Review of Advocacy

for people with a learning disability and or autistic people who are inpatients in mental health, learning disability or autism specialist hospitals

Different types of advocacy and people's rights to access it

This document explains about different types of independent advocacy. Understanding these will help with supporting people to access different types of advocacy.

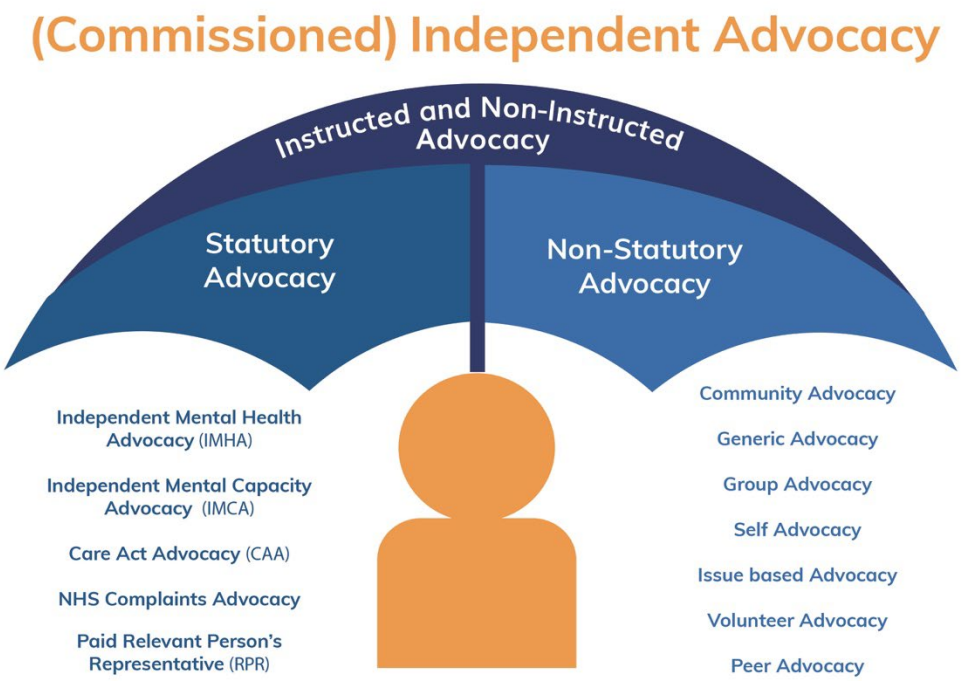
Independent advocacy is generally understood as:

"Advocacy is taking action to support people to say what they want, secure their rights, pursue their interests, and obtain services they need. Advocacy providers and Advocates work in partnership with the people they support and take their side, promoting social inclusion, equality, and social justice."[1]

Advocacy has its roots in social models of disability, of justice, of empowerment and of increasing citizenship. Advocates set out to support people to self-advocate; enabling the person to have increased agency, rights, choice, and control in their own life and essentially to get the great life they want.

Independent advocacy is an essential component of the health and social care system, offering support to people who are at risk of exclusion. Access to independent advocacy helps people say what they want, secure their rights, represent their interests, and obtain services they need – in relation to the health, social care, education systems and beyond. This is particularly important to people with a learning disability and autistic people who experience many barriers in accessing community services which can result in being detained in mental health inpatient settings where they experience a number of restrictions.

1 The Advocacy Charter, NDTi 2018 https://qualityadvocacy.org.uk/resources/advocacy-charter/



Advocates work in partnership with people who access the service. They aim to be 'instructed' or directed by the person at all times and to enable the person to 'self-advocate' as far as possible; it is an empowering relationship.

The advocate must always represent the person and their interests. Advocates don't do things or talk to people without their partner's consent, where the person is able to give this. They don't withhold information from the person that others have shared about that person. They support people to get the information they need and to consider their options and make decisions. They support people to be listened to, respected, and understood. People might have an advocate working with them who is able to provide all the different types of statutory and non-statutory advocacy, or they may have support from different advocates at different times.

The provision of independent advocacy, in all its forms is based on a set of underpinning principles and values. These are set out in The Advocacy Charter which was developed by Action for Advocacy and published in July 2002. This was then updated in 2014 and again in 2018 by NDTi[2].

2 Advocacy Charter, 2018 https://qualityadvocacy.org.uk/resources/advocacy-charter/

Non-instructed Advocacy

Some people may not be able to 'instruct' their advocate in either some or all of the work that the advocate is undertaking with them; that is, they may not be able to consent to the advocate's involvement or tell the advocate what they do and don't want them to do. This is known as 'non-instructed advocacy'.

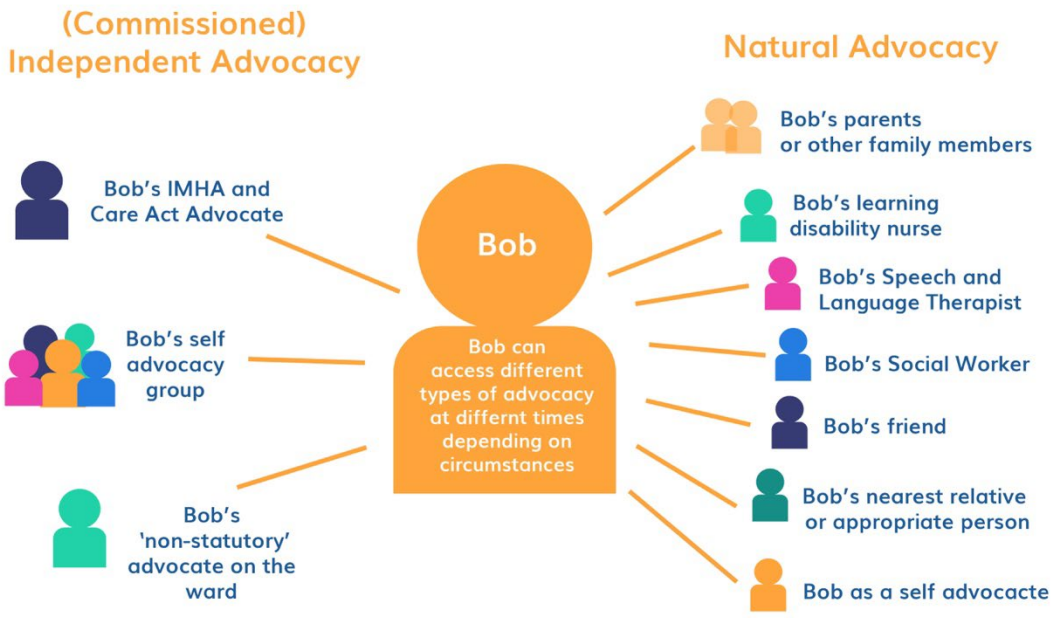
In addition, some people may be considered not to have the mental capacity to make some decisions – this doesn't automatically lead to non-instructed advocacy being provided but may be a trigger for ensuring that someone has access to independent advocacy to ensure their views, wishes and preferences are represented within decision-making processes.

The goal of the non-instructed advocate is the same as the instructed advocate: advocacy remains grounded in promoting voice, choice, and rights. The non-instructed advocate must work on establishing what is important to and for the person and understand how they communicate their preferences. At times they are part detective and take a variety of approaches to build up their understanding of the unique person they are supporting; this might be through speaking with family, friends and members of the person's paid support network, who know them well, spending time with the person in different settings and with different people, observing the person from a distance, particularly when the person indicates they don't want the advocate in their close presence. Non-instructed advocates may access the person's records and reports and attend meetings. They must maintain a level of professional curiosity throughout so as to ensure they are not taking information or other people's views and opinions at face value. In reality, advocacy with any one individual is often a mix of instructed, non-instructed or partially instructed advocacy. The advocate needs to be mindful of how they shift between approaches and be clear with others about how they are working with someone.

Statutory Advocacy

Statutory advocacy describes the type of advocacy that a person has a legal right to access. People are entitled to access different types of advocacy support at different times and in different circumstances. People may have an advocate that supports them through providing all the different types of statutory advocacy as and when needed. People may have access to more than one type of advocacy support at the same time.

In the image below we can see that Bob, who is currently detained under the Mental Health Act, has a range of different advocates supporting him.



Across England, local authorities have the responsibility for ensuring provision of a range of types of independent advocacy for adults and are required to commission:

- Advocacy under the Care Act 2014[3]
- Independent Mental Capacity Advocacy (IMCA)[4]
- Paid Relevant Person's Representative (Paid RPR)[5][6]
- Independent Mental Health Advocacy (IMHA)[7]
- NHS Complaints Advocacy[8]
- Advocacy for Children and Young People[9]

Broadly and briefly, the different types of advocacy are available to people as follows:

Care Act Advocacy is for people who have 'substantial difficulty' participating in Care Act process, who don't have anyone else 'unpaid' to support them. Support is for care and support assessments, planning, reviews as well as safeguarding processes.

IMCAs support people who don't have anyone unpaid to support or represent them and who lack mental capacity to make decisions about serious medical treatment, where they

3 Care Act (2014)

4 Mental Capacity Act (2005)

5 Mental Capacity Act (2005)

6 Deprivation of Liberty Safeguards - Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice (2008)

7 Mental Health Act (1983)

8 The Health and Social Care Act (2012)

9 The Children Act 1989

will live and when decisions are being made about potentially depriving someone of their liberty through the Deprivation of Liberty Safeguards (DoLS)[10]

Paid RPRs support people who are deprived of their liberty via a DOLs authorisation in all matters related to the DoL, including raising challenges.

IMHAs support people who are subject to the Mental Health Act, both in and outside of hospital.

NHS complaints advocates support people to make complaints about NHS care and treatment.

Children and young people's advocates provide support to 'Looked after' children and young people, those going through child protection proceedings and those leaving care.

These are very brief descriptions. You can find out more about eligibility for the different types of advocacy in chapter 2.4 of our full report, reviewing advocacy for people with a learning disability and autistic people.

Non-Statutory Advocacy

Non-statutory advocacy may also be provided, and this can take many forms including general advocacy, community advocacy, one-to-one advocacy, peer advocacy, group advocacy, self-advocacy, and volunteer advocacy. Whilst recognised as highly valuable and good practice, there are no duties on any statutory body to commission these kinds of supports.

General or Community Advocacy is often provided on a one-to-one basis and is sometimes focused on a particular issue someone wants or needs support with or a particular circumstance someone is experiencing. This could be for people who are inpatients in mental health settings informally, people in care and health settings in the community, people needing support with benefits, housing, parenting etc.

Volunteer Advocacy Is advocacy provided by volunteers. It can be short or longer term, focused on an issue or situation or be more general and holistic.

Self-Advocacy[11]

Self-advocacy is speaking up for yourself. This can be with encouragement and support from someone you trust.

Self-advocacy is learning the skills to speak up confidently.

Self-advocacy is understanding who you are as a person.

[10] The Mental Capacity Act

11 Definitions from People Frist Independent advocacy

Self-advocacy is knowing your rights and responsibilities.

Self-advocacy is about having self respect.

Self-advocacy is about speaking out for what you believe in.

Group Advocacy[12]

Group advocacy is where a group of people come together, to have their voices heard. This can be any group such as:

- A residents' or patients' group
- A self-advocacy group

All groups are made up of people with different skills and knowledge. People will all have a range of shared experiences as well.

In group advocacy everyone benefits from sharing and passing on information.

Group advocacy is about supporting each other (**peer support**)

Everyone is treated equally, and their needs are respected.

Group Advocacy can help build a person's confidence by knowing that their situation might not just affect them, it can affect other people too.

Group advocacy can inspire people to support others. People can then work together to achieve common goals.

Peer Advocacy[13]

Peer advocacy is about one or more people with 'something in common'.

This could be having the same diagnosis or disability. This could be having the same experience. These people are called peers. The peers can help the other person to speak up for themselves.

A peer advocate really understands the other person's situation. They can use this shared understanding to provide information and support.

This can either one to one or in a group.

Peer advocates can help the person 'speak up' for themselves. They can support them in meetings with professionals. They can speak with them. This helps others understand what that person is feeling or wants.

Peer advocates should have training to help them stay safe.

They should be provided with emotional support if they need it. They can be paid or volunteer. They can also be part of an advocacy group or an independent advocacy service.

12, Definitions from People Frist Independent advocacy

13 Definitions from People Frist Independent advocacy

A peer advocate can support someone in hospital. It is important that they are 'well' themselves and not in hospital. This is because if both people are unwell, it might make things worse for them.

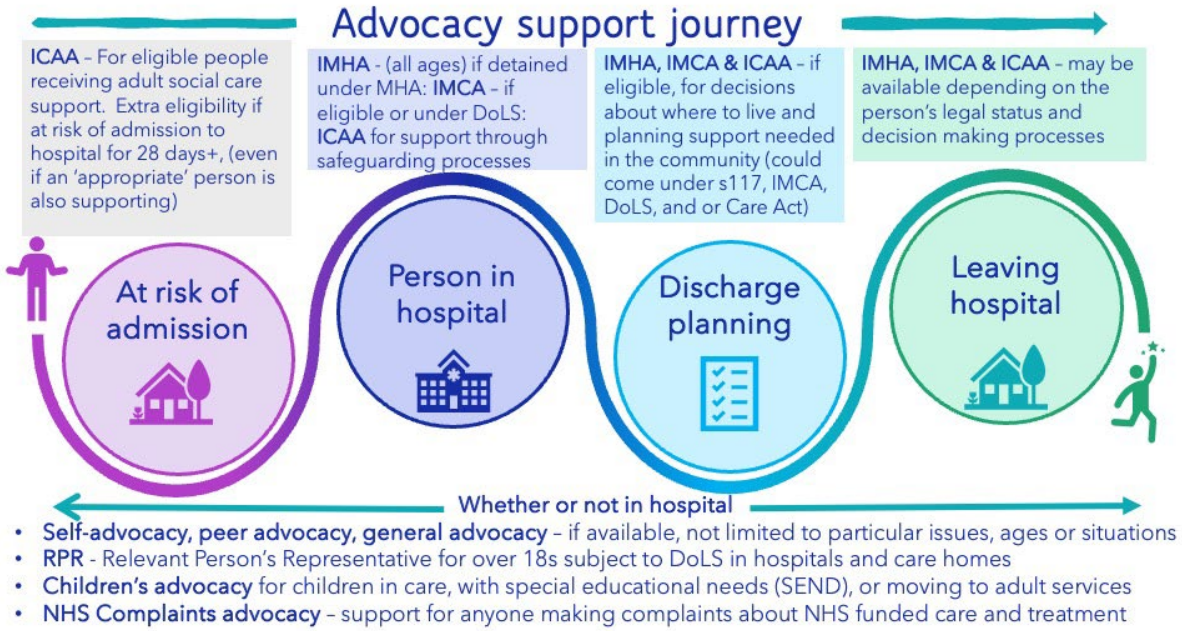
Informal Advocacy

Many people have friends and family who are natural allies in their lives. The term informal advocacy can be used to describe the advocacy role that people's friends and family members can take in their lives. Just because this advocacy isn't commissioned, doesn't mean it isn't highly important. It is. Friends and families are the people who know the individual best and are able to instinctively put forward what is important for the individual.

When to access different types of advocacy?

Different types of advocacy have different eligibility criteria, which means that people aren't always entitled to an advocates, even when they want or need one. Chapter 2.2 in the full report, goes into more depth about when people can access different types of advocacy and some of the challenges that this poses to people.

This graphic illustrates someone's journey from before they are admitted until after they leave hospital and shows what types of advocacy can be accessed and when.



Different types of advocacy in action

Here are some examples of how different types of advocacy can support people with a learning disability and autistic people who are inpatients.

This first story shows[14] how continuity and consistency can be achieved when one advocate provides all the one-to one advocacy someone draws upon. It also shows how people can access different types of statutory and non-statutory advocacy at different points in their life.

James is 28, loves football and goes to the park on most days to kick a ball about. His friends are also important to him, and he sees them 3-4 times a week.

He lives in a residential home with four other young people who have a learning disability and/or autism. James has a Deprivation of Liberty Safeguard because he cannot consent to his care arrangements and has at least one member of staff supporting him twenty-four hours a day. James has an advocate, Nadia, who acts as his paid RPR and visits him once a month in this capacity. When James has his Care Review, Nadia is also asked to be his Care Act Advocate to support him through the review and share his views about his care and support.

James experiences some unsettling changes and finds it hard to cope with these which causes his mental health to deteriorate. The staff where James lives are worried about him and James is admitted to hospital under a section of the Mental Health Act for support and treatment. A referral for an IMHA is made to the local advocacy IMHA service and Nadia is able to be James' IMHA, visiting him in hospital and ensuring he is okay. She helps him understand what is happening and helps him talk to the Dr.s and nurses. She can also help him to appeal his section if he wants to.

While he is in hospital James joins the patient's advocacy group that meets once a month.

When the time comes for James to be discharged from hospital Nadia is able to be James' IMHA and Care Act advocate during the discharge planning process. A decision is being made about where James should live after he is discharged and as James may move to live somewhere other than his previous home, an IMCA referral is made for James. Nadia is able to stay supporting and representing James as his IMCA in this decision. The decision is made for James to move to a new residential home where he will be under a new DoLS. Nadia will be James' IMCA39a advocate and continue to be James' RPR in the new home. She is also able to be his Care Act Advocate at his 6-week review.

After he has been discharged, James needs some advocacy support in relation to his finances and as the local advocacy services has some non-statutory advocacy funded, Nadia can support James with this too.

There is a self-advocacy group that meets near his new home and James joins the group.

[14] This story came from an advocacy provider who took part in the focus groups. Some details have been changed to protect anonymity.

This next example shows what Peer Advocacy for someone in hospital can look like:

*"A **peer advocate** came to visit me in hospital every week.*

They took time to get to know me.

They talked to me about how I was feeling and how things were going.

They understood how I was feeling and what changes I wanted to make.

They helped me talk to the staff on the ward and helped them see things differently.

They talked to me about when they were in hospital and what their life is like now.

*When I leave hospital, I want to be a **peer advocate**."*