

The Role of an Independent Advocate

A Sage Advocacy Information Resource
October 2024

Nothing about you

without you

Purpose

THE PURPOSE of this document is to provide clarification on the role of an Independent advocate both generally and in specific contexts for the benefit of clients, family members, all who interact with a person both professionals and non-professionals. It also aims to set out in more detail the scope of the advocate's role, providing examples of actions that can and cannot be taken by an advocate.

About Sage Advocacy

Sage is the National Advocacy Service for Older People and it also provides support and advocacy to survivors of institutional abuse and other vulnerable adults and to healthcare patients in circumstances where no other service is available. It responds according to a person's needs with Information - Support - Advocacy - Safeguarding and often a combination of all these approaches. It also identifies, analyses and highlights issues which require systems changes through Systemic Advocacy.

Quality Standards

Six Quality Standards guide the work of Sage Advocacy

The Sage Advocacy approach at all times reflects the six quality standards outlined in the Quality Standards for Support and Advocacy Work with Older People which can be applied generally to support and advocacy work with all vulnerable adults and healthcare patients.

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.

^{*}Access the complete Quality Standards here

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What is Independent Advocacy?

NDEPENDENT advocacy is a relatively new concept and practice that emerged in the 20th century out of a diverse range of movements concerned with human, civil, social and political rights for the individual citizen.

It has a significant role to play in ensuring that vulnerable adults are protected and have their human and legal rights upheld as far as possible. It is particularly important where people are vulnerable because of place of residence, or a lack of trusted confidant, or of networks characterised by trust, honour and integrity and, even more so, for people who have reduced decision-making capacity. The independent advocate – providing a service that is free, confidential and independent of relatives, service providers and systems interests – can be hugely valuable in creating a bridge between those parties and a person whose voice needs to be heard in interactions with them.

Two definitions are quoted here which succinctly sum up what independent advocacy is about:

...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.

Kerr, L. and Kerr, V. (2003) Older People Doing it for Themselves: Accessing Information, Advice and Advocacy. York: Joseph Rowntree Foundation (p.11)

Useful Links

- Sage Advocacy Quality Standards
- Sage Advocacy Policies and Procedures Guidelines
- Decision Support Service Code of Practice for Independent Advocates
- Decision Support Service guidance documents

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.

> Advocacy Guidelines, Citizens Information Board



DVOCACY 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

The Decision Support Service Code of Practice defines independent advocacy as:

A professional support service provided by an organisation that is free from conflict of interest and is independent of family and service providers.

Delivering a professional independent advocacy service means providing a trained independent advocate who, on the basis of an understanding of a relevant person's will and preferences, will support that person to make a decision and who will, if appropriate, go on to negotiate or make a case for them.

Independent advocates are recruited, vetted, trained, supported, and supervised by an advocacy organisation.

Their work is guided by the quality standards, robust policies, and guidelines of the advocacy organisation with which they are affiliated.

An independent advocate may work with and for the relevant person, where they have difficulty expressing their will and preferences with regard to a specific issue.

Instructed and Non-Instructed Advocacy

ON-INSTRUCTED advocacy has been defined (by Henderson, R) 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 noninstructed 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."

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

Advocacy may be instructed or non-instructed

Instructed advocacy is working with or on behalf of an individual person on the lawful instructions of that person;

Non-instructed advocacy is where an advocate acts independently of the individual if they need support but it is not possible for them to communicate their consent to it. We can act on this basis in order to safeguard the person's human rights.

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 Person-centred approach approach All people have Based on the certain fundamental development human rights that of long-term, need trusting and to be mutually protected respectful relationships between advocates and people

* See section 3.3 for more information on Sage Advocacy's NIA policy

Who might benefit from independent advocacy services?

(CONTEXTS IN WHICH SAGE ADVOCACY WORKS)

Older people, irrespective of where they are

People with reduced decision-making capacity

People who come under the provisions of the Assisted Decisionmaking (Capacity) Act 2015

Vulnerable adults at transition points between home/care/ hospital settings where no other service can assist People in residential care settings, including people in nursing homes

Survivors of institutional abuse

People with physical disabilities in both residential and community settings

Hospital patients

The Role of an Independent Advocate

NDEPENDENT advocates are uniquely positioned to support older people and vulnerable adults in interactions with the state and private bodies that have responsibilities in relation to upholding their human rights. As we are all too aware in Ireland, abuse and exploitation can come at the hands of the individuals, organisations and family members who have been entrusted to provide care.

Access to an advocacy service that is independent of service providers and family members, therefore, is of vital importance.

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



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



Supporting the will and preferences of the individual and ensuring that the user/citizen remains at the centre of all decisions affecting them directly or indirectly



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



Complementing other support services such as social/friendship networks and professional services



Complementing the role of the Decision Support Service, HIQA and the Office of the Ombudsman



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



Assisting people during court or tribunal processes arising from the provisions of the ADM Act 2015



Building on the concept of multi-perspective approaches whereby multidisciplinary teams involve independent advocates, either alone or accompanying a vulnerable person, in discussing and planning supports and services for individuals

Scope of an Independent Advocate's Role

An independent advocate supports decision making by for example:

Supporting and enabling a person who has difficulty in exercising their rights, expressing their will and preferences, exploring options, and making informed choices.

Optimising participation in decision making by explaining information in a way the relevant person can understand and meeting with them at a time and place where they are best able to engage with the process

Assisting a person to express their will and preferences through their preferred methods of communication. e.g. verbally or through sign language, language interpretation, images, assistive technology, or by other means

Supporting a person where there is family conflict or a family member believes they have the right to make a decision on their behalf

In any interaction, apply the Guiding Principles contained in the Assisted Decision-Making (Capacity) Act 2015 Endeavouring to ensure that a person's decision is communicated and respected.

An independent advocate **MUST NOT** for example:

Make decisions with or on behalf of a person they are supporting Carry out a formal functional capacity assessment Make legal representations on a person's behalf

Assess the suitability of a residential placement or care plan

Influence, persuade or put pressure on a person to choose one option over another

Enter into a formal decision-making arrangement such as becoming a codecision maker or decision-making representative for a Relevant Person Share personal information with family members or professionals without a person's consent (See section 3.4 on Confidentiality and Information sharing for exceptions).

Role of an Independent Advocate

EXAMPLES IN CONTEXT

Given that older people and 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.

IN COURT

In the Court context an independent advocate may:

- Explain court process to a person in a way they can understand.
- Provide a report to the court on the voice of the person, outlining their will and preferences, values and beliefs
- In specific circumstances, attend the court hearing to give evidence and communicate the will and preferences of a relevant person.
- Identify and follow up on any safeguarding or advocacy issues identified in the process of engaging with the relevant person and share the information with the court, if appropriate.
- Support a person to access legal representation e.g. by making an application to the Legal Aid Board on their behalf or supporting them to contact a solicitor of their choice.
- Support a relevant person to attend court in person or by video link
- Support the person with understanding the specifics of a court order and proposed Decision Making Representative.
- Further information on the role of an independent advocate in context of court applications can be found here.



In a hospital setting an independent advocate may:

- Attend Multi-Disciplinary Team (MDT) meetings with or on behalf of a person (with their consent)
- Support where there is a concern of undue influence by third parties

 Provide an unbiased perspective independent from family and system's interests e.g where healthcare professionals or family members disagree with the persons wishes

- Support a person to communicate their will and preference around healthcare treatment when their capacity is in question and no one has legal authority to consent on their behalf (HSE consent policy Section 6.2)
- Where there is question of deprivation of liberty, an independent advocate should ensure the person's voice is heard. (HSE consent policy Section 8.1)
- Where a person is reluctant to consent to assessment of capacity to make a decision (Section 5.5.2) or if a person disputes the findings of the assessment (HSE consent policy Section 5.7.4) an advocate could support them in understanding the reason of the assessment, potential consequences and their rights in relation to it.
- Support with conversations around discharge planning
- Support with access to a private solicitor or legal aid when required

IN NURSING HOME OR RESIDENTIAL CARE

SETTING In a residential care setting, an independent advocate may:

- Support a person to regain access to finances;
 support with financial management; and to arrange various affairs following admission to nursing home
- Support a person whose wish is to return home from nursing home or to be placed in alternate longterm care setting - support in exploring their options
- Support a person to challenge unnecessary restrictions on their liberties in congregated care settings including the use of convenience medication and incontinence wear
- Support a person with regard to mobility requirements they may need
- Support a person to express their preferences regarding room sharing, food, activities
- Support a person's request to access services and activities that are typically provided outside of the nursing home setting
- Respond to safeguarding concerns
- Support with access to a private solicitor or legal aid when required.

IN THE COMMUNITY

In the community, an independent advocate may:

- Support a person to access services to help them to live independently for as long as possible e.g. meals on wheels, home care, day centre, cleaning services etc
- Support a person with future planning e.g.
 Think Ahead form, AHD, EPoA etc
- Support a person to access primary care services
- Respond to safeguarding concerns.
- Support with access to a private solicitor or legal aid when required
- Strengthen circles of support around the person
- Support with Financial Management
- Support with Social Welfare entitlements in Ireland and abroad



Role of Independent Advocacy in Safeguarding Vulnerable/ At-risk Adults

HE ROLE of advocacy is clearly stated in the HSE Safeguarding Policy: "Advocacy services may be preventative in that they can enable vulnerable persons to express themselves in potentially, or actually, abusive situations" (p.16).

The continuum of support and advocacy provided by Sage Advocacy aims to offer the above to any vulnerable person. In addition, we believe the will and preference of the vulnerable adult in question should be central in all discussions about matters affecting them directly or indirectly.

The independent advocate's role in the adult safeguarding context might involve

- Informing people of their rights
- Explaining safeguarding processes
- Assisting people to participate in the development of safeguarding plans
- Supporting them to express their views and wishes
- Helping them to engage with the primary care team, home care agencies, Gardaí, HSE Safeguarding and Protection teams

Sage Advocacy works in line with the HSE Safeguarding Vulnerable Persons at Risk of Abuse Policy and Procedures (2014) and seeks to minimise the negative impacts of risk, while respecting and upholding the human rights and inherent dignity of all people involved with the Sage Advocacy service.

Sage Advocacy works towards achieving the correct balance between safeguarding and independence, thus empowering all vulnerable adults in our society. While it may not be possible for a person to be 'independent', the individual's autonomy should be respected. There is a clear distinction to be made between autonomy in decision-making and autonomy in executing a decision.

We operate on the premise that no endeavour, activity, or interaction is entirely risk free. In some cases, living with risk can be outweighed by the benefit of having a quality of life that an individual values and freely chooses.

For more information on Sage Advocacy's Safeguarding policy and procedure see pg 30 of our service policies and guidelines document **here**.

Sage Advocacy's Key Policies and Procedures

Below is an overview of some of the Key policies relevant to the work of Sage Advocacy. For more detailed information see Sage advocacy's full Service policies and guidelines document **here**.

3.1

Accessing Sage Advocacy Services

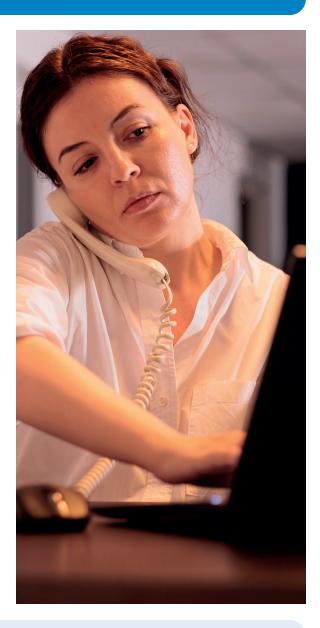
REFERRAL to Sage Advocacy can be made by an individual on their own behalf (self-referral) or by an individual on another person's behalf (family members, all who interact with a person both professionals and non-professionals). All referrals should be directed to Sage Advocacy's Information and Support Service.

Referrals will be responded to within ten working days, (see Sage Advocacy Referrals Policy and Guidelines on p10 here). The waitlist length of time will depend on demand in a particular region.

Where it is not possible to deal with a referral immediately it will be placed on a waitlist, the referrer and the individual referred, where possible, will be informed of the likely time scale and of the basis on which priority is determined.

Assessment of eligibility for Sage Advocacy service takes into account the following factors:

- Whether or not a person is deemed to be at risk, e.g., abuse or breach of their rights
- The resources available in a particular geographical area
- The nature of the support being sought



- The referral options available if Sage Advocacy is not in a position to provide the service immediately, or if there is a more appropriate service
- Initiatives targeted at a particular group or catchment area at a specific point in time

In deciding whether or not to take a referral, Sage Advocacy will apply the following criteria individually and collectively:

Without support and advocacy, a person is unable to obtain (or has difficulty in obtaining) services and supports or negotiating the service pathways A person's human rights or legal rights are being infringed

The person's quality of life is being impacted on negatively

There is a risk of harm to the person's health, safety or wellbeing There is alleged or suspected abuse of any kind or where it is suspected that an offence has been committed against the person or their property

Whether or not benefits are likely to accrue from our intervention

Whether or not an individual is likely to be able to assert their will and preferences without independent support and advocacy



Whether or not there

The absence of trusted natural social support networks - relatives, friends, support groups

The availability or not of other services/ supports to the person (e.g., Social Worker support)

is evidence of due process having been observed in dealing with a particular issue and whether or not all potential avenues of redress have been already fully explored



Sage Advocacy Consent Policy

- Sage Advocacy will apply the Guiding Principles set out in the Assisted
 Decision Making (Capacity) Acts, and will presume every individual as having capacity until the contrary is shown.
- **Consent** from an individual will always, therefore, be sought in the first instance where possible;
- At all times, Sage Advocacy's involvement will be on the basis that such involvement is to assist and support the person and that the person understands the nature and purpose of such involvement and gives his/her consent accordingly;
- Where possible Sage Advocacy will seek the consent of the person being referred **prior** to providing an advocacy service, or will seek consent from them at the first meeting where consent is not initially possible over the phone;

- Sage Advocacy operates on the basis of getting written consent from people where this is possible and practicable. Where, for whatever reasons, it is not possible to get written consent, other means of verifying consent through means that facilitate the person, will be sought;
- Sage advocacy will at all times respect a refusal of consent once the communications criteria set out above have been observed;
- Where a third party (e.g., a service provider or relative) withdraws consent for Sage Advocacy involvement, Sage Advocacy will at all times **seek direction from the person themselves**. Where getting such direction is not possible, Sage Advocacy will make a balanced judgement on the merits or otherwise of our ongoing involvement. Safeguarding concerns will be central in this regard.

3.3

Sage Advocacy Policy on Non-Instructed Advocacy

Where it is not possible to obtain consent, Sage Advocacy's involvement or continued involvement will proceed using a rights safeguarding/ 'non-instructed' support and advocacy approach in accordance with Non-instructed (Rights Safeguarding) Support and Advocacy Policy.

In establishing whether to intervene in a rights safeguarding (non-instructed) advocacy role, Sage Advocacy applies the following criteria:

- A person's basic human rights or legal rights are being infringed;
- The person's quality of life is being impacted on negatively;
- There is a risk of harm to the person's

health, safety or wellbeing;

- There is alleged or suspected abuse of any kind;
- Whether or not benefits are likely to accrue from our intervention;

In all non-instructed advocacy cases, Sage Advocacy will use an approach or combination of approaches considered appropriate from a rights safeguarding perspective and which are likely to be relevant in ascertaining a person's will and preference, including, for example,

Person-centred/biographical - life story work. For example, if appropriate, communication with others to seek insight into person's previously expressed opinions

Observation of daily living routines or reactions in particular circumstances

Input in relation to the wellbeing of the person

Taking on board the views and recommendations of the Case Management Group

Confidentiality and Information Sharing

Any information recorded by Sage Advocacy about a person will be limited to what is necessary in order to provide the support required by that person;

All information that Sage Advocacy receives from or about a person is confidential and will not be passed on to any third party (including relatives, professionals and service provider staff) without the person's consent. Any requests from third parties (e.g., relatives, service providers, health and social care professionals) for information held by Sage Advocacy about a person will be dealt with in accordance with Sage Advocacy's Client Confidentiality Policy, GDPR, Section 60 of the Data Protection Act 2018 and Sage Advocacy's data protection guidelines.

Exceptions to this are:

• If there is a legal obligation to provide information

- If Sage Advocacy is of the view that there is a risk of serious harm to the person or to another person if the information is not shared
- A 'duty of care' or rights safeguarding role requires a sharing of information with others
- Where a person is deemed to lack capacity to make a specific decision about whether to disclose information, a decision is made based on a duty of care or in order to safeguard a person's rights;
- Sage Advocacy operates on the basis that An Garda Síochána must be informed in cases where a criminal offence has been, or is alleged to have been, committed.
- Sage Advocacy operates in alignment with Data Sharing obligations under the Data Protection Act 2018.

3.4

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 skilful 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

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.

Advocacy Competencies

Have the skills both to collaborate with service providers and professionals where possible and to challenge them where necessary Have a general understanding of decision-making capacity and how to engage with people whose decision-making capacity may be reduced 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 reduced decision-making capacity to enable them to maximise their capacity Able to communicate with people who are non-verbal or who have hearing difficulties

Have an understanding of different cultures

Able to talk to others (e.g. client's family) to establish person's likely will and preferences. Sage Advocacy has published **standards** which are intended to be applied to all types of advocacy and support work with and for older persons, as well as to all individuals acting in the role of advocate.

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. See p2 and at the **link**.

Acknowledgements

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