*

Advocacy may be instructed or non-instructed.<sup>29</sup>

- **Instructed advocacy** is working with or on behalf of an individual person or group on the lawful instructions of the person or group;
- **Non-instructed advocacy** is where the advocate acts independently of the individual, in some cases through necessity, as the individual's decision-making capacity may be impaired or s/he may not have the skills to advocate for themselves. Capacity to instruct or understand can be diminished for a number of reasons, for example, mental health problems, dementia, or learning disabilities.

Non-instructed advocacy has been defined as:

*“Taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person's rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.”<sup>30</sup>*

If people lack capacity or have such profound communication difficulties that they cannot tell people what they want in life, then they are additionally marginalised and therefore have a greater need for independent advocacy. The role of the advocate in such a situation would involve gathering as much information about the person and their past and present wishes (if appropriate) as they can. This may be from family, friends, care staff and other people involved in that person's life. It is important to acknowledge that a person's capacity can vary from day to day depending on their condition or the issue with which they are dealing. It is also obviously centrally important that communication difficulties would not in any way be equated with reduced decision-making capacity.

Non-instructed advocacy is perhaps the most challenging form of advocacy and there are three recognised inter-related approaches:

- Rights-based approach – all people have certain fundamental human rights that need to be protected

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<sup>29</sup> <https://www.sageadvocacy.ie/media/1336/quality-standards-for-support-and-advocacy-work-with-older-people-final-061015.pdf>

<sup>30</sup>Henderson, R. Non-instructed Advocacy in Focus  
[http://aqvx59.dsl.pipex.com/What\\_is\\_non\\_instructed\\_advocacy.pdf](http://aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf)

- Person-centred approach – based on the development of long-term, trusting and mutually respectful relationships between advocates and people
- Witness/observer approach – in which the advocate observes or witnesses the way in which a person leads his/her life and how s/he interacts with those providing care and support.

## Independent Advocacy

Given that vulnerable adults may experience barriers in having their voice heard by professionals (and also by family members), it is crucially important for people to have access to an independent advocacy service to support them and enable them to speak for themselves, or, where appropriate, to speak on their behalf. The independent advocate can be particularly valuable in creating a bridge between the service providers/professionals and service users/patients.

It is important to recognise that many of those who provide social and health care services to people – nurses, doctors, social workers - see advocacy as part of their role. The principles and values of advocacy resonate closely to those espoused by these professions and the relationship between the client/patient and advocate is an important component of the role of many professionals. Engaging and networking between a broad range of services with and on behalf of clients can be identified as a feature of the work of some professions and for some, using an approach that empowers clients to build on their strengths is fundamental to their role.<sup>31</sup> Murray (2016) notes, for example, that a significant number of older respondents in her study involving those living in sheltered accommodation identified their resident warden as being their independent.<sup>32</sup>

### *Advocacy and Health and Social Care Professionals*

Legal advocacy is obviously provided by lawyers to clients as required. The advocacy role of health and social care professionals is also referenced in various codes of practice.

The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives<sup>33</sup> states that nurses and midwives should advocate for patients' rights and "act as an advocate on behalf of patients who require you to do so to ensure their rights and interests are protected".

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<sup>31</sup> Murray, A. (2016), *Social Workers, Independent Volunteer Advocates and Older Peoples Understandings and Experiences of Advocacy*, Thesis presented in partial fulfilment of the requirements for the Master in Social Work School of Social Work and Social Policy, Trinity College.

<sup>32</sup> *Ibid.*

<sup>33</sup> <https://www.nmbi.ie/Standards-Guidance/Code>



The Code of Professional Conduct and Ethics for Social Workers <sup>34</sup>includes the following stipulation:

“Subject to your duty to act in the best interests of your service users, you have a responsibility to engage and advocate with the relevant authorities to promote the provision of appropriate resources and facilities.

Acting in the best interests of service users respect and, where appropriate, promote or advocate the views and wishes of service users and carers”.

Hospital Consultants’ Contracts <sup>35</sup>explicitly recognise the Consultant’s role as an advocate and includes the following provisions:

- a) The Consultant may advocate on behalf of patients / service users or persons awaiting access to service.
- b) In the first instance such advocacy should take place within the employment context through the relevant Clinical Director or other line manager.

The Occupational Therapists Registration Board Code of Professional Conduct and Ethics<sup>36</sup> requires occupational therapists to be an advocate for service users and to “promote occupational justice in your practice by:

- (a) Advocating on behalf of service users to enable full occupational engagement and participation in everyday life;
- (b) Informing the proper authorities of any concerns you have about service user safety and quality of service.

While this advocacy component to the role of health and social care professionals is significant, at the same time, it is also necessary to recognise that service providers and professionals may sometimes experience a conflict between advocacy and their primary role in an organisation. For this reason, an independent advocacy service should be regarded as a vital part of safeguarding vulnerable persons’ rights and should be regulated for accordingly.<sup>37</sup>

### *Role of families/relatives*

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

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<sup>34</sup> [http://www.coru.ie/uploads/documents/typeset\\_Social\\_Worker\\_Code\\_Feb\\_2010.pdf](http://www.coru.ie/uploads/documents/typeset_Social_Worker_Code_Feb_2010.pdf)

<sup>35</sup> <https://www.hse.ie/eng/staff/resources/terms-conditions-of-employment/ccontract/contractnov2012.pdf>

<sup>36</sup> [http://coru.ie/uploads/documents/OTRB\\_Code\\_of\\_Professional\\_Conduct\\_and\\_Ethics\\_Bye-Law\\_25\\_11\\_14.pdf](http://coru.ie/uploads/documents/OTRB_Code_of_Professional_Conduct_and_Ethics_Bye-Law_25_11_14.pdf)

<sup>37</sup> Reed, 2004. “Involvement, Empowerment and Advocacy”, in Nies, H., and Berman, P., (Editors), Integrating Services for Older People: A Resource Book for Managers, Dublin: European Health Management Association, p.7.



relation to people who are full-time carers and who frequently have to engage forcefully with health and social care providers 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.

### *The Role of the Independent Advocate*

It is unfortunately true that vulnerable adults have on occasions experienced abuse and exploitation at the hands of individuals, organisations and family members who were charged with caring for them<sup>38</sup>. This makes it all the more important that vulnerable adults have access to an advocacy service that is independent of both service providers and family members.

Independent advocacy, in an ideal world, would be delivered by people and/or organisations that are fully separate from the services that deliver health and social care, as well as from the family of the person to whom the advocacy service is being provided. This ideal is difficult, if not impossible, to fully achieve if the provider of the advocacy service is funded by, dependent on, commissioned by or regulated by the same agencies that are delivering, for example, social or healthcare services that are not meeting the needs of a vulnerable person. Structures and protocols are therefore needed that maximise and protect the independence of the advocacy provider.

It is also important that the advocate her/himself should not be unduly influenced or directed by his/her employing organisation, even where that organisation enjoys adequate independence from the state.

Independent advocacy has the potential to provide significant impetus in the following areas of social inclusion, empowerment and safeguarding as they apply to vulnerable adults.

- (i) Enhancing people's right to have their 'voice' heard and to participate in the making of decisions which affect them and to fully participate in choices concerning their well being
- (ii) Supporting the will and preferences of the individual and ensuring that the user/citizen remains at the centre of the service
- (iii) Supporting the general thrust of enabling people to live in the community and, where this is not possible, enhancing people's continuing connectedness with their community

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<sup>38</sup> Clancy, M. et al (2011), "National Profiling of elder abuse referrals" *Age and Ageing* 40: 346-352

- (iv) Complementing other support services such as social/friendship networks and professional services
- (v) Complementing the role of the Decision Support Service, HIQA and the Office of the Ombudsman
- (vi) Building on and complementing existing support frameworks, viz., patient charters, right to protection from the courts as well as the provisions of UN and European charters and conventions
- (vii) Assisting people during any court or tribunal processes arising from the provisions of the ADM Act 2015 any other relevant legislation<sup>39</sup>
- (viii) Building on the concept of multi-perspective approaches whereby multi-disciplinary teams involve independent advocates, either alone or accompanying a vulnerable person, in discussing and planning supports and services for individuals

### Access to independent advocacy

Ensuring that people have access to independent advocacy can pose a challenge. Many potential beneficiaries may not be in a position to know about the availability or relevance to them of an independent advocacy service. Other parties, including in some cases service providers or family members may be disinclined to allow or encourage access to advocacy. While targeted advocacy publicity can improve knowledge and access, a strong argument can be made that legislative provision is absolutely essential.

The reality is that some people, due to circumstances, age, isolation, disability or cognitive impairment are not able to defend their rights and interests. For example, they may not be aware that abuse is taking place or may not know or have access to a means of dealing with violations to their human rights. In addition, in many cases where abuse or violation of rights occur, such people are under the control of the perpetrator of the abuse or violation and fear retaliation. In other cases, there are higher levels of abuse where people do not have the capacity to voice their concerns. NGOs working with vulnerable adults are at times frustrated in assisting people they believe to be vulnerable because of the lack of a statutory framework within which the role of independent advocates is recognised and acknowledged.

Independent advocates play a key role in supporting people to have a stronger voice and to have as much control as possible over their lives. They help people to know and understand what choices they have, and what the consequences of those choices may be. Therefore, it is the essential that people are able to access an independent advocate in situations where decisions require to be made about their care.

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<sup>39</sup> See ADM Act 2015, Section 35(8) and Section 100 (12)

In emphasising the necessary role of independent advocacy, it is important to state that provision must be made for the inclusion of independent advocacy in any 'mandatory system of inter-agency collaboration, review and planning'.<sup>40</sup> In this regard, there is potential for independent advocacy services to provide an integrative role by bringing the experience of the person/client to service providers collectively so that they can work more effectively and optimise their respective contributions.

### Advocacy and human rights

Advocacy clearly does not operate in a vacuum and the literature suggests that it is useful to adopt a rights-based approach when discussing independent advocacy. Advocacy is both grounded in and reflects a rights-based approach. The human rights approach places the individual centre stage in all decisions affecting him/her. A rights-based approach is particularly relevant to vulnerable adults in that it views people as subjects rather than objects and as equal citizens and stakeholders in society and challenges the "social impulse to rank people in terms of their usefulness and to screen out those with significant differences"<sup>41</sup>.

### What are human rights?

Human rights are rights held by individuals simply because they are part of the human species. They are essentially the rights one has as a human being and are shared equally by everyone regardless of sex, race, nationality, and economic background. They are universal in content.<sup>42</sup> Personhood grants us special moral standing.<sup>43</sup>

- (a) Human rights are *equal* rights – one either is or is not a human being, and therefore has the same rights as everyone else (or none at all)
- (b) Human rights are *inalienable* rights – one cannot stop being human, no matter how badly one behaves or how barbarously one is treated
- (c) Human rights are *universal* rights – in the sense that we consider all members of the species *Homo sapiens* 'human beings' and thus holders of human rights<sup>44</sup>

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<sup>40</sup> Opening Statement by Sage Support & Advocacy Service to the Joint Oireachtas Committee on Health on Adult Safeguarding 4<sup>th</sup> October 2017

[https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint\\_committee\\_on\\_health/submissions/2017/2017-10-04\\_opening-statement-sage\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/submissions/2017/2017-10-04_opening-statement-sage_en.pdf)

<sup>41</sup> Quinn, G. and Degener, T. (2002), 'The moral authority for change: human rights values and the worldwide process of disability reform' in Quinn, G. and Degener, T. (eds.) with Bruce, A., Burke, C. Castellino, J., Kenna, P. Kilkelly, U., Quinlivan, S. *Human Rights and Disability*, United Nations, New York and Geneva.

<sup>42</sup> Ishay, M. R. (2008), *The History of Human Rights*, University of California Press. Berkley.(p.3)

<sup>43</sup> Carlson, K. and Kittay, E. F. (2010), 'Introduction: Rethinking Philosophical presumptions in Light of Cognitive Disability' in Kittay, E. F. and Carlson, L. (eds.), *Cognitive Disability and its Challenge to Moral Philosophy*, Wiley-Blackwell.

<sup>44</sup> Donnelly, J. (2003), *Universal Human Rights in Theory and Practice*, Cornell University Press

In relation to persons with disabilities, a rights approach means “abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights”.<sup>45</sup>

## Human rights charters and conventions

Contemporary international conceptions of human rights can be traced to the foundation of the United Nations. The Charter of the United Nations recognises the existence of human rights and calls for their promotion and respect. Article 1(3) of the Charter includes as one of the purposes of the UN to promote and encourage “respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion” (United Nations 1945: Article 1(3)).

### *Universal Declaration of Human Rights 1948*

The Universal Declaration of Human Rights (UDHR), widely regarded as a milestone document in the history of human rights, sets out, for the first time, fundamental human rights to be universally protected. It emphasises the indivisibility, interdependence, interrelation and equal importance of all human rights (civil, cultural, economic, political and social).<sup>46</sup>

The European Convention on Human Rights (ECHR) (*Convention for the Protection of Human Rights and Fundamental Freedoms*) built on the Universal Declaration to provide an international treaty to protect human rights and fundamental freedoms in Europe.<sup>47</sup>

The European Social Charter (Council of Europe 1996) is a Council of Europe treaty guaranteeing basic social and economic rights which concern all individuals. Adopted in 1961 and revised in 1996, the European Social Charter sets out rights and freedoms and establishes a supervisory mechanism guaranteeing their respect by the States Parties. The right to work and to a fair remuneration, the right to social security, the right to protection against poverty and social exclusion and the right to housing are particularly significant.

## Human Rights Principles

The underlying principles of a rights-based approach have been summarised as<sup>48</sup>:

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

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<sup>45</sup> Quinn, G. and Degener, T. (2002), The moral authority for change: human rights values and the worldwide process of disability reform’ in Quinn, G. and Degener, T. (eds.) with Bruce, A., Burke, C. Castellino, J., Kenna, P. Kilkelly, U., Quinlivan, S. *Human Rights and Disability*, United Nations, New York and Geneva.

<sup>46</sup> The Universal Declaration of Human Rights was given expression in 1976 in the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.

<sup>47</sup> The Convention entered into force on 3 September 1953 and the text of the Convention was subsequently amended in 1971, 1994, 1998 and 2010.

<sup>48</sup> Quinn, G. and Degener, T. (2002), *op.cit.*

Rights-based advocacy discourages *en bloc* compartmentalisation of identities (*viz.* older persons, people with disabilities) and focuses instead on the complexity and multiplicity of identifiers. People are understood primarily in terms of the challenges and opportunities faced at each stage of the life-cycle rather than as members of 'identity-groups'

A number of components of a rights-based approach can be identified which are centrally relevant to a rights-based approach to advocacy and which are set out in Figure 2 below.

**Figure 2: Components of a rights-based advocacy**

Citizenship	The right of individuals “to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in society”. It confers a social and economic status independent of the market and a redressing of imbalances in market outcomes.
Social inclusion	Positive affirmation of people’s shared citizenship at all points of engagement with societal structures and institutions.
Recognition	The esteem that one feels based on the respect that is afforded by others. It is based on the notion of each person being able to observe and feel that s/he has a recognised identity, experiences a sense of belonging and is given due regard by others accordingly.
Individual autonomy	Being able to determine one’s own life course, including at the end of life. It assumes that physical and functional independence is not a prerequisite to retaining autonomy. There is a crucial distinction to be made between 'decisional autonomy' and the 'autonomy of execution’.
Personal agency	Participation and inclusion in critical decisions that affect one’s life. It has been argued <sup>49</sup> that there is a need for a more collaborative conception of agency (involving others in a supportive role), one that is, in reality, appropriate to all, but especially useful in relation to people with a cognitive impairment. Supporting people to maximise decision-making capacity is a basic component of the Assisted Decision-making (Capacity) Act 2015.
Voice	The right of each individual to express his/her views freely in all matters affecting him/her. This includes having control over one's accommodation, daily routines, activities, and general life direction.
Equality	All citizens being equally enabled to maximise their potential. While people may differ profoundly in capacity, character and intelligence, they are equally entitled as human beings to consideration and respect and society should provide appropriate supports accordingly.

Even a cursory application of the above components to the reality of the lives of many vulnerable adults will indicate that they remain largely aspirational and, indeed, even contentious.

### ***Autonomy and the Right to Self-Determination***

Of particular relevance to independent advocacy is the principle of autonomy and the right to self-determination. This includes having control over one's accommodation, finance, daily routines, activities, and general life direction.

The provisions of the UN Convention on the Rights of Persons with Disabilities (CPRD) are centrally relevant to advocacy. 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.

The following autonomous rights are enshrined in the UN Convention:

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<sup>49</sup> Carlson, K. and Kittay, E. F. (2010), *op.cit.*

- 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)
- 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)

The focus on empowerment and personal autonomy in the Convention is strongly echoed in the Council of Europe Statement on the Rights of Older Persons<sup>50</sup> which states that older persons are entitled to lead their lives independently, in a self-determined and autonomous manner (Principle 111(9)). This Statement outlines in detail what is required to ensure that older persons' rights are protected. The Statement refers, *inter alia*, to the need for supports to enable people to make independent decisions and includes a requirement on States to provide medical, health and care supports in accordance with need. A statutory-based independent advocacy service would seem to be a core requirement in this regard.

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<sup>50</sup> 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).

### ***Deprivation of Liberty***

A right to independent advocacy is crucially important for people who already have or who might have their freedom removed. In order to ensure that all those at risk of being deprived of their liberty have effective assistance to challenge the deprivation, it is essential that independent advocacy is available to all persons admitted to residential care facilities or who continue to reside in relevant facilities. There needs to be specific provision in legislation for independent advocates in order to safeguard against deprivation of liberty. Indeed, the concept of autonomy and self-determination demands that the person be placed at the centre of all decisions affecting him/her. This obviously includes situations where a person's liberty is under threat.

In order, therefore, to reflect the underlying principles of a rights-based approach contained in the ADM 2015 Act, a statutory provision for an Independent Advocate is required. Indeed, the Oireachtas Joint Committee on Health and Children's Report on the Role of Advocacy in Health and Social Care Services in Ireland (January 2016)<sup>51</sup> commented that the lack of statutory powers for advocacy acts as a barrier of access to advocates by vulnerable people.

As part of work to draft the non-healthcare statutory codes of practice under the 2015 Act (at the request of the Department of Justice and Equality), the NDA has developed a draft code of practice for advocates. These advocates would be independent of the relevant person and healthcare professionals, and would work with the relevant person to support them to make the decision in question. As part of the drafting process, the NDA has recommended that the 2015 Act make provision for the setting up of a panel of independent advocates by the Director of the Decision Support Service for the purpose of supporting relevant persons under the 2015 Act to make their own decisions.

The National Safeguarding Committee in its Submission on the Preliminary Draft Heads of Deprivation of Liberty Bill called clearly for legislative provision to be made for independent advocacy.

### **Advocacy and supported decision-making**

Put simply, the goal of advocacy for people with reduced decision-making capacity, e.g., those with dementia, people with intellectual disability or other cognitive impairment, is to support them as individuals in achieving what they wish and in having access to what they value. There are a number of key considerations here:

- (i) Whether a person has the capacity to give instructions or not, the advocate's role is to ensure that his/her voice is heard;

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<sup>51</sup> <https://webarchive.oireachtas.ie/parliament/media/committees/healthandchildren/health2015/jchc-report-on-advocacy.pdf>



- (ii) There is a need to explore alternative ways of facilitating agency by people with cognitive impairment;
- (iii) There is a crucial and important distinction between decisional autonomy and the ability of a person on his/her own to execute those decisions;
- (iv) The focus on providing support to people with dementia as individuals must fully take into account that people are (or certainly have been) part of a wider community including family, service provider staff and friendship networks;
- (v) For many people with dementia, there are likely to be some aspects of their lives where they can make decisions and others where they are unable to so do – recognising these aspects and providing support accordingly is at the very core of advocacy work;
- (vi) The principle that the individual and the advocate work together to ensure optimum outcomes for the individual is particularly important where the individual's desired outcomes are difficult to ascertain clearly;
- (vii) People with cognitive impairment in residential care settings may be vulnerable, not only because of their individual needs, but also because historically the system of service provision has tended to be based on a dependency model rather than on an approach that maximizes choice, supported decision-making and independence.

The ADM Act (2015) legislates for supported decision-making to assist vulnerable people with limited capacity and sets out key guiding principles. A basic premise of the 2015 Act is that everyone should be presumed to have capacity to make decisions. Legal capacity means the capacity to have rights and the power to exercise those rights. Three levels of support are identified:

- Where a person has the ability to make decisions with only minimal support, e.g. easy to read information
- Supported decision-making where a person is supported by someone they trust to make a decision
- Facilitated decision-making – this is used as a last resort where the person's will and preferences are not known. Here a representative has to determine what the person would want, based on what is known about the person and the best understanding of their wishes

Independent advocates have a potentially significant role to play in supported decision-making in that it is crucially important that support is provided at the appropriate level – in

other words, adequate but the least restrictive in terms enabling individuals to maintain independence and autonomy to the greatest extent possible.

## Advocacy and legislative provision in Ireland

**Figure 3: Advocacy for Vulnerable Adults in Ireland: Key Milestones**

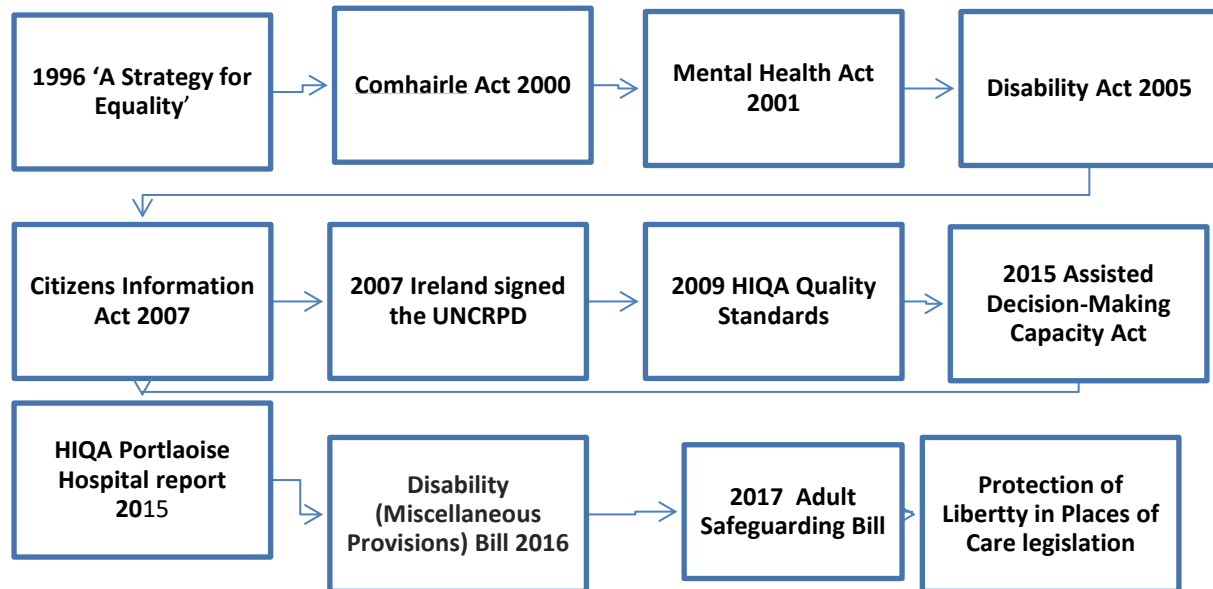


Figure 3 above outlines key transition points in the development of advocacy discourse.

The first specific reference in Ireland to advocacy was in the 1996 Report of the Commission on the Status of People with Disabilities, *A Strategy for Equality*.<sup>52</sup> This report suggested that advocacy should be provided in institutional settings and that authority for this type of advocacy should be set out in legislation. The report also acknowledged citizen and self-advocacy as beneficial for people with disabilities and suggested that access to an advocate should be a legislative entitlement, where necessary to ensure access to justice or access to essential social services. However, in subsequent reports, this broad interpretation of advocacy was confined to the need for legal advocacy in the mental health care setting. This was recognised in the Mental Health Act 2001, which provides for a person to be appointed independent legal representation in the review process of involuntary detention.<sup>53</sup> While the term advocacy is not used in the Act, effectively there is statutory provision for legal advocacy for people with mental health difficulties in that it provides for a person to be

<sup>52</sup> Commission on the Status of People with Disabilities, *A Strategy for Equality* (Dublin: Stationery Office, 1996).

<sup>53</sup> Section 16(2)(b), Mental Health Act 2001. This narrow construction of advocacy was criticised at the time by the Forum of People with Disabilities in their report on *Advocacy – A Rights Issue* (Dublin: Forum of People with Disabilities, 2001). This argued for a broader approach to advocacy and suggested that advocacy should be a legislative entitlement for all vulnerable individuals in society, not just people with disabilities.

appointed independent legal representation in the review process of involuntary detention.

It should be noted, however, that legal advocacy in the context of the Mental Health Act does not include independent advocacy in the more general way which people frequently require.

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 (PAS).<sup>54</sup> 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.

Actions by governments to comply in particular with the provisions of Article 12 of the CRPD and with the interpretation of Article 12 by the UN Committee on the Rights of Persons with Disabilities have provided an impetus and focus for consideration of independent advocacy provision. Article 12 deals with the right of individuals to legal capacity and the accompanying obligation on the State to provide support for the exercise of legal capacity. The establishment of the Decision Support Service under the Assisted Decision-making (Capacity) Act 2015 will bring about necessary regulatory change in this regard. The Adult Safeguarding Bill 2017 contains provision for an independent advocate. Also, the Disability (Miscellaneous Provisions) Bill<sup>55</sup> is aimed at introducing legislative amendments necessary to implement the UN Convention on the Rights of Persons with Disabilities (CRPD) and to make reasonable accommodation accordingly. It is intended that the Deprivation of Liberty Bill will address issues such as the Convention's requirements in relation deprivation of liberty and include provision for independent advocacy.

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

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

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<sup>54</sup> The Personal Advocacy Service was deferred by the Government in the light of budgetary circumstances and the service has not been established.

<sup>55</sup> The General Scheme of the Disability (Miscellaneous Provisions) Bill was submitted to the Oireachtas Committee on Justice and Equality in June 2016 as part of the pre-legislative scrutiny process. The Bill was given a Second Reading in January 2017 and is currently at committee stage in the Oireachtas.

for the guidance of persons acting as advocates on behalf of relevant persons  
10(3)(2)

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

Under the Adult Safeguarding Bill 2017, the Safeguarding Authority can arrange for a person who is independent (an “independent advocate”) to be available to represent and support an individual. The condition for appointment of an independent advocate is that the Authority considers that, were an independent advocate not to be available, the individual would experience substantial difficulty in doing one or more of the following:

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

### **Advocacy Practice: Quality standards, skills and competencies**

One of the key characteristics of the role of the independent advocate is that s/he solely represents the will and preferences of the person. This demands that:

- 1) The independent advocate is skillful in engaging with clients and in conveying their views succinctly to decision makers;
- 2) Advocates must acquire a sound knowledge of legislative and policy frameworks along with knowledge of the entitlements and rights of the client; and
- 3) The independent advocate must behave ethically, with particular diligence and commitment to the virtues of honouring and voicing the viewpoint of others and is sustained by an ongoing commitment to the development of expertise.<sup>56</sup>

While there has been a limited range of initiatives to develop ‘good’ specialist and generic advocacy services, it is notable that ownership of standards in advocacy has been inconsistent, specifically in the area of advocacy for older people.<sup>57</sup> Sage Advocacy has published standards<sup>58</sup> which are intended to be applied to all types of advocacy and support

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<sup>56</sup> Trevithick, P. (2012) *Social Work Skills and Knowledge: A Practice Handbook*. 3rd ed. Maidenhead: McGraw-Hill Open University Press.

<sup>57</sup> Dunning, A. (2005) *Information, Advice and Advocacy for Older People: Defining and Developing Services*. York: Joseph Rowntree Foundation.

<sup>58</sup> <https://www.sageadvocacy.ie/media/1336/quality-standards-for-support-and-advocacy-work-with-older-people-final-061015.pdf>

work with and for older persons, as well as to all individuals acting in the role of advocate. It is suggested that these standards have the potential to clarify the role of the independent advocate and to ensure 'a level' of consistency that will sustain the development of best practice in services for older people and vulnerable people.

It is clear from the literature that there are a number of potential benefits to be gained by developing standards for advocacy services. These may also include the provision of a benchmark by which to gauge the effectiveness of performance; clarity around the expectations of what the service can provide; transparency through accountability, which, in turn, serves to maintain the integrity of the service, and above all, protect and safeguard vulnerable people from a poor service.<sup>59</sup>

Advocacy quality standards nationally and internationally are based on a broad common understanding of what advocacy<sup>60</sup> is about.

- 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.

There are a number of Advocacy Standards Documents which are relevant in the Irish context. For example, the Scottish Independent Advocacy Alliance has developed Non-Instructed Advocacy Guidelines: A companion to the Code of Practice for Independent Advocacy.<sup>61</sup> The Advocacy Network Northern Ireland, Code of Practice for Independent Advocates<sup>62</sup> is also informative as is the Age Concern (2013) publication, *An Advocate's Guide to Independent Non-instructed Advocacy, Older People and Dementia Principles, Practice and Guide to Further Resources*.<sup>63</sup> Here, in Ireland, the Citizens Information Board (2007) has developed Advocacy Guidelines<sup>64</sup> to inform the work of both NAS and CISs and

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<sup>59</sup> Dunning, A. (2005), *op .cit.*

<sup>60</sup> Adapted from <http://www.agedrights.asn.au/rights/whatis.html>

<sup>61</sup> [http://www.siaa.org.uk/wp-content/uploads/2014/02/SIAA\\_Non\\_Instructed\\_Advocacy.pdf](http://www.siaa.org.uk/wp-content/uploads/2014/02/SIAA_Non_Instructed_Advocacy.pdf)

<sup>62</sup> <http://www.hscboard.hscni.net/download/PUBLICATIONS/ADVOCACY/Code-of-Practice-for-Independent-Advocates.pdf>

<sup>63</sup> <http://opaal.org.uk/app/uploads/2015/09/An-Advocates-Guide-to-Non-Instructed-Advocacy-2013.pdf>

<sup>64</sup> [http://www.citizensinformationboard.ie/publications/downloads/advocacy\\_guidelines\\_2007.pdf](http://www.citizensinformationboard.ie/publications/downloads/advocacy_guidelines_2007.pdf)

Sage Advocacy has published *Quality Standards for Support & Advocacy Work with Older People*.<sup>65</sup>

In her introduction to the Sage Advocacy Quality Standards, Ms Justice Mary Laffoy of the Supreme Court stated:

*“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”.*

Based on this understanding and building on public and stakeholder consultation and a review of the international literature, the Sage Advocacy *Quality Standards for Support & Advocacy Work with Older People* set out six Standards and related components which, it is suggested, provide a good basis for developing national standards for independent advocacy.

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.

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<sup>65</sup><https://www.sageadvocacy.ie/media/1336/quality-standards-for-support-and-advocacy-work-with-older-people-final-061015.pdf>

## Advocacy skills and competencies

While relevant education and training for advocates is clearly essential, there are currently no national or international standards to define the work or the skills required for the practice of advocacy. Some educational and training organisations offer courses, and in Ireland there is a QQI Level 6 course in '*Information, Advice and Advocacy*' and courses related to advocacy are provided by a number of Institutes of Technology. Also, NUIG offers an MA in Public Advocacy and Activism – this is an interdisciplinary programme that combines training in the practical skills of advocacy and activism with an exploration of the theories and concepts which inform these fields.<sup>66</sup>

There is a need to address the skills required by people who are called upon to advocate on behalf of others - particularly on behalf of those with fluctuating or diminished capacity, people with serious mental health challenges and people with limited capacity to communicate. Advocacy on behalf of individuals requires qualities such as commitment, courage, competence, compassion and creativity. It also requires an understanding of how to handle challenge, how to communicate, aspects of relevant legislation, powers of observation, recording and endless amounts of time and patience.

### *Advocacy Practice Skills*

Limited recognition has been given to advocacy as a practice skill. This is perhaps due to the fact that this may be due to the fact that advocacy has a strong record in the field of welfare rights, and technical knowledge of social security systems has been favoured over the development of advocacy skills.<sup>67</sup> To be an effective advocate, an in-depth knowledge of the process of advocacy, specifically the tactical and negotiation skills required, are just as important as technical knowledge and personality. Ultimately, the motivating force behind any use of advocacy skills is the ethical stance of the advocate combined with the committed due-diligence in which they are applied. Bates argues that the core skills required for effective advocacy include: assertiveness, litigation, legal knowledge, research, self-management, negotiation and interviewing.<sup>68</sup> See Appendix 3 for a detailed list of core advocacy competencies.

## Advocacy and vulnerable adults: the practice in other jurisdictions

Over recent years there has been much evidence of change and adaptation within government agencies in many countries, resulting from the development and implementation of legislation prompted by the implications of the UN Convention on the Rights of Persons with Disabilities (CRPD). This, in turn, has necessitated changes in the

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<sup>66</sup> <http://www.nuigalway.ie/publicadvocacy/>

<sup>67</sup> Bateman, N (2009) *Advocacy Skills for Health and Social Care Professionals*. London: Jessica Kingsley Publishers.

<sup>68</sup> *Ibid.*

approaches taken regarding advocacy provision by health authorities, social care authorities, and by the voluntary sector.

There has, therefore, been considerable emphasis placed on the development of approaches to advocacy in the context of mental health legislation, legal capacity, and related matters. Many countries, including Australia, Canada and New Zealand are in the process of moving from approaches that were rooted in guardianship-type legislation to one that better reflects the CRPD.

This has meant, however, that the needs of other vulnerable adults – i.e. those for whom the question of decision-making capacity is not an immediately defining characteristic – have not received as much attention.

Reviews of advocacy provision, for example, across the UK<sup>69</sup> express concerns that the focus on statutory advocacy may be at the expense of advocacy of other types.

### **The UK experience**

Advocacy in England, Scotland, Wales and Northern Ireland is shaped, to a large degree by the various country-specific pieces of legislation that provide for statutory advocacy provision. As noted earlier, these provisions are targeted primarily at people who are formally assessed as lacking decision-making capacity at a particular time about issues such as their long-term accommodation, serious medical treatment or protection from abuse.

The various Acts require local NHS Boards (Health & Social Care Boards/Trusts in Northern Ireland) and Local Authorities to provide access to advocacy services. These various authorities, across the UK, commission mainly voluntary, specialist, non-profit organisations to deliver the advocacy service, thereby ensuring that the service can be viewed as being an independent advocacy service.

In Scotland, the Mental Health (Scotland) Act 2015 builds on the right to independent advocacy services provided for in the Mental Health (Care and Treatment) (Scotland) Act 2003. It requires local authorities, Health Boards, and the State Hospitals Board for Scotland to provide information to the Mental Welfare Commission about how they are meeting their duties under the 2003 Act to provide independent advocacy services, at least every two years.

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<sup>69</sup> *Review of Advocacy Services for Children and Adults in Northern Ireland.*

<https://rqia.org.uk/RQIA/files/d7/d79ff542-b906-4118-b56d-ac405f10d9f2.pdf>

*A Map of Advocacy Across Scotland. 2015-2016 Edition* [https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA\\_Advocacy\\_Map\\_2015-16-1.pdf](https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA_Advocacy_Map_2015-16-1.pdf)

*Advocacy by and for adults with learning disabilities in England.*

[https://www.ndti.org.uk/uploads/files/IHAL\\_2012-03\\_Advocacy.pdf](https://www.ndti.org.uk/uploads/files/IHAL_2012-03_Advocacy.pdf).



National guidelines relating to the commissioning process are published, usually, at a national level<sup>70</sup>. Independent advocacy provider organisation, in many instances, also delivers other services to a special-interest group and/or to the wider community.

In Northern Ireland, the five Health and Social Care (HSC) Trusts have responsibility for commissioning advocacy services from independent advocacy providers. These are commissioned through a tendering process. Advocacy services are commissioned across various programmes of care, primarily within children and adult learning disability, child & adult mental health, and adult physical disability. Specific advocacy services for conditions such as dementia and autism are commissioned on a short-term basis, as and when required.

Independent advocacy providers are responsible for the delivery of the advocacy services for which they have agreed contracts in place with either the HSC Board or trusts. Independent advocacy providers are supported by the HSC Board and individual trusts to work in specific services and localities, engaging with patients, service users and carers in both acute and community settings.

Providers also engage with the HSC Board and individual trusts through attending regular management, policy, service delivery, and budgetary meetings.

While advocacy services other than those required under mental capacity legislation are commissioned, there is no statutory duty on the commissioners to fund such activities. Independent advocacy providers across the UK report that it is normal practice for the commissioning bodies to allow, and even encourage, them to deliver as wide an advocacy offering as they wish. However, the commissioning bodies do insist that the provision of statutory advocacy takes precedence over all other forms of advocacy. This frequently results in a diminution of the provider's ability to serve the needs of their wider client groups.

In order to present a general picture of the scale of advocacy provision in the UK, the example of Scotland is presented in bullet point, below. All data<sup>71</sup> refers to the year April 1<sup>st</sup> 2015 to March 31<sup>st</sup> 2016.

- Scotland, has a population of over 5.3 million
- It has 14 Health Boards
- They commission over 50 independent advocacy organisations to deliver advocacy
- Over £11 Million is provided by way of statutory funding by the Health Boards

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<sup>70</sup> For example: *Independent Advocacy; Guide for Commissioners*. NHS Scotland. 2013.

<sup>71</sup> [https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA\\_Advocacy\\_Map\\_2015-16-1.pdf](https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA_Advocacy_Map_2015-16-1.pdf)

- A further £732,780 is provided by the Scottish Government for other associated activities
- The services also access £707,082 from charitable trusts and other grant awarding sources
- The independent advocacy organisations employ 436 staff, including full-time and part-time
- They have a total of 482 volunteer advocates
- Over 30,000 people accessed advocacy services

## Developing a National Framework for Independent Advocacy in Ireland

A national framework is required in order to create a context within which the practice, skills, development and coordination of advocacy can be effectively realized. The lack of statutory powers for advocacy are considered to be a barrier which can prevent advocacy services from accessing or acting on behalf of vulnerable adults. This is a matter regularly highlighted by NAS and Sage Advocacy and by other NGOs working with people with disabilities and older people. Also, the Oireachtas Joint Committee on Health and Children 2016 report on the role of advocacy in health and social care services in Ireland<sup>72</sup> acknowledged that the lack of statutory powers for advocacy are considered a barrier which can prevent advocacy services from accessing or acting on behalf of people with disabilities.

Despite the references in the 2016 *HIQA National Standards for Residential Care Settings for Older People in Ireland*<sup>73</sup> regarding access to independent advocates, the experience of Sage Advocacy, for example, is that some nursing homes continue to disregard the right of their residents to see an advocate of their choice – insisting instead that they (the nursing home) have their own ‘advocate’. Also, anecdotal evidence from Sage Advocacy personnel indicates that sometimes nursing homes may side with relatives to exclude an independent advocate on the basis that ‘the family are the best advocates’.

A number of agencies working with vulnerable adults have called for independent advocacy to be put on a statutory footing, including HIQA, Safeguarding Ireland and many NGOS particularly in the context of supported decision-making and the right to liberty enshrined in both the ECHR and the UNCRPD.

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<sup>72</sup> Joint Committee on Health and Children; report on the Role of Advocacy in Health and Social Care Services in Ireland, January 2016.

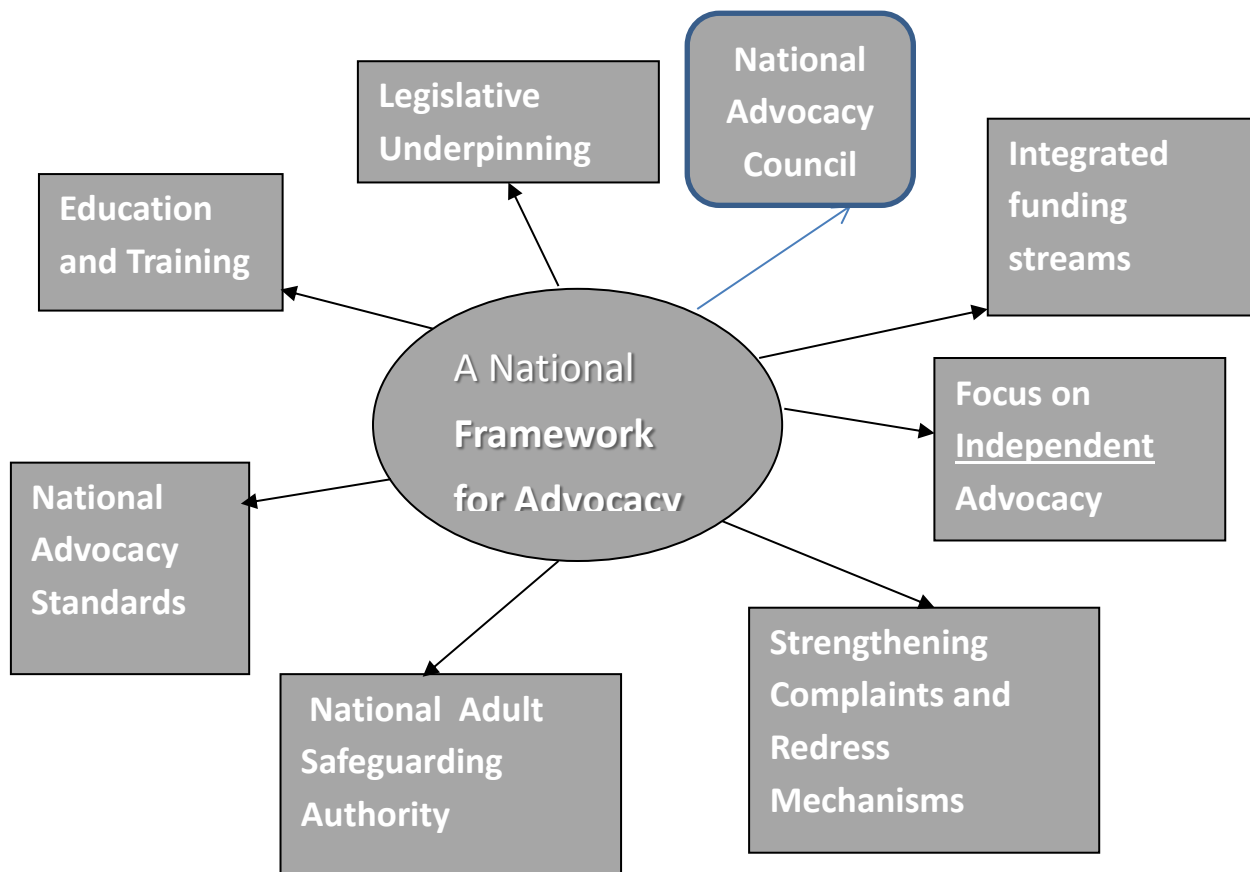
<http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2015/JCHC-Report-on-Advocacy.pdf>

<sup>73</sup> <https://www.hiqa.ie/system/files/National-Standards-for-Older-People.pdf>

The Joint Committee on Health Report on Adult Safeguarding (December 2017)<sup>74</sup> acknowledged that advocacy has an important role to play in adult safeguarding. The Committee also acknowledged that education is required in understanding the role and benefits of independent advocacy. The representatives from Sage Advocacy reported to the Committee that they often experience resistance from families who may prefer “the ‘safety’ of the current living situation of a relative with a disability as more important than a move to a more ‘self-directed’ way of life”.

The Adult Safeguarding Bill 2017 makes provisions for adults at risk accessing an independent advocate<sup>75</sup>.

**Figure 3: Components of a National Framework for Independent Advocacy**



As already stated, the need for a stronger legislative framework for independent advocacy in Ireland was highlighted in the Oireachtas Joint Committee on Health and Children 2016

<sup>74</sup> [https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint\\_committee\\_on\\_health/reports/2017/2017-12-13\\_report-adult-safeguarding\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/reports/2017/2017-12-13_report-adult-safeguarding_en.pdf)

<sup>75</sup> Adult Safeguarding Bill 2017, Section 12

Report on the role of advocacy in health and social care services in Ireland.<sup>76</sup> That report acknowledged the important role that advocates can play and noted that the lack of statutory powers for advocacy was a barrier which can prevent advocacy services from accessing or acting on behalf of people with disabilities.

There are a number of domestic and international factors that suggest that the time is ripe for a refocusing on legislative provision for independent advocacy in Ireland. At a domestic level, these include the implementation of the Assistant Decision-making (Capacity) Act 2015 and the related ratification of the UN Convention on the Rights of Persons with Disabilities which has resulted in a renewed focus on innovative mechanisms, such as advocacy, which aim to respect, protect and defend the rights of vulnerable adults in our society. In addition, as already stated, the Adult Safeguarding Bill 2017 contains provision for an independent advocate.

In many jurisdictions where advocacy is incorporated into government policy documents and legislation, this has occurred as a result of continuous pressure from community and voluntary advocacy organisations and the broader disability rights movement to have their efforts formally recognised and associated funding provided.<sup>77</sup> In Ireland, advocacy was referred to in government policy documents as far back as 1996 onwards but did not emerge as a distinct activity with specific organisations describing themselves as “advocacy groups” until the establishment of the Irish Advocacy Network in 1999.<sup>78</sup>

All of the foregoing discussion in this Scoping Document points to an urgent need for legal recognition in Ireland of the practice of independent advocacy. This is necessary in order to ensure coherency, transparency equality of access to services, as envisaged under the Disability Act 2005, and to facilitate supported decision-making as provided for in the Assisted Decision-making (Capacity) Act 2015.

The practical implications of such legal recognition will need to be further identified and implemented through the establishment of a National Council for Advocacy (see below).

While legal recognition of the practice of independent advocacy would almost certainly help to raise rights awareness, more proactive investigative mechanisms are necessary, particularly to ensure that people with reduced decision-making capacity residing in institutions are informed of their legal rights and assisted in accessing them.

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<sup>76</sup> Joint Committee on Health and Children; report on the Role of Advocacy in Health and Social Care Services in Ireland, January 2016.

<http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2015/JCHC-Report-on-Advocacy.pdf>

<sup>77</sup> These include the UK, Canada and the US. See for example, Winter, J.A., “The Development of the Disability Rights Movement as a Social Problem Solver” in Blanck, P., ed., *Disability Rights* (London: Routledge, 2005).

<sup>78</sup> See McGowan, P., “The Time Is Right – A History of the Irish Advocacy Network”, presented as part of the “Irish Voices” stream of the *Health4Life Conference*, Dublin City University, 10-12 September 2007. In addition, it should be noted that community and voluntary advocacy in Ireland was first developed in the mental health sector, with the establishment of the Irish Advocacy Network.

## Challenges to independent advocacy in the Irish context

Gaining access for independent advocates can be particularly problematic, especially in relation to people where non-instructed advocacy engagement is required. Access can be difficult, and sometimes impossible, not just in highly controlled congregated settings but also in domestic situations where a family group, or a single individual, can deny access.

Five specific areas of concern can be identified:

### *Vulnerable adults*<sup>79</sup>

While it is generally accepted that people with disabilities should be considered to be vulnerable and at risk, there is less clarity regarding the need to provide advocacy services to other people who may be marginalised or disadvantaged, including older persons with reduced decision-making capacity and people experiencing mental health difficulties .

### *Places of custody and care*

In residential care settings, it may sometimes still be the case that the traditional mode of control and ‘best interests’ continues to operate and, as a result, these facilities are to all intent and purpose places of detention as well as care. An ethos of identifying and respecting the will and preferences of people with reduced decision-making capacity and responding accordingly may still not be the norm in some facilities.

### *People experiencing mental health difficulties*

Some people with mental health difficulties are reported as lacking the confidence to raise concerns about public services that they receive, including mental health services. The significant picture that emerges from a 2017 pilot study<sup>80</sup> is that for a group of people who use mental health services in an area of high deprivation and poverty, there is a clear need for greater access to advocacy supports, as well as information on how to make a complaint to the HSE.

### *Family concerns*

In the context of increasing efforts by the HSE to deal with the issue of congregated settings for people with an intellectual disability, where independent advocates become involved (e.g., NAS or Sage Advocacy), there may be strong reactions from family members who see the ‘safety’ of the current living situation of a relative with a disability as more important than a move to a more ‘self-directed’ way of life. In such situations their fears are

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<sup>79</sup> A person who may require care and support services because of physical or intellectual disability, cognitive impairment or mental health difficulties and who is unable to take care of him/herself without assistance or unable to protect him/herself against abuse or exploitation. This includes adults with physical, sensory and mental impairments which have been there since birth or which have arisen during the course of the life-cycle.

<sup>80</sup> [The Advocacy Needs of Mental Health Service Users Living in the Community: A Pilot Study](#)

reinforced as people with disabilities start finding their own voice and move away from their family.

### *Regulation overreach*

As moves from congregated settings occur and people who may be vulnerable start leading more self-directed lives, the role of regulators can become unnecessarily intrusive. This is a grey area and more attention is required to achieving a more appropriate balance between autonomy and safeguarding.

## **A Changed Discourse**

The discourse on advocacy in the Irish context has shifted significantly since the Personal Advocacy Service (PAS) was proposed.

### From

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

### To

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

While PAS was not put in place at the time for resource reasons and a different model is now necessary arising from the provisions of the ADM Act, a critical analysis of the provisions for the Personal Advocacy Service in the Citizens Information Act 2007 is informative in respect of any future legislative provisions.<sup>81</sup> In particular, the State's obligation to ensure that all vulnerable adults have a legal entitlement to independent advocacy was understated in that legislation.

## ***A National Advocacy Council***

In order to develop the national framework proposed and to create an integrated context within which the practice, skills, development and coordination of advocacy can be effectively realised, there would be much merit in having a National Advocacy Council to engage all relevant government departments – Health, Justice, Employment and Social Protection, the HSE, other agencies of state such as the Decision Support Service, HIQA, Office of the Ombudsman, Mental Health Commission as well as inter-sectoral entities such as Safeguarding Ireland and educational institutions (the latter to calibrate appropriate courses and qualifications for advocates).

The role of such a Council could include, *inter alia*:

- Enabling access by all vulnerable adults to independent advocacy
- Integrating the various funding strands for advocacy and related reporting structures

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<sup>81</sup> O'Brien, C., "Advocacy Service Delay Criticised" *Irish Times* (10 July 2008).

- Providing for uniform access to independent advocacy by all vulnerable adults
- Overseeing funding requirements
- Standards,, qualifications and training
- Codes of practice
- Research, monitoring and evaluation
- Data information systems

Such a Council could also be the source of funding for advocacy bodies such as the Irish Patients Association, Sage Advocacy<sup>82</sup>, Irish Advocacy Network, etc

It is suggested that active consideration be given to establishing such a Council and that initial scoping should be carried out to explore how such a Council might operate. Key questions to be addressed in this regard are:

- How would such a body relate to the the National Patient Safety Office and the development by that office of a Patient Complaints and Advocacy Policy and a National Patient Advocacy Service
- Who would draw up a National Advocacy Plan and oversee its implementation?
- Who needs to be consulted in order to identify the most appropriate model of independent advocacy?
- Will the advocacy service be run by paid advocates or volunteers or a judicious blend of both?
- What competencies and qualifications will be required of advocates?
- Who will manage advocacy services?
- Who will fund independent advocacy services?
- Who will recruit, train and supervise the advocates?
- How will the advocacy service link with staff in residential care facilities, acute hospitals, primary care and GPs?
- How can the experience to date of delivering advocacy services in Ireland be built upon?
- What standards will be used to define the minimum quality of service and how will these be enforced?

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<sup>82</sup> Patient Focus has recently been merged with Sage Advocacy.

- How would it relate to new legislative provisions for the appointment of independent advocates and to the Code of Practice for Advocates being developed by the Decision Support Service?
- How would it link in with the National Adult Safeguarding Authority (Adult Safeguarding Bill 2017) and the ongoing role of Safeguarding Ireland?

There will be a need to put in place a structure for the establishment and servicing of such a Council and options will need to be identified and explored in this regard, perhaps using an existing State agency.

## Overview and Conclusion

Advocacy is clearly not a stand-alone intervention and advocacy alone is clearly not the answer. It requires:

- Rights-based structures, context and frameworks
- A commonly agreed and understood language about independent advocacy
- An open dialogue about where it best fits in a continuum of services and supports
- A national framework for the development and funding of independent advocacy
- An inter-agency approach

There is a critical need at this juncture to put in place a national framework for the development of independent advocacy as an integral part of the rights protection and service delivery infrastructure. This is necessary in order to ensure that all vulnerable adults, irrespective of ability/disability or geographical location or place of residence are fully protected. The current *ad hoc* approach to advocacy provision is totally inadequate in the context of meeting the requirements of the UN Convention on the Rights of Persons with Disabilities and the related provisions of the Assisted Decision-making (Capacity) Act 2015.

The guiding principles of the Adult Safeguarding Bill 2017 and the related establishment of a National Adult Safeguarding Authority need to be kept to the forefront of policy development with particular reference to:

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

Critical to realising the full potential of new legislation will be the development of independent advocacy in all care settings to support the capacity needs of vulnerable older people. Independent advocacy gives voice: it means that those who 'cannot shout the loudest' have someone to 'speak up' for them to ensure that they can be heard. It promotes equality, social inclusion and social justice and is embedded in a human rights paradigm.it



has significant potential in the areas of self-determination and deprivation of liberty. However, it is not a solution to resolve inadequacies and gaps in service provision in the 'ever-more complex' social sphere. There is an obvious need for a more integrated approach between independent advocates and advocacy support provided by social workers and other professionals.

Within current state/independent advocate relationship structures, the translation of human rights norms into meaningful action can be very difficult and policy makers may differentiate between international laws and conventions that require compliance (such as EU Directives) and human rights monitoring processes that are seen to exert little more than moral pressure.

The relationship between the client and advocate is an important shared element of the role of the many professionals. Engaging and networking between a broad range of services with and on behalf of clients can be identified as a feature of the work of some professions and for some, using an approach that empowers clients to build on their strengths is fundamental to their role (Murray 2016).

The full implementation of the Assisted Decision-making (Capacity) Act and the passing of the Adult Safeguarding Bill 2017, the Disability (Miscellaneous Provisions) Bill 2016 and the Deprivation of liberty Bill provide the necessary context and impetus for a systematic and sustained stakeholder dialogue on advocacy. The key questions to be addressed are:

- 1) What is the role of independent advocacy in safeguarding vulnerable adults?
- 2) What is the responsibility of government generally, individual departments and the HSE in this regard?
- 3) What will be the delivery mechanisms for independent advocacy?
- 4) How will these be funded in order to ensure independence, consistency, transparency and accountability?

It has been suggested that the establishment of a National Advocacy Council would be an important step in addressing these matters.

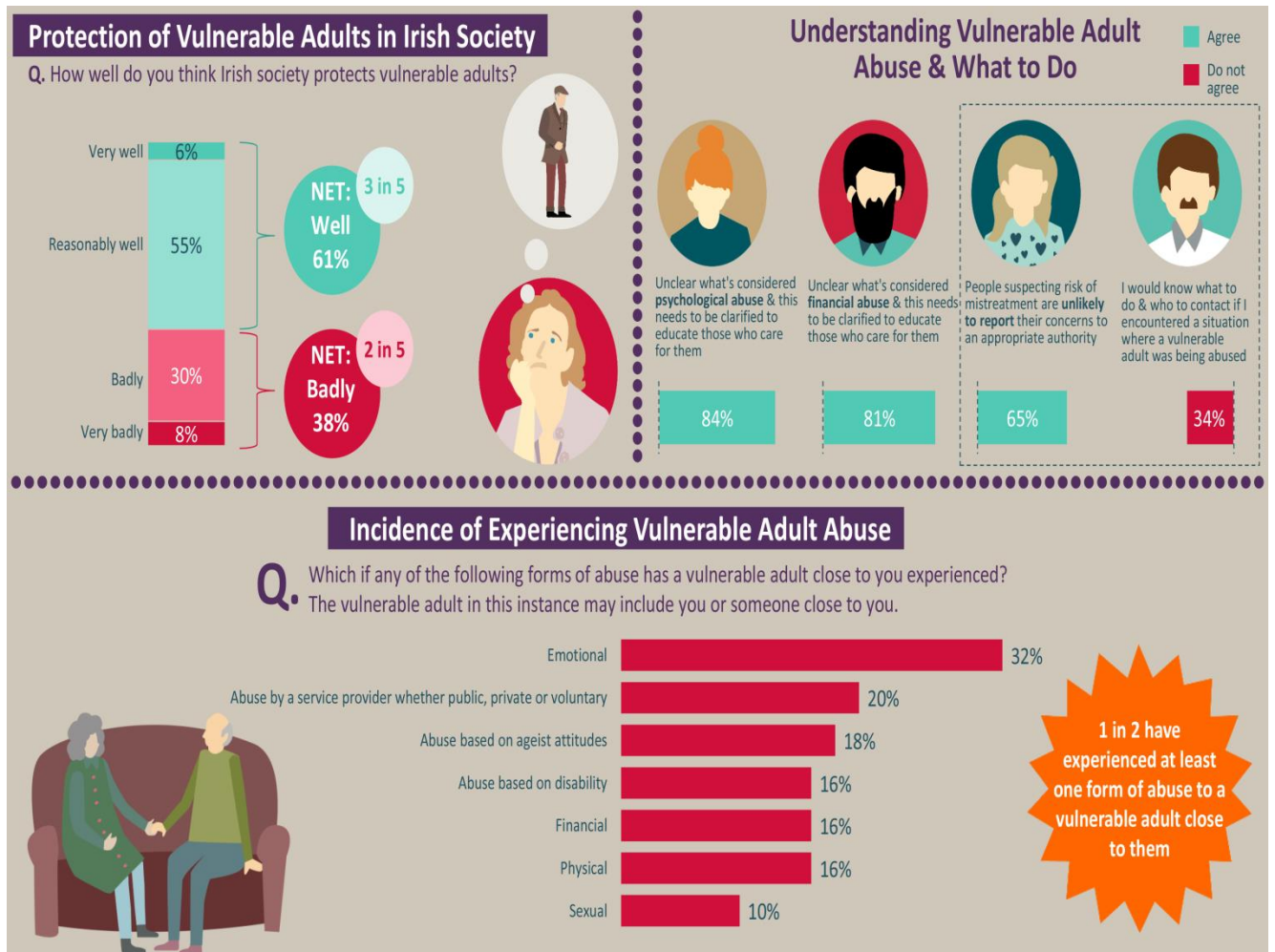
Despite the creation of new legislative rights to services, including advocacy, many vulnerable adults remain unaware of their entitlements or how to access them. In the case of the most vulnerable individuals, it is clear that legislative provision for independent advocacy is essential in order to adhere to the principle of state responsibility for advocacy provision and to overcome current blockages arising from the absence of a legal remit for independent advocacy.

Very importantly, recent legislation, reflecting a rights perspective does not include any reference to a 'best interests' principle, thus posing the question: how will service providers

and professionals manage this 'paradigm shift' in the ever more complex interfaces with citizens who may be vulnerable.

## Appendix One

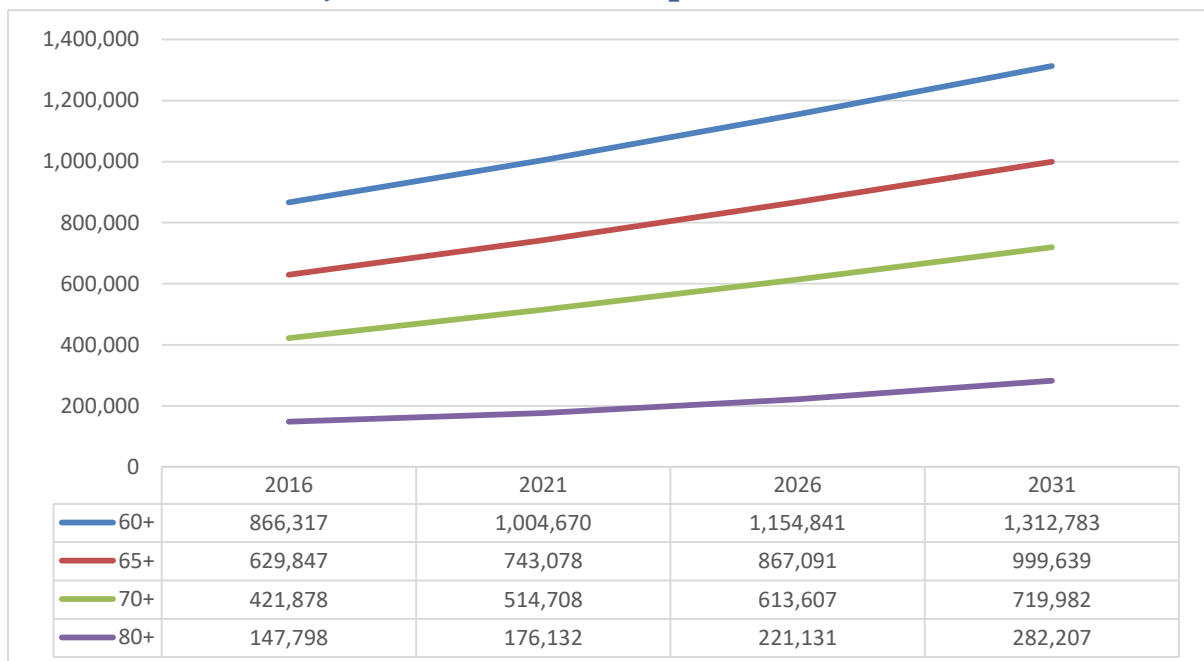
### Public Perspectives on Abuse of Vulnerable Adults in Ireland



Source: Safeguarding Ireland, <http://safeguardingcommittee.ie/wp-content/uploads/2017/04/Red-C-Survey-Vulnerable-Adults-in-Irish-Society-Key-Info-Low.png>

## Appendix Two

### Current and Projected Over 60 Population in Ireland



Source: CSO and ALONE <http://alone.ie/wp-content/uploads/2018/07/Housing-Choices-for-Older-People-in-Ireland-Time-for-Action-1.pdf>

## Appendix Three

### Advocacy competencies<sup>83</sup>

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#### CORE COMPETENCIES

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- Communication with a wide range of people (in writing, in person, on the phone) - using language that is appropriate to person, listening skills, rapport-building skills, etc.
- Provide clear general information (on advocacy, on a person's wishes and preferences) to the public, to health and social care providers and people's relatives
- Form relationships with people, especially people who may be vulnerable and elicit their trust
- Collaborate, negotiate and agree plans with others; work in partnership with service deliverers/families/social networks
- Develop and maintain good relations with others involved in care, treatment and support including HSC personnel
- Support people to develop their skills in self-advocacy and assertiveness
- Have particular attributes and attitudes:
  - Approachable, friendly and easy to talk to; non-judgemental; sensitive to others; involving and inclusive
  - Respectful of people, their privacy and of their relationships with family members/social networks
  - Self-aware, assured without being arrogant or egotistic
  - Value individual autonomy, self-determination and empowerment - encouraging of client's assertiveness and of their status as 'free and equal' individuals with legal capacity and the right to decide for themselves
  - Proactive and willing to take initiative regarding raising advocacy awareness among H&SC services personnel
  - Vigilant - attentive to instances of lack of quality of status for vulnerable adults
  - Open to self-review, receiving feedback and accepting support and supervision
  - Independent (free of any competing interest)
  - Compassionate as well as passionate about enabling vulnerable people to have their voice heard
  - .
- Have an understanding of the general legal framework, including law on capacity/assisted decision-making, basic human rights/legal rights, suspected abuse, discrimination and diversity
- A general awareness of the 'territory' and policy landscape:
  - Human rights and legislative provisions
  - The health system and how to access health and social care services
  - Options generally available to people (e.g., re: housing, care, decision-making, etc.)
- An ability to maintain records and to use data recording and case management systems

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<sup>83</sup> Source:Sage Advocacy Internal Staff Recruitment and Training Document.

## SPECIFIC ADVOCACY COMPETENCIES

- Able to persist with a case even in the face of set-back and resistance from others
- Able to deal with complex cases where there is a multiplicity of need and/or where other avenues have been exhausted
- Communicate/work with people with cognitive impairment to help them maximise their capacity.
- Communicate with people who are non-verbal and/or from different cultures.
- Able to talk to others (e.g. client's family) to establish person's likely will and preferences in a way that shows due regard for the person's dignity and privacy. Able to explain policies and enable people to grasp their meaning and significance.
- How to observe/keep a 'watching brief'
- Being able to challenge others without alienating them
- Understand what service provision should be like, what constitutes 'acceptable' service in specific settings and how to raise concerns with staff if service 'gaps' are evident
- Have a general understanding of dementia and how to be with/advocate for someone with dementia
- Able to research options available to a person in a given set of circumstances

### Advocacy skills required in specific settings

PRIMARY CARE & COMMUNITY	NURSING HOME & RESIDENTIAL CARE	ACUTE HOSPITAL
<p>Prior professional skills of a legal, social work, health or social care nature;</p> <p>A good understanding of General Practice and community care, especially from perspective of vulnerable adults.</p>	<p>Prior professional skills of a legal, social work, health or social care nature;</p> <p>A good understanding of NH/residential care especially from perspective of vulnerable adults</p>	<p>Prior professional skills of a legal, social work, health or social care nature;</p> <p>A good understanding of A&amp;E and hospital care, especially from perspective of vulnerable adults</p>