

## Advocacy services for adults with health and social care needs

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the <u>Yellow Card Scheme</u>.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should <u>assess and reduce the environmental</u> <u>impact of implementing NICE recommendations</u> wherever possible.

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## Overview

This guideline covers advocacy for people using health and social care services in all adult settings (including young people under 18 using adult services). It describes how to commission and deliver effective advocacy, as well as identifying who should be offered advocacy (including who is legally entitled to it). It also covers monitoring and improving advocacy services, and training and skills for advocates and practitioners.

## Who is it for?

- Commissioners and providers of health and social care services, and of advocacy services
- Integrated Care Board
- Health and Wellbeing Boards
- Safeguarding Adults Boards
- Health and social care practitioners who work with advocates
- Advocates, including peer advocates, citizen advocates and professional advocates
- Training providers
- People using health or social care services, their families and carers and the public

It may also be of interest to regulators.

## Context

Advocacy helps to ensure that people's voices, wishes and preferences are heard, their rights are upheld and their needs are met, particularly when they have difficulty in speaking up for themselves or are concerned that they are not being heard.

An advocate helps someone with health and social care needs to express their needs and wishes, and to weigh up and take decisions about options available to them. Advocates can help people find services, make sure correct procedures are followed and challenge decisions made by councils, health services and other relevant health-based organisations. Advocacy helps protect human rights and plays a critical part in safeguarding. The advocate is there to represent the person's interests, which they can do by supporting them to speak, or by speaking on their behalf, including when the person is unable to instruct the advocate. (Adapted from the <u>Think Local, Act Personal Care and Support Jargon Buster</u>.)

This guideline covers advocacy delivered by a trained person whose sole engagement is to support the person and help ensure that their voice, needs and preferences are heard (referred to in law as 'independent advocacy'). Family members and friends play a vital role in the lives of people who draw on support, for example ensuring that the person's voice and concerns are heard. However, the focus of this guidance is on a trained person whose sole involvement is as an advocate.

Several Acts of Parliament specify the local authority's responsibility to ensure the provision of independent advocates and the situations in which they must make an advocate available. But many more people at certain points in their lives could benefit from access to the services of a trained advocate.

Little information is available about how many people access independent advocacy or how many independent advocates are currently operating. There is a widely held view that there is a shortage of advocates. The commissioning of advocacy services, their availability and the ongoing training and support of advocates varies significantly across the country, although the National Qualification in Independent Advocacy is widely recognised.

This guideline aims to help advocates and those who train and manage them, as well as those who commission their services and health and social care practitioners who interact

with them, by setting out key aspects of service quality. It will also be of interest to people who use advocacy services and their families and carers.

This guideline is relevant to people who need advocacy regardless of their condition or life circumstance. For more specific guidance about conditions or circumstances where advocacy is likely to be helpful, see the <u>NICE guidelines on decision making and mental capacity</u>, people growing older with learning disabilities, people experiencing <u>homelessness</u> and <u>safeguarding adults in care homes</u>.

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in <u>NICE's information on making decisions about your care</u>.

<u>Making decisions using NICE guidelines</u> explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

The recommendations in this guideline apply to both instructed and <u>non-instructed</u> <u>advocacy</u>. When providing non-instructed advocacy, advocates will need to take additional steps to determine as far as possible what the person's wishes, feelings and desired outcomes are likely to be, to best represent the person.

If the person lacks the capacity to instruct an advocate, advocates will need to act based on the person's likely wishes, feelings and desired outcomes.

## 1.1 Legal right to advocacy

- 1.1.1 Advocacy must be offered according to the relevant legislation. The criteria for when and to whom to offer it are described in the:
  - <u>Care Act 2014</u> and the <u>Care and Support statutory guidance</u> for independent advocates for people using social care services
  - <u>Mental Capacity Act 2005</u> and its <u>Code of Practice</u> for independent mental capacity advocates
  - <u>Mental Health Act 1983</u> and its <u>Code of Practice</u> for independent mental health advocates.
- 1.1.2 Local authorities must make appropriate arrangements for independent advocacy services to provide assistance to people making or intending to make complaints as described in the <u>Health and Social Care Act 2012</u>.

For a summary, see box 1 on the legal entitlement to advocacy, as well as supporting information and resources on the <u>Social Care Institute for</u> <u>Excellence's information on advocacy</u>.

For more guidance on helping people to make complaints, see the <u>NICE</u> guidelines on patient experience in adult <u>NHS</u> services and <u>service</u> user <u>experience</u> in adult mental health.

Box 1 Legal entitlement to advocacy

Adapted from the <u>Care Act 2014 statutory guidance</u>, the <u>Mental Capacity Act Code of</u> <u>Practice</u>, the <u>Mental Health Act 1983: Code of Practice</u> and the <u>Health and Social</u> <u>Care Act 2012</u>.

#### Care Act 2014

From the point of first contact, the local authority must appoint an independent advocate if an adult would experience substantial difficulty in any of these 4 areas:

- understanding the information provided
- retaining the information
- using or weighing up the information as part of the process of being involved
- communicating the person's views, wishes or feelings.

#### And

There is thought to be no one appropriate and independent to support and represent the person, for the purpose of facilitating their involvement.

This applies to adults taking part in:

- a needs assessment
- a carer's assessment
- preparing a care and support or support plan
- revising a care and support or support plan
- a child's needs assessment
- a child's carer's assessment
- a young carer's assessment
- a safeguarding enquiry

- a safeguarding adult review
- an appeal against a local authority decision under Part 1 of the Care Act (subject to further consultation).

#### Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014

The Care and Support (Independent Advocacy Support) (No. 2) Regulations is a Statutory Instrument, which adds to the Care Act 2014 section 67(2). It extends the circumstances in which a person is entitled to an independent advocate to where an assessment or plan is likely to result in a hospital stay of more than 28 days or a stay in a care home for more than 8 weeks (although there are some exceptions).

#### Mental Capacity Act 2005

An independent mental capacity advocate (IMCA) must be instructed, and then consulted, for people lacking capacity who have no one else to support them (other than paid staff), whenever:

- an NHS body is proposing to provide serious medical treatment **or**
- an NHS body or local authority is proposing to arrange accommodation (or a change of accommodation) in hospital or a care home.

#### And

- the person will stay in hospital longer than 28 days or
- they will stay in the care home for more than 8 weeks.

An IMCA **may** be instructed to support someone who lacks capacity to make decisions concerning:

- care reviews, if no one else is available to be consulted
- adult protection cases, whether or not family, friends or others are involved.

#### Mental Health Act 1983

People are eligible for support from an independent mental health advocate, irrespective of their age, if they are:

- detained under the Mental Health Act 1983 (excluding certain short-term sections)
- liable to be detained even if not actually detained, including those who are currently on leave of absence from hospital or absent without leave, or those for whom an application or court order for admission has been completed
- conditionally discharged restricted patients
- subject to guardianship
- subject to a community treatment order
- being considered for treatment under section 57 of the Act or, for under-18s, any treatment under section 58A.

#### Health and Social Care Act 2012

The 2012 Health and Social Care Act amendment to the 2007 Local Government and Public Involvement in Health Act.

The local authority must make arrangements for independent advocacy services to provide assistance to people making or intending to make a complaint:

- under a procedure operated by a health service body or independent provider
- section 113(1) or (2) of the Health and Social Care (Community Health and Standards) Act 2003
- to the Health Service Commissioner for England
- to the Public Services Ombudsman for Wales, which relates to a Welsh health body
- under section 73C(1) of the National Health Service Act 2006

- to a Local Commissioner under Part 3 of the Local Government Act 1974 about a matter which could be the subject of a complaint under section 73C(1) of the National Health Service Act 2006
- of such description as the Secretary of State may by regulations prescribe which relates to the provision of services as part of the health service and is made under a procedure of a description prescribed in the regulations, or gives rise, or may give rise, to proceedings of a description prescribed in the regulations.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on legal right to</u> <u>advocacy</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review A: who has a legal right to advocacy?
- evidence review E: enabling and supporting effective advocacy.

### 1.2 Who else may benefit from advocacy

1.2.1 Offer advocacy to people who are not covered by the legal entitlement but who would otherwise not be able to express their views or sufficiently influence decisions that are likely to have a substantial impact on their <u>wellbeing</u> or the wellbeing of someone they have caring or parental responsibility for. For a short explanation of why the committee made this recommendation and how it might affect practice or services, see the <u>rationale and impact section on who else</u> <u>may benefit from advocacy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review B:</u> who else would benefit from advocacy and how do we identify them?

## 1.3 Information about effective advocacy and signposting to services

- 1.3.1 Local authorities must meet the requirement of the Care Act 2014 to make information and advice publicly available about care and support services for adults in their area. This should include advocacy services.
- 1.3.2 Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should provide everyone legally entitled to advocacy (including young people who are using adult services) with information about their entitlement to advocacy and what this means. There should be proactive signposting to the information using accessible formats.
- 1.3.3 Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should provide everyone who would benefit from advocacy (whether or not they are legally entitled to it) with information about:
  - what advocacy services are available to them
  - how an advocate could help them
  - how to access and contact advocacy services.
- 1.3.4 Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should ensure that all information about advocacy is provided in a variety of ways to suit people's needs (including for family, friends and carers), using accessible formats where relevant. Examples include using interpreters, sign language and versions

such as Easy Read, large print, braille and audio. For more guidance on communicating and providing information, see the <u>NICE guideline on</u> <u>patient experience in adult NHS services</u> and the <u>NHS Accessible</u> <u>Information Standard</u>.

- 1.3.5 Local authorities, health authorities, NHS trusts, health and social care providers and advocacy services should repeat information about advocacy and how to access it at each key point in the person's interaction with health and social care.
- 1.3.6 If a person is offered healthcare, care or support out of their home area, the organisation arranging the placement should give them (and their family, friends or carers, as appropriate) information about the advocacy support available and help them to access it.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>information about effective advocacy and signposting to services</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review C: information about effective advocacy and signposting to services
- evidence review F: what does effective advocacy look like?

## 1.4 Improving access to advocacy

This section should be read alongside the section on training and skills for health and social care practitioners who work with advocates.

- 1.4.1 Health and social care providers should ensure that advocates can meet people in person to support them to make initial contact with advocacy services.
- 1.4.2 Health and social care providers in all settings, including hospitals, care

homes and prisons, should ensure that policies and procedures do not act as an obstacle to people accessing advocacy. This includes finding alternative methods to mitigate any risks, for example from infection.

- 1.4.3 If a person has been detained under the <u>Mental Health Act 1983</u> and has legal representation, they still have a legal right to advocacy and therefore mental health services must continue to facilitate access to independent mental health advocacy (IMHA) support. See the <u>section on</u> <u>legal right to advocacy</u>.
- 1.4.4 Commissioners and advocacy providers should make it easy for people to access advocacy by having:
  - flexible ways to make contact, including by self-referral
  - a simple process that directs people to the right advocacy support without them needing to know what type of advocacy they need (for example, a universal point of access).
- 1.4.5 Advocacy providers should aim to support continuity by offering people the same advocate for different types of advocacy (for example, statutory advocacy in line with the <u>Care Act 2014</u>, IMHA, independent mental capacity advocate [IMCA] and non-statutory advocacy). If this is not possible, they should ensure that systems for handover are in place that are not reliant on a new referral.
- 1.4.6 Independent mental health advocates should make regular visits to inpatient settings to identify people who would benefit from advocacy and help them to access it. This includes taking all necessary steps to ensure that people who would otherwise be unable to instruct an advocate, or who would find it particularly difficult, do not miss out on statutory advocacy services. Particular efforts should also be made to facilitate access to advocacy for people in isolation, seclusion or segregation.
- 1.4.7 Advocacy providers, hospital and health trusts and commissioners should offer IMHA on an <u>opt-out</u> basis so that everyone who is eligible meets an advocate and is offered the service.

- 1.4.8 Advocacy organisations should ensure that IMHA is offered at the earliest opportunity and then regularly afterwards to people who are eligible. This includes people who have initially declined support. For these people, advocacy organisations should explore, where appropriate, the reasons why the support was declined and what could be done to help them access advocacy.
- 1.4.9 IMHA services should raise awareness of disabled people's organisations and user-led organisations, <u>self-advocacy</u> groups or patient participation forums and promote <u>peer advocacy</u> and self-advocacy options.
- 1.4.10 Advocacy organisations should have a plan for how to ensure that their services are taken up by the people with the greatest need, who may not be able to ask for them.
- 1.4.11 Local authorities and advocacy providers should collaborate to make it clear how people can access advocacy and how they can provide support to help them to do so if they:
  - are supported outside of their home area or
  - are carers who care for someone outside their area.
- 1.4.12 Health and social care practitioners should ensure that people who are unable to ask for an advocate get advocacy when they are entitled to it.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>improving access to advocacy</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review D: improving access to advocacy
- evidence review E: enabling and supporting effective advocacy
- <u>evidence review G: partnership working and relationships with families and carers,</u> <u>commissioners and providers</u>
- evidence review H: planning and commissioning services for advocacy.

## 1.5 Enabling and supporting effective advocacy

- 1.5.1 Health and social care practitioners and other referrers should:
  - identify the need for advocacy as early as possible and
  - make a referral to an advocacy service without delay.
- 1.5.2 When the need for advocacy is identified, allow enough time:
  - to appoint an advocate if the person does not have one
  - to make any other arrangements, for example if the person needs an interpreter
  - for the advocate to help the person prepare before any meetings or discussions, and to ensure they understand the outcome afterwards.
- 1.5.3 Service providers should accommodate the availability of the advocate when planning and scheduling meetings, ward rounds or other situations where decisions are being made, including rearranging meetings where needed and practicable.

- 1.5.4 If people have not had enough time to prepare with their advocate before a meeting, their advocate should support them in requesting to rearrange the meeting.
- 1.5.5 Advocacy organisations should ensure that there is adequate time for the advocate and person to build relationships and trust according to their individual needs.
- 1.5.6 Service providers should ensure that people can have discussions with their advocates in a private area where they can talk in confidence without being overheard.
- 1.5.7 Health and social care practitioners should involve a person's advocate in all discussions with the person until a decision has been made and explained to the person, and they have had a chance to challenge the decision if they want to.
- 1.5.8 Health and social care practitioners should facilitate advocacy, for example by:
  - respecting the advocate's independence
  - sharing information appropriately with advocates
  - supporting the person and building good working relationships with them
  - encouraging and supporting ongoing contact between the person and their advocate
  - giving the person privacy to talk to their advocate
  - supporting people to understand about advocacy and to ask for the advocacy that they would want, or ask for it on their behalf if appropriate
  - responding to advocates in a timely manner
  - supporting any communication needs, such as arranging for an interpreter.
- 1.5.9 Health and social care providers should offer practical support to help people to communicate with their advocate remotely. This may include providing:

- access to computers, the internet and phones
- support to use technology
- help to schedule and remember meeting times.
- 1.5.10 Advocacy providers should use <u>digital platforms</u> to communicate with the person when necessary or the person prefers it, and only when it is safe, effective and appropriate to do so.
- 1.5.11 Health and social care practitioners responsible for decisions should ensure that all formal and informal concerns that are raised, by either the person or the advocate on their behalf, are understood, responded to and recorded.
- 1.5.12 Health and social care providers should periodically audit cases to assess whether referrals have been made to advocacy services in line with statutory duties.
- 1.5.13 If gaps in compliance (for example, people not being informed of their right to an advocate) are identified by audits, or otherwise, health and social care providers should develop action plans to improve compliance.
- 1.5.14 Local authorities and health and social care providers should consider including the numbers of referrals they make to advocacy services as a part of their corporate performance information.
- 1.5.15 Advocacy services should ensure that advocacy staff know when and how to report and act on safeguarding concerns.
- 1.5.16 Advocacy services should ensure that their advocacy staff are delivering effective safeguarding by:
  - having robust internal guidance
  - keeping detailed, accurate records that are written at the time of the discussion or event
  - appointing a safeguarding lead

- developing systems for tracking and monitoring concerns
- training, supervision and reflective practice
- providing input to local Safeguarding Adults Boards
- learning from adverse events
- continuing to advocate for the person throughout the process.

For more guidance on communicating and discussing complex information, see the <u>NICE guidelines on people's experience in adult social care services</u>, <u>patient experience in adult NHS services</u> and <u>shared decision making</u>.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>enabling and supporting effective advocacy</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review D: improving access to advocacy
- <u>evidence review E: enabling and supporting effective advocacy</u>
- evidence review F: what does effective advocacy look like?

### 1.6 Effective advocacy

1.6.1 Advocacy providers should ensure that their advocacy service is accessible, for example by:

- making face-to-face advocacy available unless this is not possible
- using remote advocacy if the person prefers this and it is effective
- operating outside normal working hours if possible as well as during them
- making referral processes simple, flexible and clear

- making referral forms easily available online
- ensuring that meeting places are accessible in all aspects
- clearly describing available services
- producing policies, procedures and publicity materials in accessible formats, including Easy Read
- meeting people's communication needs
- providing advocacy free of charge for people who are eligible
- making efforts (directly and indirectly through other organisations) to reach under-represented and underserved communities
- providing non-instructed advocacy.
- 1.6.2 Advocacy providers should ensure that their advocacy service is person centred, for example by:
  - ensuring that advocates are directed by the wishes and interests of the person they are advocating for
  - being non-judgemental and respectful of the person's needs, views, values, culture and experiences
  - avoiding and challenging stereotyping
  - supporting and helping the person to <u>self-advocate</u> as much as possible
  - supporting the person to choose their own level of involvement and the way they and their advocate work together to progress matters
  - enabling the person to lead and be involved in addressing the advocacy issue or decision-making processes
  - clearly agreeing with the person their advocacy needs, their impact and desired outcomes
  - only consulting, meeting or accepting information and documentation from third parties with the consent of the person, or if the person is unable to consent and it is in their best interests

- offering a choice of advocate (for example, gender and culture) for people seeking support.
- 1.6.3 Advocates should work with the person they are supporting to develop a shared understanding of what the person wants to achieve. They should discuss and agree with the person whether they have achieved the outcome they wanted and what to do if this does not happen, and review regularly.
- 1.6.4 When people lack capacity to instruct their advocate, advocacy providers should ensure that the advocacy remains person led and involves people with an interest in the person's welfare.
- 1.6.5 Advocacy providers should include people with lived experience of <u>health inequalities</u> or using health and social care or advocacy services in their organisation, for example, as paid advocates or as part of management committees or boards.
- 1.6.6 Advocacy providers must promote equality throughout their services for everyone with protected characteristics under the <u>Equality Act 2010</u>.
- 1.6.7 Advocacy providers should deliver effective advocacy in relation to safeguarding by supporting their advocates to:
  - be sensitive and alert to what the person is telling them and to observe the person's communications and circumstances to identify any safeguarding concerns
  - respond to concerns about poor practice that fall below the threshold for safeguarding
  - challenge decisions if safeguarding concerns have been raised but the local authority has decided they do not meet the threshold for action
  - continue to advocate for a person throughout any safeguarding processes
  - take action if they observe other safeguarding issues while they are advocating for a person
  - provide non-instructed advocacy.

- 1.6.8 Advocacy providers should ensure that the same advocate works with a person throughout the advocacy process, if possible and the person prefers it.
- 1.6.9 Advocacy providers should maintain independence from any other organisations the person is in contact with, to avoid any conflict of interest. Ways to do this include:
  - establishing themselves as a free-standing organisation with governance documents that promote and protect their independence
  - ensuring that their independence is clearly reflected in all publicity material, including on their website
  - ensuring that their service is structurally independent of any other services offered
  - developing an organisational culture that encourages advocates to challenge freely and as directed by the people they are working with
  - having a conflict of interests policy, keeping a register of conflicts that might influence board members, staff and volunteers, and ensuring that advocates are free from any conflicts of interest
  - actively seeking funding from more than 1 source
  - ensuring that funders, commissioners and external health and social care practitioners are not involved in organisational decisions such as how or by whom advocacy is delivered
  - putting in place engagement protocols that govern the organisation's interaction with other organisations.
- 1.6.10 Advocacy providers should, wherever possible, have advocates specialising in different types of advocacy and multi-skilled advocates who can provide different types of advocacy to the same person.
- 1.6.11 Advocacy services should ensure that they can provide access to interpretation and translation services when the person needs them.
- 1.6.12 Advocacy services should ensure that advocacy is culturally appropriate

by respecting and taking into account the person's cultural needs, preferences, customs or religious beliefs and experience of health inequalities.

- 1.6.13 Advocacy services should support their staff to develop <u>cultural</u> <u>competence</u> to meet the needs of the populations in their local areas, for example by training, supervision and <u>reflective practice</u>.
- 1.6.14 Advocates should maintain confidentiality, and explain the principles and the limitations of confidentiality in advance to people they are supporting. This should include:
  - what information will be shared, who with, and when and
  - when confidentiality may need to be breached, for example, to make a child or adult safeguarding alert or when required by law.
- 1.6.15 Advocacy providers should work together to promote best practice and consistency. This could be done, for example, by sharing learning, insight and tools, and developing joint publications, guidance and resources.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>effective advocacy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review F:</u> what does effective advocacy look like?

# 1.7 Partnership working and relationships with families, friends and carers, commissioners and providers

1.7.1 Advocates should liaise with family members, friends and carers when the person wants them to or when the person cannot express a view about this but it is in their best interests. This includes, for example, and where appropriate:

- seeking information from family members, friends and carers to help understand the person's circumstances, communication preferences, views and wishes
- sharing information with family members, friends and carers about the work that they are doing on the person's behalf.
- 1.7.2 Advocacy providers should be familiar with local support services, such as health, social care, education, employment support and community action, and what these services offer so that they can give up-to-date and accurate information to people accessing advocacy.
- 1.7.3 Safeguarding Adults Boards should ensure that they have input from advocacy providers, for example by having them as board members and giving them the opportunity to give feedback about services.
- 1.7.4 Commissioners should support advocacy providers to ensure that information is available to people who may use advocacy services, for example ensuring there is enough time in contracts to develop and provide the information in accessible formats.
- 1.7.5 Advocacy providers should work with commissioners and service providers to develop protocols that facilitate effective advocacy (for example, referrals, engagement and dispute resolution).
- 1.7.6 Commissioners of advocacy services should work with other local commissioners and commissioning bodies, and those in other geographical areas, to:
  - identify and address any current gaps in services
  - develop a long-term view of what advocacy services are needed and plan how to achieve this.
- 1.7.7 Practitioners should share relevant elements of individual risk assessments and safety plans with advocates to ensure their safety, and the safety of the people they support.
- 1.7.8 Health and social care providers and advocacy providers should ensure that their staff understand when and how advocates can access a

person's records, in line with legislation.

- 1.7.9 Commissioners of IMHA services should work in partnership with commissioners of mental health services to understand and maximise the impact of IMHA provision on mental health service development.
- 1.7.10 Advocacy providers and commissioners should work in partnership with other organisations to ensure culturally appropriate advocacy that meets local needs. For example, by:
  - providing advocacy as an integral part of wider Black community and voluntary sector mental health service
  - working closely with a south Asian community group to share insights and improve access to advocacy
  - providing mental health advocacy as a discrete casework advocacy service managed by a Black community and voluntary sector service
  - increasing the diversity of staff within advocacy services to reflect the local population
  - co-locating different types of advocacy services, for example, an African and Caribbean advocacy service located in the same community centre as a mental health advocacy service.
- 1.7.11 Advocacy providers should liaise with and facilitate the regulator in carrying out their role, including in inspecting regulated services.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>partnership working and relationships with families, friends and carers, commissioners and providers</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review G:</u> partnership working and relationships with families and carers, commissioners and providers.

## 1.8 Planning and commissioning services for advocacy

- 1.8.1 Commission advocacy services based on an assessment of local need, building on the Joint Strategic Needs Assessment and taking into account the effects of structural, systemic and <u>health inequalities</u> on the population, in co-production with people who use health and social care services.
- 1.8.2 Commissioning bodies in a locality should work together to agree and publish a long-term plan for advocacy based on the assessment of need. Commissioners should take into account the broad range of advocacy needs when planning and commissioning advocacy. This includes the need for statutory and non-statutory advocacy, <u>peer advocacy</u> and <u>self-advocacy</u>.
- 1.8.3 Consider commissioning advocacy services that can also be used by people who do not meet the criteria for statutory advocacy but could benefit from using them (see the <u>section on who else may benefit from advocacy</u>).
- 1.8.4 Consider taking into account wider public policies, strategy, legislation and guidance to inform advocacy commissioning decisions.
- 1.8.5 Local authorities and commissioners should engage with health and social care service providers and community stakeholders to help them understand and address gaps in advocacy provision, including their duty to develop the market under the <u>Care Act 2014</u>.
- 1.8.6 Commissioners and local authorities should involve people who use advocacy services in planning and designing advocacy services, including in monitoring contracts. For more guidance on involving people who use services, see the <u>NICE guideline on community engagement</u>.
- 1.8.7 Commissioners must ensure that sufficient advocacy services are available to meet statutory duties for people who are detained or deprived of their liberty in independent hospitals.

- 1.8.8 Commissioners should ensure that contracts support advocacy providers to maintain their independence and operate in line with advocacy principles, for example by avoiding caps on the number of hours an advocate can spend supporting someone.
- 1.8.9 When drafting contracts and specifications for advocacy services, commissioners should take account of the overall resources needed, so that providers have enough time and funding for advocates to undertake continuing professional development and training.
- 1.8.10 Consider the benefits of advocacy providers having an external quality accreditation, such as the <u>Quality Performance Mark</u>.
- 1.8.11 Commissioners should ensure that service specifications, service costs and contracts with advocacy service providers specify that the service should be person centred and based on the relationship between the person and their advocate. For example, specify that advocacy services:
  - allow the person to receive advocacy on issues that have a major impact on their health and social care needs
  - ensure adequate and long-term support for people in situations that place them at high risk (for example, risk of exclusion or abuse).
- 1.8.12 When planning and providing support, commissioners and advocacy providers should consider whether reasonable adjustments can be made to protect against or help the person deal with discrimination or inequalities arising from a person's protected characteristics as defined by the <u>Equality Act 2010</u>, or from other life circumstances and experiences such as health inequalities (see box 2).

Box 2 Characteristics, life circumstances or life experiences relating to inequalities

#### Protected characteristics of the Equality Act 2010

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation.

## Examples of life circumstances and experiences that could lead to discrimination or inequalities

- transitioning from children's to adult care services
- communication impairment
- learning difficulties
- learning disability
- poor literacy
- refugee status
- English not being a first language
- being an offender
- homelessness
- being from a Gypsy, Roma or Traveller community

- coercive control
- health inequalities.

Note: Some people could have multiple protected characteristics or life circumstances and experiences listed here and <u>intersectionality</u> may occur.

- 1.8.13 Commissioners and advocacy providers should consider working with local organisations that have the skills, knowledge and networks to help promote access to advocacy for underserved groups (for example, people with refugee status and people from Gypsy, Roma and Traveller communities).
- 1.8.14 When commissioning advocacy services, consider commissioning flexibility in services and a range of services so that:
  - providers can have multidisciplinary advocates or specific ones, depending on the needs of clients
  - services tailored to the local population are made available, for example, peer advocacy, family advocacy, group advocacy, statutory advocacy and nonstatutory advocacy.
- 1.8.15 Commissioners should ensure that the role of advocates in safeguarding is included in specifications when commissioning, developing policy and practice, and by promoting the value of advocacy in safeguarding people.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>planning and commissioning services for advocacy</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review D: improving access to advocacy
- evidence review F: what does effective advocacy look like?
- evidence review H: planning and commissioning services for advocacy
- evidence review I: training, skills and support for advocates
- evidence review K: monitoring services and collecting data for quality improvement.

### 1.9 Training, skills and support for advocates

- 1.9.1 Commissioners and advocacy providers should work with public bodies and providers to increase investment in training for advocates so that they are trained and competent to support people from a variety of backgrounds and with a variety of needs.
- 1.9.2 Advocacy providers should ensure that training, skills development and support for advocates covers the health, social care, housing, welfare and justice processes that are relevant to their role, so they can support people to navigate these services. These could include:
  - NHS continuing healthcare and other health-funded support
  - adult social care
  - personal budgets, personal health budgets and integrated personal budgets
  - personal independence payments
  - mental health services

- section 117 aftercare under the Mental Health Act 1983
- safeguarding procedures.
- 1.9.3 Advocacy services should provide training, skills development and support including induction, to their advocacy staff. Training could include:
  - core advocacy principles, for example those laid out in the Advocacy Charter
  - anti-oppressive practice and culturally appropriate advocacy training
  - communication, including specialised communication skills, for example communicating with people with a learning disability
  - identifying abuse or neglect
  - understanding human rights and how to promote them
  - <u>health inequalities</u>
  - making information available to people about how to make complaints, for example about health and social care services or local authorities
  - social skills, for example being approachable and building rapport
  - perseverance and tenacity
  - time management
  - managing expectations
  - confidence to challenge decisions
  - consistency
  - maintaining General Data Protection Regulation (GDPR) compliance, report writing and record keeping
  - understanding structural inequalities and intersectionality
  - equity, diversity and inclusion.
- 1.9.4 Advocates should complete the National Qualification in Independent

Advocacy.

- 1.9.5 Advocacy organisations should ensure arrangements are in place for the regular support and supervision of all advocates.
- 1.9.6 Training for advocacy staff should include when and how to use <u>non-instructed advocacy</u>.
- 1.9.7 Consider giving advocates who deliver non-instructed advocacy increased access to support, supervision and <u>reflective practice</u> to ensure their advocacy remains person led, independent and outcome focused.
- 1.9.8 Advocacy services should ensure any volunteer advocates are trained and given adequate support and supervision.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>training, skills and support for advocates</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review I: training, skills and support for advocates
- evidence review J: training and skills for practitioners who work with advocates
- evidence review K: monitoring services and collecting data for quality improvement.

## 1.10 Training and skills for health and social care practitioners who work with advocates

1.10.1 Providers and commissioners should ensure that information about advocacy is included in training for all health and social care practitioners at induction, with refresher training every 2 to 3 years or as needed, so that they understand:

- what advocacy is
- who is entitled to advocacy support under current legislation
- what advocacy support services are available locally in addition to those required by law
- when and how to request advocacy
- how to facilitate advocacy
- the role of the advocate in different settings and situations.
- 1.10.2 Providers and commissioners should ensure that staff who may be the first point of contact for people using health and social care services that regularly work with advocacy services (for example receptionists) understand:
  - who is entitled to advocacy support under current legislation
  - what additional advocacy is available locally
  - when and how to request advocacy.
- 1.10.3 Providers and commissioners should ensure that staff in organisations working with advocacy services (including social workers, members of Safeguarding Adults Board members and commissioners of advocacy) have training in the role and function of advocates. This includes understanding that advocates:
  - help people to get the support they need from services, for example by offering to attend meetings, writing letters and emails, and making phone calls
  - support the person to make decisions, for example by providing information about available support services, making sure people understand their options and exploring the potential outcomes of the possible options
  - represent only the views of the person they are supporting
  - ensure the person's voice is heard and their rights are respected in all discussions

- aim to empower the person to develop personal agency, <u>self-advocacy</u> and confidence
- are independent of any provider service
- share information they receive with the person they are supporting
- challenge decisions and poor practice
- know what to do about safeguarding
- have a role in protecting a person's rights and promoting <u>wellbeing</u>
- are involved in <u>non-instructed advocacy</u> and know what this is.
- 1.10.4 Providers of training on advocacy should:
  - tailor training to practitioners' roles and responsibilities
  - include people with lived experience of using advocacy services when designing and delivering training
  - be able to deliver training in different formats, including face-to-face, digitally (for example, as e-modules) and self-paced.
- 1.10.5 Health and social care providers should check that practitioners are using the knowledge and understanding of advocacy obtained through training, in their day-to-day practice, for example through supervision and <u>reflective practice</u>.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on training</u> and skills for health and social care practitioners who work with advocates.

Full details of the evidence and the committee's discussion are in:

- evidence review D: improving access to advocacy
- evidence review F: what does effective advocacy look like?
- evidence review J: training and skills for practitioners who work with advocates.

## 1.11 Monitoring services and collecting data for quality improvement

#### Agreeing outcomes

- 1.11.1 Advocacy service providers, commissioners, people who use advocacy services and other stakeholders should work together to agree:
  - what service-level outcomes should be achieved (for example, making sure people's voices are heard, improving people's experience of safeguarding, empowerment and reducing <u>health inequalities</u>)
  - how these outcomes will be reported (for example, information on outcomes could be separated out based on protected characteristics or other disadvantaged groups, such as those experiencing health inequalities).
- 1.11.2 Advocacy service providers and commissioners should work together to agree how they will record their progress against the service-level outcomes.
- 1.11.3 When monitoring advocacy services, advocacy providers and commissioners should measure outcomes that show the impact of advocacy on:

- people using an advocate (for example, to what extent they feel, or are, protected from harm, and the effects on their voice being heard, personal control and independence, their opportunities, challenging injustice and having their rights upheld)
- the health and care system (for example, the effects on the quality-of-service response and experience of people using it, person-led decision making and health inequalities)
- communities (for example, the effects on social inclusion; access to community services; and opportunities for people to contribute positively to society and get involved in their local community and engage with local forums, such as partnership boards and Safeguarding Adults Boards)
- the way advocacy services are run (for example, the effects on access to advocacy, governance and best practice; co-production; and how advocacy is delivered).

#### What data to collect

- 1.11.4 Commissioners should ensure that measuring outcomes or monitoring activity does not compromise the independence or integrity of the advocacy provider, or individual privacy.
- 1.11.5 Advocacy providers, in partnership with commissioners, should record anonymised information on people who use advocacy services, including:
  - protected characteristics in the Equality Act 2010
  - the main subject of advocacy support
  - identified health inequalities
  - communication need and preferences
  - reasons for referral
  - type of location or residence (such as urban, rural, care home or independent accommodation)

- whether the advocacy provided is instructed or non-instructed.
- 1.11.6 Advocacy providers should collect information about the impact of their services. Types of information include:
  - survey data (such as satisfaction with the service provided)
  - examples or short case studies describing how outcomes have changed as a result of advocacy
  - the number of people reporting a particular outcome or the proportion of people who achieved a particular outcome
  - detailed feedback on the experiences and views of people using advocacy services.
- 1.11.7 Local authorities and commissioners should monitor:
  - whether health and social care providers are telling people about advocacy and the criteria for accessing it and take steps where there are gaps in this
  - access to advocacy and take up of it by different populations in the local community.
- 1.11.8 Commissioners should check that advocacy providers have a robust method of quality assurance that monitors and reports on their quality of service.

#### How to collect data

- 1.11.9 Advocacy providers, in partnership with commissioners, should develop shared, consistent, practical and robust methods to record and collect information and data.
- 1.11.10 Advocacy providers, in partnership with commissioners, should tailor the formats and methods of seeking feedback about advocacy support to the person's communication needs and preferences.
- 1.11.11 Advocacy providers should find ways of gathering feedback that maximise the person's ability to provide that feedback anonymously and

without the input of the advocacy provider.

#### Evaluating and sharing data

- 1.11.12 Commissioners should use the outcomes, data and information on user demographics and the impact of advocacy services to evaluate the effectiveness and quality of current advocacy services and to plan future services.
- 1.11.13 Commissioners, advocacy providers and health and social care providers should work together to evaluate data they have collected on advocacy services. They should use this to make any changes that are needed to health, social care or advocacy services so that they meet the needs of all communities within the local population, including under-represented groups, those with protected characteristics or those experiencing health or other inequalities.
- 1.11.14 Commissioners and advocacy providers should share insights and key information on common trends and themes from data they have collected on advocacy services and issues affecting people using advocacy services with relevant stakeholders. For example, health and social care providers, voluntary and community sector organisations, the Care Quality Commission, Safeguarding Adults Boards, integrated care partnerships and boards and local Healthwatch.

#### Monitoring advocacy in safeguarding

- 1.11.15 Local authorities and commissioners should monitor how advocates are involved in supporting people experiencing safeguarding concerns.
- 1.11.16 Safeguarding Adults Boards should be assured that local authorities have auditing processes in place to monitor how people and their advocates are included in safeguarding processes.
- 1.11.17 Advocacy providers should report to Safeguarding Adults Boards on the extent to which partner organisations fulfil statutory duties for advocacy and safeguarding.

#### Adhering to statutory duties

- 1.11.18 Commissioners and health and social care providers should ensure that they:
  - consistently adhere to and monitor the statutory duties to refer to and involve advocacy
  - address failures in the duty to refer to statutory advocacy.

For a short explanation of why the committee made these recommendations and how they might affect practice or services, see the <u>rationale and impact section on</u> <u>monitoring services and collecting data for quality improvement</u>.

Full details of the evidence and the committee's discussion are in:

- evidence review F: what does effective advocacy look like?
- <u>evidence review G: partnership working and relationships with families and carers,</u> <u>commissioners and providers</u>
- <u>evidence review K: monitoring services and collecting data for quality</u> <u>improvement</u>.

## Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline. For other definitions, see the <u>NICE glossary</u> and the <u>Think Local</u>, <u>Act Personal Care and</u> <u>Support Jargon Buster</u>.

## Anti-oppressive practice

The phrase describes a critical examination of the impact of power, inequality and oppression on people. This could include examining an organisational structure while taking into account the wider social, cultural and political context. Anti-oppressive practice seeks to lessen the exclusion of certain social groups from social equality, rights and social justice.

Anti-oppressive practice may include:

- recognising the barriers that people might face, such as personal, cultural or structural barriers
- recognising a person's place in a structure or culture and how this might affect other people
- working to understand people's experience of oppression
- recognising people's attributes and contribution
- empowering people to realise their rights.

## **Cultural competence**

Cultural competence is the ability to understand and respond to a person's particular religious, cultural or language needs and experiences.

## **Digital platforms**

This describes digital spaces where communication can occur, or information can be exchanged, securely. This could include some social media.

## Health inequalities

Systematic, unfair and avoidable differences in health across the population and between different groups within society. They arise because of the conditions in which we are born, grow, live, work and age. These conditions influence our opportunities for good mental and physical health.

## Intersectionality

The interconnection of social categorisations such as age, disability, gender reassignment, pregnancy and maternity, marriage or civil partnership, race, religion or belief, sex and sexual orientation and other characteristics or experiences listed in <u>box 2</u>, creating unique overlapping and interdependent systems of discrimination or disadvantage.

## Non-instructed advocacy

When a person cannot communicate their views or wishes in a way that can be understood by other people, then advocates may use recognised approaches to ensure that what may matter most to the person is represented. Advocates will need to take additional steps to determine as far as possible what the person's likely wishes, feelings and desired outcomes are likely to be, to best represent the person. The advocate's role in non-instructed advocacy may include: upholding the person's rights; making sure that their likely concerns are recognised and responded to; ensuring access to support; and encouraging decisions to be taken based on what is important for the person, and challenging any that appear not to be. A person's ability to communicate what is important to them might fluctuate and advocates may move between using non-instructed advocacy and using instructed advocacy.

## Opt-out

Opt-out is when a person is automatically referred to the advocacy service unless they opt out of the referral. The opt-out system is designed to ensure that people who are eligible for advocacy are made aware of independent mental health advocacy services and have the opportunity to access them. An opt-out measure may overcome barriers to access.

## Peer advocacy

Peer advocates have lived experience and can support others with a similar disability or experience.

## **Reflective practice**

A process for staff to:

- reflect on previous practice
- talk about why they made the decisions they made, and why they acted or behaved in particular ways
- talk about their emotional responses to their actions and the actions of others
- engage in continuous learning.

Reflective practice may also provide insight into personal values and beliefs, and help staff understand how these influence action and decision making.

## Self-advocacy

The action of representing oneself or one's views or interests. This may be with respect to the care and support that people receive or the way that services are organised locally.

## Structural inequalities

The phrase refers to the inequalities that are systemically rooted in the normal operations of social institutions, in which different categories of people may not be seen as having equal status. This can result in the marginalisation of, or discrimination against, certain categories of people and manifest itself in areas such as unequal access to healthcare, housing or education.

## Wellbeing

The Care Act 2014 defines 'wellbeing' as a broad concept, relating to the following areas in particular:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal
- suitability of living accommodation
- the individual's contribution to society.

## **Recommendations for research**

The guideline committee has made the following recommendation for research.

## 1 Ways of providing advocacy services

What is the effectiveness and acceptability of providing advocacy through different approaches?

For a short explanation of why the committee made this recommendation for research, see the <u>rationale section on monitoring services and collecting data for</u> <u>quality improvement</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review K:</u> <u>monitoring services and collecting data for quality improvement</u>.

## **Rationale and impact**

These sections briefly explain why the committee made the recommendations and how they might affect services.

## Legal right to advocacy

Recommendations 1.1.1 and 1.1.2

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

The committee agreed that the legislation covering statutory entitlement to advocacy is complex and can be difficult to understand. Referring to guidance in legislation would make it easier for advocacy providers, health and social care practitioners and other referrers to find the information they need and help them to understand when they are legally required to offer advocacy.

#### How the recommendations might affect practice

The recommendations bring together statutory guidance. Any change in practice would be a result of becoming compliant with current legal requirements.

Return to recommendations

### Who else may benefit from advocacy

Recommendation 1.2.1

#### Why the committee made the recommendation

For more information about how this recommendation was developed, see the <u>section on</u> <u>developing the recommendations</u>.

The committee noted that advocacy was often mentioned in NICE guidance.

In their experience, the reasons that a person may benefit from advocacy are related to their circumstances or situation rather than their personal characteristics. Therefore, the committee focused on defining these circumstances.

#### How the recommendation might affect practice or services

The provision of non-statutory advocacy services varies widely across areas and service providers. Many areas have little or no provision beyond what is legally required. Therefore, investment is needed to expand the scope and range of services.

Although there was no economic evidence included in the evidence review for this topic, several published NICE guidelines recommended the use of non-statutory advocacy as it was considered both effective and cost effective in the populations they covered, because it reduced or prevented the need for medical or other interventions. The populations considered in those guidelines had a substantial overlap with the population covered here, so the results are likely to be generalisable to this guideline.

If people who would benefit from non-statutory advocacy do not receive it, their needs often eventually escalate to a point at which they meet the threshold for statutory provision. So, providing non-statutory advocacy often does not represent new costs, but rather costs incurred sooner. Given the lower level of need for this group, the time needed for advocacy is likely to be substantially lower than for statutory advocacy. It is likely to reduce unplanned hospital admissions and the need for residential care. This should also lead to a higher quality of life by addressing needs earlier and preventing escalation. This reduction in time needed should also free up capacity in the statutory advocacy system, although this may take a few years. This will reduce or remove the need for longer-term investment in services, especially in employing new advocates.

Return to recommendation

## Information about effective advocacy and signposting to services

Recommendations 1.3.1 to 1.3.6

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

Local authorities have a legal duty to make information available about the care and support services in their area, but the committee were aware that this does not always happen.

In the committee's experience, advocacy services are not widely known about and people are often unaware of their entitlement to advocacy. So, they do not access services. The committee agreed that providing this information should help to ensure that those with a legal entitlement to advocacy know about these services and can access them.

They also agreed that awareness of non-statutory advocacy services is particularly low. So, giving information to people who are not legally entitled to advocacy, but could benefit from it, is equally important. In their experience, if a publicly funded service is provided, there is also a duty to give people information to help them access it. The committee agreed that providing information about non-statutory advocacy would increase knowledge and uptake.

The Accessible Information Standard requires information to be given in accessible formats. The committee's experience is that this often does not happen for information about advocacy services. So, there is a risk of inequalities in access to both statutory and non-statutory advocacy. For example, people with communication difficulties might be less able to access services.

In the committee's experience, some people who initially decline an advocate later change their minds. Repeating information at different times means that the person has the knowledge and opportunity to use an advocate when they want to.

In the committee's experience, there is often confusion about who should provide information about advocacy services if someone is offered an out-of-area placement. They agreed that this responsibility needs to be clear.

#### How the recommendations might affect practice or services

There is a legal requirement for all advocacy services to provide information and

signposting. But there are inconsistencies in how well this is met in different areas. There may be some change in practice for those not fully compliant with statutory requirements. For example, information is not always given in a range of formats, so there will be a cost for areas not currently adhering to this requirement.

Providing information and signposting to people using out-of-area services will be a change in practice, because there is currently variation and confusion about who should do this. But implementing this recommendation is not expected to need extra resources.

Providing information about non-statutory advocacy services is currently not a legal requirement. But it will not need any additional resource use because it can be included on existing information sources, such as printed leaflets or online. There may be an increase in resource use from more people using non-statutory advocacy services.

Return to recommendations

### Improving access to advocacy

Recommendations 1.4.1 to 1.4.12

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

In the committee's experience, meeting in person was routine practice before the COVID-19 pandemic. But to reduce costs, many services have continued with remote meetings after restrictions have lifted. The committee discussed the benefits of advocates meeting with people in person to help them start using advocacy services. These include being able to see each other's body language, which is an important way of getting to know and understand each other, and it can speed up the process of developing trust. This is particularly important when people are accessing advocacy services for the first time. Furthermore, advocates physically being in the same space with the person can help them to raise issues that are usually unspoken or non-verbalised, for example safeguarding issues. They agreed that in-person meetings for the first contact would improve access for people who would otherwise be unwilling to use advocacy services. But they also noted that although in-person meetings were optimal, there are situations for which remote meetings using digital platforms could still be effective and some people may prefer them.

The committee were aware that advocates experienced difficulties accessing certain settings due to blanket restrictions. These increased during the COVID-19 pandemic (for example, limits on hospital and care home visiting). The committee agreed that access to an advocate was an essential part of upholding people's rights.

Having legal representation does not fulfil, or negate, the legal entitlement to advocacy. But in the committee's experience, there are often misconceptions that people do not need an independent mental health advocate if they have legal representation.

From their knowledge and experience, the committee were aware of difficulties with referrals, which are often sent back when the right information is not included. This delays access to services and may reduce service engagement. Based on the evidence and their experience, the committee agreed that making access easier may help hard-to-reach groups and improve empowerment and self-advocacy.

The evidence indicated that there can be problems with continuity and access when people transition between different types of advocacy. Effective advocacy depends on developing trust and mutual understanding between the advocate and the person receiving support, so keeping the same advocate (for example, by having multi-skilled advocates) is important. But when this is not possible, ensuring that systems are in place for handover will make it less likely that people are lost to services.

Healthcare practitioners should refer people for non-instructed advocacy if they need it, but in the committee's experience, this does not routinely happen. If independent mental health advocates are regularly present in inpatient settings, people are less likely to miss out on their statutory right to advocacy. The committee agreed that this could also have an important safeguarding effect, because it will give the advocates a comprehensive view of people's circumstances and environment.

The expert testimony highlighted barriers to access, such as lack of awareness or understanding and negative attitudes, and stated that an opt-out system for independent mental health advocacy (IMHA) could help to overcome these barriers. Based on their experience, the committee agreed that referrals are not always made when they should be and that offering advocacy on an opt-out basis is an effective way of ensuring access to statutory advocacy. In the committee's experience, late referrals to IMHA services do not give people enough time to arrange advocacy support or meet their advocates before key meetings or events. This means that they cannot participate fully and effectively in decision making. Ensuring that people are offered IMHA early will help to avoid this. The committee agreed that repeating the offer of an advocate would give people more opportunities to take up advocacy support if they need it, especially if they had declined the original offer. For example, people who were too unwell when advocacy was first offered or people whose circumstances changed.

Based on their own experience and evidence from the expert testimony, the committee agreed that raising awareness of service user groups and supporting peer and self-advocacy is important, because some people may prefer to seek advocacy from a peer rather than from a professional. People may feel better understood by, or more trusting of, people who have had similar experiences. Self-advocacy can also help the person to develop skills such as communication or decision making. This is in line with the advocacy ethos of supporting independence.

In the committee's experience, people with the greatest need for advocacy services may not be able to ask for them, and so they do not get the support they are entitled to. Based on the evidence, the committee agreed it was therefore important for advocacy organisations to have a plan to proactively offer support to people who may want to use the service.

Based on the evidence and the committee's experience, it is often unclear who is responsible for providing advocacy services when someone is supported out of their home area. This can form a barrier to accessing services and cause delays, potentially leading to ineffective advocacy. Under the Care Act 2014, local authorities have a duty to make information available about the care and support services in their area. This includes advocacy services. The committee agreed that, as part of this, it would be sensible to provide information about access to advocacy for people supported out of their home area. This would need collaboration with advocacy providers.

In the committee's experience, people who are unable to ask for an advocate often are not offered advocacy services, despite being entitled to them. They agreed that it was the responsibility of healthcare and social care practitioners to ensure that advocacy is provided for everyone who needs it, even if they are not able to ask.

#### How the recommendations might affect practice or services

During the COVID-19 pandemic, most meetings with advocates were by phone or videoconference. Increasing the number of in-person meetings, especially initial meetings, is likely to increase the average time of a meeting. It will also increase the need for advocate travel to levels at or near to those before the pandemic. In-person meetings may also increase the uptake of advocacy, again increasing costs. But there would be likely cost savings in the long term because greater uptake, and improvement in the quality of interactions, would result in identifying problems earlier. This would avoid costly medical interventions, such as unplanned admissions to hospital, and prevent duplicate or inappropriate referrals.

Remote meetings are likely to be less expensive, but if the added convenience increases uptake those cost savings will be reduced.

The removal of blanket restrictions should not increase resource use, apart from the effect of in-person meetings restarting. Most new places that advocates would visit would not need substantially more travel or time than existing venues. Although extra time may be needed for visiting prisons, to clear security protocols, this will only be relevant to a small percentage of visits.

Providing a simple process to access advocacy services will need some resources. But this is likely to mean shifting existing resources to fewer access points, rather than providing new ones. Cost savings should also occur from the economies of scale of having fewer access points, and a reduction in repeated or inappropriate referrals. Regular visits to inpatient settings by independent mental health advocates will be a change in practice in most places.

The committee agreed that providing continuity of access could have some upfront costs to employ multi-skilled advocates where these are not currently used, but this should be offset in part through more effective use of resources.

There is likely to be an increase in resource use from IMHA services making regular visits to hospital wards, both from the visits and from an increase in people using the service. Healthcare practitioners should already be making referrals for non-instructed advocacy, but in many places, this does not happen. Although it is likely to increase costs, savings are also likely to be made through improved safeguarding practices and through advocates obtaining a better understanding of peoples' needs. This should allow for better

management of needs, improving quality of life and preventing costly unplanned hospitalisations.

Providing an IMHA to people who are eligible for one is a legal requirement. But making access to IMHA opt-out rather than opt-in will mean that more people are aware of their right to access independent mental health advocates, and barriers to access (whether from process, lack of understanding or negative attitudes) will be substantially reduced. This is likely to increase access to those most in need of IMHA services, who may have had difficulty opting in, and to increase the number of meetings between advocates and people using their service. Although there is likely to be a significant resource impact in the short term, it will lead to improved access to advocacy services, and the benefits of these could offset costs in the longer term.

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## Enabling and supporting effective advocacy

Recommendations 1.5.1 to 1.5.16

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> on developing the recommendations.

The committee noted that the Care Act 2014 sets out who is legally entitled to have an advocate but that there is variation in how quickly this is currently determined. In the committee's experience, referrals to advocacy services are often made too late. This can mean the service does not have time to tailor meetings to the person's needs, for example communication needs. The committee also agreed that timely appointments mean the advocate can help the person prepare for meetings. They noted that delays to this would have a detrimental effect on the outcomes because advocacy helps people to take part effectively in decision making. From their knowledge and experience, the committee were aware that the inconsistency is partly because it is difficult to specify how much time is needed. This depends on the person's individual circumstances and needs, for example if they need an interpreter.

Many people who use an advocate have a statutory right to be represented at meetings. This is also crucial for non-statutory advocacy, so that people have their voices heard when decisions are being made. But in the committee's experience, the availability of the advocate is often not taken into account when arranging meetings. This may be because of other urgent commitments, competing demands and service pressures. The committee noted that checking advocate availability will make planning more efficient by reducing the need to reschedule meetings.

From their knowledge and experience, the committee were aware that delays in appointing advocates or not checking the availability of the advocate also put the person under time pressure. Lack of preparation time has a negative impact on the outcomes of meetings. So, the committee agreed it was important to give people the chance to rearrange meetings if they think that the time with their advocate was insufficient.

The committee agreed that building relationships and trust is a fundamental aspect of advocacy services. In their experience, effective advocacy is only possible when advocates have adequate time to build this relationship, so people feel comfortable sharing personal information and what is important to them. The committee were aware that the time it can take to build a trusting relationship could vary greatly based on individual needs, communication styles and personalities. Their experience was that this is often not factored in sufficiently when advocacy services are arranged.

The committee agreed on the importance of privacy and ensuring that people can talk to their advocate in private spaces, without being overheard. This promotes a trusting relationship and allows people to talk frankly about their goals, wishes and needs.

The committee discussed involving advocates in all discussions with the person. This promotes continuity of care, allowing the person using advocacy services to feel supported throughout the process. In the committee's experience, advocates are often only used during the decision-making process and less so after decisions have been made. But they noted that the discussions in meetings may sometimes be hard for the person to take in. This means that they may misinterpret what they have agreed to. The committee therefore decided that an advocate should be involved in all discussions (before and after meetings) to ensure that the person has understood fully what decisions have been made and the impact they may have, so that they have opportunities to challenge decisions and to raise any concerns.

The committee agreed that health and social care practitioners need to work collaboratively with advocacy services. This could facilitate decision making with the person in many ways. In the committee's experience, health and social care practitioners

are often busy and sometimes assume that once they have made a referral, that their job is completed. But their ongoing support is necessary to enable effective advocacy to take place. Based on their experience, the committee provided examples of how to facilitate advocacy effectively. They agreed that it is important to encourage practitioners and advocates to build good relationships from the start so that they can work together effectively and in the best interests of the person.

The committee agreed that for advocacy services to be effective, advocates need to be able to meet the person and resources need to be used efficiently. They also noted that virtual meetings have become common and that people may need support with the software to access such meetings. From their knowledge and experience, they were aware that more practical support is needed to help people communicate remotely with their advocate or help them access virtual meetings that may otherwise not go ahead or be postponed. The committee discussed that this could include access to the internet, support to use technology, and help when scheduling meetings. The committee were aware of a person's need for privacy while communicating remotely with their advocates. The committee discussed that digital platforms could help advocacy services to engage with people and therefore ensure they are regularly contacted, get timely updates and are informed and empowered.

The committee agreed on the vital role of advocates in supporting a person to have their voice heard. This includes ensuring that concerns raised by the person (or on their behalf) are not only listened to but are also interpreted in the way they are intended, are acted on and are noted in records. This can then be referred to in any future meetings and followed up for a response if necessary.

In the committee's experience, there is wide variation in referrals for statutory advocacy, and non-compliance with legal duties is common. They highlighted the need to audit and monitor advocacy services to identify gaps in service delivery. The committee recognised that if health and social care practitioners developed action plans, this would help to improve compliance, by having clear steps that need to be taken to bring advocacy services up to the standard required by the legislation. The committee also agreed that including the numbers of referrals in corporate performance information would help to highlight discrepancies between the amount of advocacy commissioned and the number of people supported.

The committee noted that advocacy services commonly deal with vulnerable people who may experience discrimination or abuse. If an advocate has reasonable cause to suspect a

person has experienced, is experiencing or is at risk of abuse or neglect, they must follow local safeguarding policies as set out in the Care Act (2014). But in the committee's experience, there is variation in advocates' knowledge of the actions required in these situations. Not acting in accordance with statutory safeguarding processes could have serious consequences.

The committee agreed that in their experience, the quality of safeguarding from advocacy providers varies and guidance is needed to ensure that safeguarding is effective, consistent and in line with legislation. They agreed that robust internal guidance would ensure providers consistently work to the required standard. Having effective governance, leadership, lines of communication and responsibilities also ensures that these processes are followed. The committee were aware that a safeguarding lead is already part of many local safeguarding policies but emphasised the need for this role to maintain good practice. The committee agreed on other examples that would ensure that staff know the relevant actions to take, so that they can prove that concerns have been raised and that actions have been taken. The committee also noted that safeguarding situations and related legislation are complex, and that training and supervision can help advocates feel confident in what to do if issues arise.

The committee noted that guidance on communicating and discussing complex information is covered by the NICE guidelines on people's experience in adult social care services, patient experience in adult NHS services and service user experience in adult mental health.

#### How the recommendations might affect practice or services

There is variation in how effectively advocacy is enabled and supported in different areas, so the impact on practice will vary. More advocacy hours will be needed to allow time and availability to help a person prepare before any meeting and ensure adequate arrangements are made, such as providing an interpreter if needed. Services may need to employ additional advocates. It may be possible to reallocate staff from other roles as services are streamlined and fewer meetings are repeated or decisions challenged.

Ensuring that service providers consider the availability of the advocate when planning and scheduling meetings is expected to lead to more productive meetings with less revisiting of decisions. This could lead to cost savings or free up resources.

Involving advocates until decisions have been communicated will need a reorganisation of

resources but is not expected to lead to additional cost or need for advocacy hours. There might also be some resources associated with rearranging meetings. But this might mean that meeting time is used more effectively, resulting in fewer decisions being challenged and resources being used more efficiently.

The type of information that gets audited may change, but this is not expected to need additional time or costs and will make data collection compliant with statutory requirements.

The guideline will reinforce best practice for health and social care workers facilitating advocacy and ensuring that advocates know how and when to act on safeguarding concerns.

Digital platforms are already in almost universal use since COVID-19. It is unlikely that further changes would be needed to this part of the service.

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## **Effective advocacy**

Recommendations 1.6.1 to 1.6.15

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

The committee agreed that people were more likely to access advocacy if organisations provided accessible services. Based on their knowledge and experience, they agreed on ways that advocacy providers could make their services more accessible, for example by making efforts to reach underserved communities. The committee agreed that access needs are not just physical but also involve the environment and location and the person's sensory needs. They also drew on their knowledge of the <u>Advocacy Charter</u> and <u>Quality</u> <u>Performance Mark</u> (QPM), to agree on ways to improve accessibility and tailor advocacy to the person's individual needs, for example physical or communication needs. This will enable the person to be fully involved in processes and meetings at which decisions are made.

The committee noted that providing person-centred services that adapt to each person's needs and circumstances is essential to effective advocacy. The committee agreed on specific suggestions for ensuring this, based on the advocacy QPM and their knowledge and experience. These included taking account of the person's views, values, culture and other experiences. The committee agreed that this individualised approach is vital to ensure that the person is comfortable and to help establish trust. The committee acknowledged that although it is an important part of making people comfortable and building relationships, offering people a choice of advocate might be difficult for some organisations, particularly smaller ones. Based on their experience, the committee agreed that the person-centred approach would have benefits beyond the effectiveness of the service. It would it also show other professionals and people using services what effective advocacy looks like, and what to expect from the service.

The committee agreed that a fundamental element of advocacy support is a shared understanding about what the person's optimal result would be. This allows the success of the advocacy to be assessed. But the committee were aware of variation in practice and the need to standardise good practice. They discussed the importance of advocates continually discussing and assessing goals and desired outcomes with the person, and agreed that everyone involved with advocacy needs to work together. They discussed that goals are recorded in initial meetings, but it is also important to discuss them each time and record any changes. Based on their experience, the committee acknowledged the challenges of such ongoing discussions if people lack capacity. But they agreed it is vital to make all possible efforts to establish the person's wishes and preferred outcomes. To ensure that the service is in the person's best interests, the committee agreed that it is important to involve other people who have an understanding of what the person would want (for example, family members or carers).

The committee discussed the benefits of actively involving people with lived experience of health inequalities or using health and social care or advocacy in designing and developing advocacy services. Having had the experience of using services could give them an understanding of what works and what the person needs from an advocate. This can ensure that services are more relevant and that they address needs sensitively and comprehensively. The committee agreed on the need to encourage services to get people with lived experience involved or to help them become advocates themselves.

The committee agreed it is essential to promote equality, equity of access, social inclusion and justice, and culturally relevant advocacy for all. Despite this being a legal requirement covered by the Equality Act 2010, the committee were aware of variations in service provision.

Based on knowledge of the Care Act 2014, the committee discussed the importance of providers supporting advocates to identify and raise safeguarding concerns. They stated that not carrying out advocacy effectively and in line with safeguarding policies would potentially expose the person to discrimination, abuse or neglect, but the role of advocacy in safeguarding is often not well understood. Based on the committee's expertise and experience of safeguarding, they agreed on suggested ways in which providers can achieve effective advocacy that meets their legal safeguarding duties. Despite the Care Act 2014 specifying that local authorities must appoint an independent advocate to support someone through a Safeguarding Adults Review, the committee were aware this does not always happen.

The committee discussed that people value continuity and consistency in their advocacy services. Effective advocacy depends on developing trust and a mutual understanding of the issues that are important to the person. The committee agreed that this takes time to develop. So, to help this, the committee decided that the advocate ought to remain constant for as long as the person needs advocacy (unless the person using the advocate wishes to change).

The committee agreed on the importance of people being confident that their advocate is independent, so they know they have their advocate's full support and that there are no conflicts of interest. So, they agreed on the need for clear protocols to ensure the independence of advocacy. They agreed specific examples of ways in which advocacy services can demonstrate their independence from other services.

Advocates with mixed skillsets, such as experience in different types of advocacy, are valuable when supporting a diverse range of clients. Some people may have needs in many areas and need support in multiple issues. Having a single advocate able to provide several types of advocacy can be more effective and promote continuity of care. This could help with consistency and improving the overall quality of their advocacy. The committee conceded that sometimes specialist advocates are needed for more specific support (for example, a specialist in supporting people who lack capacity). The committee also acknowledged that it may not always be possible for all advocacy providers to provide advocates with mixed skillsets.

Advocacy services need to address inequalities in access to services and in service provision. This includes issues such as language (for example, use of interpreters) as well

as consideration of any specific groups that may be disadvantaged or experience inequalities, such as taking into account a person's cultural needs and preferences.

Effective and accessible communication and language is essential for an advocate to gain an in-depth understanding of a person's wishes and preferences. Interpreters are important if the advocate does not share the person's same first language. A lack of interpreting and translation services often poses as a barrier when using advocacy services.

The committee also noted expert testimony on the importance of culturally appropriate advocacy, which extends beyond language. They discussed that culturally appropriate advocacy is critical to achieve equity and social justice, and to reach people who are already disadvantaged and underserved by services. But there is a lack of provision for people from minority cultural backgrounds. Advocates should already be knowledgeable about existing health inequalities and would use this knowledge to influence and improve their work. The testimony highlighted that if people perceive that services are culturally relevant, in terms of their own ethnic identity, this can create a sense of shared understanding and encourage access to that service. The possible gain from providing culturally sensitive advocacy therefore should be larger than for standard advocacy.

The committee were aware from their knowledge and experience that many of a person's wishes, needs and preferences will be influenced by their cultural or ethnic identity. Advocates need to be sensitive to this, and this is integral to good practice. The committee agreed this could be facilitated by supporting staff to develop cultural competence through training, supervision and reflective practice so that they are confident in speaking to people about preferences related to culture.

Based on the committee's knowledge of the <u>UK General Data Protection Regulation of the</u> <u>Data Protection Act 2018</u> as well as legal requirements related to safeguarding, they highlighted the importance of confidentiality and privacy in person-centred advocacy. These are requirements of advocacy and fundamental to building trusting relationships. From their knowledge and experience, the committee were aware that in practice, there are some complications, particularly with confidentiality. For example, an advocate must breach a person's confidence if there are safeguarding concerns or if it appears a law has been broken. The committee agreed the key was for advocates to be open about this, maintaining confidentiality and assuring people but also explaining the circumstances or conditions under which they may need to breach confidentiality in line with legal requirements. In the committee's experience, important aspects of professional relationships are sharing learning, insights and tools; and developing joint publications, guidance and resources. They agreed this improves collective effectiveness in the advocacy sector and helps to improve standards, provide consistency and sustain a drive towards best practice. It also encourages innovation and helps services develop new tools and techniques. Based on their experience, the committee agreed that smaller providers may have less capacity for this work, and competition for funding could act as a disincentive to share best practice. But they agreed it was still important to promote this joint learning and sharing.

#### How the recommendations might affect practice or services

The largest change in practice is likely to be in translation services and culturally appropriate advocacy. There may need to be investment in translation services, co-location of services and culturally appropriate advocacy. This will increase access for people who have been less likely to access advocacy or had poorer service because of communication difficulties or lack of sensitivity to cultural needs. This will reduce inequality and unfairness in accessing advocacy services and will increase their overall uptake.

Producing best practice and shared learning materials may have a resource impact in terms of the time needed to develop, quality assure and promote such tools. This may also need time from advocates to share their experiences and knowledge with others in writing or in other ways. This may be particularly difficult for smaller providers who may not have the advocate levels or facilities to produce such tools. But sharing best practice and promoting joint learning would lead to better advocacy with less repetition, challenges to decisions or need to repeat meetings. Such tools could also be used to promote cost-effective or cost-saving practices, leading to more efficient use of limited resources.

Providing a greater range of venues for in-person meetings may mean that advocates need to travel further and may increase hosting costs. Using digital platforms for remote meetings has become common practice since COVID-19.

Organisations may need to build extra capacity in services so that advocates have flexibility to work with different people according to a person's choice of advocate.

The recommendations will lead to changes in the number and range of people involved in designing advocacy services, and to changes in the information given to people about availability of and access to services. The way that goals are recorded and updated will

also be a change in practice in some areas. All of these can be achieved by reallocating existing resources and are not expected to need additional investment.

Having the same advocate throughout the process will need multi-skilled advocates to be available at the start of a person's contact with advocacy. This may mean moving or employing multi-skilled workers, resulting in upfront costs. There may be less need for multi-skilled advocates later in the process if duplication of meetings and the need for handovers are reduced.

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### Partnership working and relationships with families, friends and carers, commissioners and providers

Recommendations 1.7.1 to 1.7.11

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

In the committee's experience, families, friends and carers commonly report that advocacy services do not work collaboratively with them. Such cooperation could be beneficial to the person and their care when the person wants them to or when the person cannot express a view about this but it is in their best interests, for example to gain an understanding of the persons' views, preferences, and desired outcomes. This is particularly important when people may not be able to communicate this effectively themselves, for example people with learning disabilities and communication challenges or when people lack capacity.

The committee discussed the importance of advocates being aware of support services that are available in their area. This will ensure they can provide people with information about other local support that may be available to them. The committee agreed that advocates are not always up to date with this information. They highlighted that it would usually be on council websites because the Care Act 2014 requires local authorities to make information about care and support services, including advocacy services, publicly

available.

In the committee's experience, advocates could help raise awareness of issues, such as problems with referrals and difficulties people may have in accessing services, and the extent of such issues. They noted that Safeguarding Adults Boards might be unaware of all issues on the front line of services, and that raising awareness could improve services and safeguarding. Safeguarding Adults Boards engaging with advocacy providers could also raise the profile of advocacy, lead to less variation and support effective advocacy.

The committee acknowledged that people in need of advocacy services would not always know how to go about finding such services. They agreed on the need for commissioners to support advocacy providers giving this information. This could include allowing time in contracts for advocates to give information about which services are available, and how, where and when to access them, as well as for delivering advocacy.

From their knowledge and experience, the committee were aware that sometimes there can be tension between advocacy providers, commissioners and service providers when balancing the need to advocate for a person with providing safe and effective services. They discussed that procedures or protocols could provide clarity, including for service referrals and dispute resolution. They particularly noted the need for jointly developed protocols to facilitate positive and consistent working relationships between services. The committee were aware that this is consistent with the advocacy QPM, which also highlights the need for protocols for promoting services.

The committee discussed the benefits of commissioners collaborating with other commissioners and commissioning bodies, locally and in other areas. In their experience, working together is important for effective commissioning. It also encourages a long-term view that considers the future commissioning and provision of services. Working together could improve the consistency and quality of advocacy services across different areas, and reduce the likelihood of gaps between geographical areas or between different parts of the health and social care system. This would also help address geographical inequalities in access to services.

The committee agreed that advocates need to be protected if there is risk, because there is the potential for ineffective advocacy if the advocate or the person they support does not feel safe. But in their experience, risks are not always clearly communicated and shared between advocacy services and care providers.

In the committee's experience, advocates do not always know whether they are allowed to access a person's notes and what the legislation is in relation to information sharing. Health and social care providers may not routinely share information, so there is inconsistency in what is made available. The committee noted that the legislation on sharing information, such as the Data Protection Act 2018 is complex, and agreed on the need for health, social care and advocacy providers to ensure that their staff understand when and how advocates may access a person's records in line with legislation.

The committee discussed that commissioners of IMHA services and mental health services working in partnership would help coordinate services and provide a good interface between them. They agreed, based on their experience, that this would also help to identify gaps in services. And it would give commissioners of one service, input into commissioning decisions made by another, which could help to improve the quality of both.

The committee discussed the importance of all organisations working together to provide culturally appropriate advocacy that meets local needs. From their knowledge and experience, and based on the expert testimony, the committee noted that mainstream advocacy provision has a narrow focus. It often fails to take account of broader issues relevant to minority communities, leading to disadvantage. The committee noted that these issues include social disadvantage, lack of equality and diversity within the workforce, and inequalities in access to services and service provision.

The expert testimony specifically highlighted support for integrating or co-locating advocacy in other Black community and voluntary sector services. The committee agreed that these organisations could play a critical role in building relationships and partnerships and addressing social disadvantage. The testimony also supported increasing the diversity of staff in advocacy services if people express a preference for advocates who share their gender, language and culture. The committee agreed that this is important to break down barriers to accessing services and building trusting relationships, which would improve the effectiveness of advocacy.

The committee were aware that regulators may need the input of advocates in order to monitor the Mental Health Act in England. Access to advocacy is an area that could be looked at as part of the monitoring. Monitoring involves visits to institutions and interviews with staff, including IMHA. The committee agreed that advocacy providers should liaise with and facilitate the regulator in carrying out their role, including in inspecting regulated services.

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#### How the recommendations might affect practice or services

The level of partnership working and relationships with families, friends and carers, commissioners and providers is variable. But many of the recommendations reinforce legal requirements, so services in almost all areas already comply.

More effective partnership working would lead to cost savings from improving services, reducing repetition and complaints, and making services more efficient.

There would be some initial costs to establish collaborative services where these are not already set up. Many advocacy providers already work with local support services to ensure they are familiar with what these services can offer, but this does not happen consistently. This may need a reorganisation of resources in some areas but it is not expected to increase costs.

Making sure that advocacy providers have the time and resources to make patient information available, including information in a variety of formats, should reduce costs even if initial upfront investment is needed. Having correct and up-to-date information on advocacy services that is accessible will speed up access to advocacy, avoid duplication, and avoid people losing contact with advocacy services if their needs escalate.

Any decrease in the efficient use of resources would be more than compensated for by the reduction in inequality and increase in the fairness of society. The suggested actions may not be cost effective in all areas, so it would be up to individual service providers to decide how best to achieve the overall objectives.

There is currently a lack of continuity of advocacy providers liaising with and facilitating the regulator in carrying out their role, so the recommendation for closer working would lead to a change in practice. However, the Care Quality Commission has existing duties to assess the quality of care provided and need to assess if people have access to advocacy, which is not expected to result in further cost. Furthermore, this would ensure an improved feedback system, which in turn would lead to an improved quality of services and reduce costs in the long term.

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## Planning and commissioning services for advocacy

Recommendations 1.8.1 to 1.8.15

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

The evidence highlighted the need to improve the commissioning of advocacy services and suggested ways that this could be done. In the committee's experience, understanding the needs of the local population is essential when commissioning services to ensure that they are responsive to local needs and targeted at the people who need them. This approach to commissioning is considered best practice. But the committee highlighted that it is not mandated, so they wanted to place a greater emphasis on this approach to standardise effective, evidence-informed commissioning. Furthermore, this approach would help to ensure that advocacy services are commissioned in a way that would avoid the effects of structural, systemic and health inequalities, which result in unequal status, treatment and opportunities among population groups.

The committee agreed that there is currently a lack of evidence of long-term proactive planning for the development of advocacy, making it less likely that people will get the support they need in future. Having long-term plans based on assessment of need would ensure that service commissioning had clear long-term intentions and would be based on future local need.

The evidence highlighted that advocacy services tend to be commissioned only to meet legislative requirements. This means that people who have a genuine need for advocacy but fall outside the statutory requirements may have difficulty accessing it. In the committee's experience, commissioning advocacy services that can be used by people who do not meet the criteria for statutory advocacy would help to close the gap in provision, ensuring that more people benefit. The committee also agreed that this would facilitate earlier intervention at a lower level of need, which could prevent an escalation to situations in which statutory advocacy might be needed. Based on their experience, the committee agreed that commissioners need to be aware of policies, legislation and guidance beyond those that explicitly address statutory requirement for advocacy (for example, the Equality Act 2010). Advocacy services may need to change so that services are compliant with these wider requirements. The committee agreed that this would

ensure that commissioning decisions create advocacy services that are as comprehensive as possible, compliant with all legislation, meet a diverse range of needs and promote equality.

The Care Act 2014 and statutory guidance require local authorities to ensure adequate high-quality care and support is provided that meets the needs of the local population. The Care Act 2014 also includes the concept of market development, which means the local authority has a responsibility to ensure there are sufficient, good quality services available in their area. In the committee's experience, closer collaboration between local authorities, commissioners, health and social care service providers and community stakeholders would help to establish a clear picture of whether or not existing services are meeting local population needs, to ensure these requirements are fulfilled.

The evidence highlighted the need to involve people who use or are likely to use advocacy services in planning, designing and monitoring services. In the committee's experience, service user involvement happens in some areas but not consistently. The committee agreed that involving service users in planning, designing and monitoring helps ensure services are relevant and suited to people's needs and preferences. They were aware of guidance on this in the NICE guideline on community engagement so they agreed to make a cross reference to support implementation of this practice.

Based on their experience, the committee agreed that the provision of advocacy services for people who are detained or deprived of their liberty in independent hospitals is inconsistent. This is despite the fact that it is a legal requirement for local authority commissioners to provide advocacy to people in these circumstances. For example, there is currently very poor commissioning for people in private mental health settings.

In the committee's experience, people have different needs and therefore need different amounts of advocacy. Having overly restrictive contracts that specify what advocates can and cannot do and limit the amount of time advocates can spend with a person compromises the independence of the advocate, makes it difficult for them to work in line with the principles of advocacy and reduces the quality and effectiveness of the advocacy they provide.

The committee agreed that advocates need to undertake training and continuing professional development to be able to provide high-quality, effective advocacy. Contracts and specifications for advocacy providers need to include time allowances to make this possible but not all of them currently do so.

In the committee's experience, quality standards provide an important benchmark to measure performance against. This helps to promote a consistent, high-quality service and identify any improvements needed. The committee were aware that the advocacy QPM is a widely used quality assurance assessment. The QPM is given to organisations demonstrating excellent service provision in line with QPM standards, the <u>Advocacy</u> <u>Charter</u> and the <u>Advocacy Code of Practice</u>. The effectiveness of the QPM was not reviewed as part of this guideline so the committee did not recommend its use. But they agreed with the benefits of external quality accreditation.

In the committee's view, taking a person-centred approach is a key principle of advocacy. Embedding this in contracts and service specifications is essential in enabling advocacy services to be truly person centred. Based on the expert testimony and a report from the Care Quality Commission (recommending a level of personalised care that equated to intensive and long-term support), the committee gave examples of steps commissioners could take to ensure that services are person centred.

In the committee's experience, it is not possible to specify a particular way of developing service specifications and contracts that would ensure that services meet the needs of everyone. When planning and providing support, it is important to allow for reasonable adjustments that promote equality and avoid disadvantaging particular people. Doing this alongside the recommendations on training (see <u>section 1.9</u> and <u>section 1.10</u>), will ensure advocates have the dedicated time and space to deliver a person-centred service and to continuously enhance their skills, all of which is essential for maintaining quality and standards.

In the committee's experience, people are most comfortable with advocates they can relate to and trust, and this tends to lead to more effective advocacy. The expert testimony highlighted that a lack of diversity and understanding of equality and issues relevant to minority communities can form a barrier to people accessing, or taking up, advocacy services. The evidence highlighted that local organisations could be better placed to support access for potentially disadvantaged groups. The committee agreed that working with local organisations would help commissioners provide services tailored to the local population. This could help remove barriers to access for underserved groups, such as those with refugee status and people from Gypsy, Roma and Traveller communities.

The evidence highlighted the lack of suitable advocacy for people with complex needs, such as learning disabilities. The committee agreed that people's different advocacy

needs can be best met by offering a variety of advocacy models and commissioning services tailored to the local population. This includes commissioning services with advocates specialising in different types of advocacy and multi-skilled advocates.

The evidence highlighted the need to establish consistent good practice in safeguarding as part of the advocacy role. Advocacy is important in safeguarding because it supports people's involvement and decision making when there are safeguarding concerns, safeguarding enquiries or safeguarding adult's reviews. Involving someone independent from other services, who is representing the person's best interests and is aware of their circumstances and living conditions, can help to identify the potential for abuse or neglect, enabling concerns about service quality to be raised before they become a safeguarding issue. But in the committee's experience, advocates are not consistently involved in safeguarding processes.

#### How the recommendations might affect practice or services

There is already a statutory duty to make information about advocacy services available. This will remind services to comply if they do not already.

The Joint Strategic Needs Assessment already involves an element of forward planning. However, this does not include agreeing and publishing long-term plans for advocacy. Therefore, some change in practice will be needed to extend the timeframe over which planning takes place. There may be some upfront costs associated with commissioning bodies working in partnership to agree and publish long-term plans, but these plans would ensure that future resources are better allocated. Once the advocacy providers have longer contracts, the initial investment made would be retained as it would result in improved retention and a long-term workforce that would not need new training.

Active analysis of public policies, legislation and guidance may initially have a resource impact but will lead to more effective, efficient practice and will potentially save costs in the longer term. Changes in practice may also occur as a result of commissioning different or modified services in line with statutory requirements and lessons from shared learning.

There may be some upfront costs associated with involving people who use independent advocacy services in planning and designing the services, especially as some groups may be challenging to recruit from and may need interventions to help them actively participate. But this should lead to services being more responsive and efficient, and avoid wastage. This would lead to cost savings. It is also in line with the general move towards shared decision making in health and social care.

Although it is a legal requirement for commissioners to ensure there are sufficient advocacy services available for people who are detained in independent hospitals, this is not happening consistently. Where it is not currently happening, there will be some costs associated with it because more people would receive advocacy. But this is expected to lead to more efficient services, with better decisions being made, leading to cost savings in the long term.

Supporting advocacy providers to maintain their independence will lead to better quality service, reducing complaints and needs for judicial reviews, therefore saving costs in the long term. There may be some resource impact associated with engaging with the community and carrying out local needs assessments on which to base commissioning of advocacy services. But in most areas, this is already happening.

Not all contracts and specification for advocacy include time allowances for training and continuing professional development so some change in practice may be needed. But having advocates who are suitably trained and competent should result in fewer complaints, improved services and the ability to identify needs before they escalate.

Ensuring that advocacy services are person centred is not expected to have a resource impact. All health and social care services should already personalise care or treatment specifically for each person who uses the service.

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## Training, skills and support for advocates

Recommendations 1.9.1 to 1.9.8

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> on developing the recommendations.

In the committee's view, advocacy is still establishing itself in the consciousness of both the people who would benefit from using it and the practitioners who can make referrals to it. If it is to be effective, it is crucial that advocacy is recognised and valued. Advocates need to be able to support people from a variety of backgrounds and with different needs. So, they need to develop the appropriate skills, knowledge and behaviours to do this effectively. In the committee's experience, comprehensive and consistent training is the most effective way to achieve this. But there is variation in the current content and availability of training.

The committee agreed with evidence from <u>NICE's guideline on decision making and mental</u> <u>capacity</u> that an increase in investment in training for advocates would improve the availability and quality of advocacy.

The evidence highlighted several areas that advocates need to be trained in. In the committee's experience, advocates need knowledge and skills in these processes and areas to undertake their role effectively. In their experience, training for advocates is inconsistent, and the committee agreed that all training needs to be brought up to an agreed standard.

Statutory guidance to the Care Act (section 7.43) states that 'Once appointed, all independent advocates should be expected to work towards the National Qualification in Independent Advocacy within a year of being appointed, and to achieve it in a reasonable amount of time'. The committee noted that the statutory guidance is vague about the timeframe for achieving this qualification and in their experience, 'a reasonable amount of time' is interpreted very differently. The committee agreed that the quality of advocacy services would improve if all advocates achieved this qualification, although they could not recommend a specific timeframe because the statutory guidance does not stipulate one.

The committee agreed that supervision of advocates is crucial. It ensures consistency across services and that advocates are meeting the necessary standards. It also provides an opportunity for all advocates to develop skills and learn from others.

In the committee's experience, people who cannot instruct an advocate are less likely to have one. Therefore, providing non-instructed advocacy helps to ensure that people's rights to advocacy are protected. In the committee's experience, the skill and confidence of advocates in using non-instructed advocacy varies across the sector. Because non-instructed advocacy is used when someone needs an advocate but cannot tell the advocate what they want, the advocate's role is more challenging. Extra steps may be needed to determine the person's likely wishes, feelings and desired outcomes in the absence of instruction. The committee agreed that providing extra training and support for non-instructed advocates would improve practice in this area.

The committee agreed it is essential that volunteer advocates receive the same support and supervision as paid advocates. This will ensure that the services provided by volunteer advocates meet the necessary standard.

#### How the recommendations might affect practice or services

There are currently variations in the training that advocates are given on health and social care, justice, legal processes and skills needed for effective advocacy. The bespoke economic model for the guideline estimated that there would be an initial resource impact from improving training, especially when training takes advocates away from core duties for a long time. But there would be cost savings in the future from advocates working more efficiently and a reduction in complaints and repeated meetings. Better training for advocates would also lead to a higher quality of service. This would improve people's outcomes and quality of life, while reducing the number of expensive interventions such as unplanned admissions to hospital.

The economic model gave an upper estimate for costs involving a qualification needing a long period of training and study. Not all advocates will need training in all the processes and areas. The amount of training needed will depend on the role and responsibility of individual advocates and the needs of the population in their local area. Because there is already a requirement for all independent advocates to work towards the National Qualification in Independent Advocacy, this should not need additional resources.

Training in non-instructed advocacy is in line with the Care Act 2014 requirement for advocates to have appropriate training, so this should not have additional resource requirements.

Currently there are inconsistencies in the amount of training provided for volunteer advocates so there may be additional costs associated with this. The amount of training needed will depend on the role and responsibility of individual advocates and the needs of the population in their local area. It is not anticipated that all volunteer advocates will need training in all the processes and areas. Training volunteer advocates will ensure that the required service standard is met, and there might also be improvements from reduced complaints.

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## Training and skills for health and social care practitioners who work with advocates

Recommendations 1.10.1 to 1.10.5

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> on developing the recommendations.

It is a legal duty for an advocacy referral to be made when people are entitled to advocacy support, and people who cannot self-refer to advocacy rely on these referrals. In the committee's experience, the different statutory duties and eligibility criteria for advocacy are complex and difficult to understand, making it hard for practitioners to know who is entitled to an advocate. In the committee's view, training would be the most effective way of improving practitioners' knowledge about entitlement to advocacy support, so that they could comply with the legal requirements on referral.

To retain organisational and individual knowledge and prevent issues associated with staff turnover, the committee agreed that training about entitlement to advocacy should form part of induction training and be regularly refreshed. This would lead to consistent practice and referrals and increase effective practice. Refresher training every 2 to 3 years achieves a balance between the need to keep knowledge current and the time needed to attend training. The committee used the evidence to decide on the most important elements of training.

The committee agreed that staff who may be the first point of contact in health and social care services need to understand who is entitled to advocacy and when and how to request it so that people do not fall through the gaps at this early stage. In their experience, this understanding is not consistent across staff.

Staff in organisations working with advocacy services should receive training on the role and function of advocacy as part of their training. In the committee's experience, this is not consistent, which can lead to misunderstandings about advocacy, poor practice and negative working relationships. Having better knowledge would enable staff in organisations working with advocacy services to facilitate advocacy more effectively and improve working relationships. The committee used their experience of common misunderstandings about the role of advocacy to decide on what this training should cover.

Different health and social care practitioners will need different levels of training in advocacy, depending on their role. In the committee's experience, tailored training is more cost effective than providing the same training for everyone. The committee also agreed that delivering training in different formats should maximise its effectiveness. For example, it may be easier and more cost effective for people to access training remotely, at a time of their choosing, rather than attending fixed, face-to-face training sessions.

In the committee's experience, it is important to include people with lived experience of advocacy services in developing and delivering training for practitioners. Having real-life input can make the training more impactful and memorable, and increase the likelihood it will be implemented. People with lived experience are likely to have different priorities for what practitioners need to know and the gaps that exist in practice.

From their knowledge and experience, the committee were aware that the knowledge gained during training is not always implemented or used effectively in practice, and so this needs to be checked.

#### How the recommendations might affect practice or services

Some changes in practice or services may be needed. Health and social care practitioners should already be receiving training in legislation and the role of advocates, but this is delivered inconsistently. Refresher training is not routine and there is variation across regions in how much training is tailored. Although there may be some changes in practice needed to deliver training, there are existing materials that can be used which would minimise cost. This is especially true for refresher training where previous training materials can be reused and costs should be minimal. Not everyone will need the same depth of knowledge and amount of training, so the training can also be tailored to individuals for efficiency.

Training does not consistently include people with lived experience. For organisations that are not currently doing this, there is likely to be a change in practice. And there will be some costs from providing support to enable people with lived experience to take part in the training and share their experiences. This would improve the overall quality of training, making it more relevant and meaningful and help to improve practitioners' understanding of advocacy. This can help the right people access advocacy at the right time, and in the long term, could improve services.

Delivering training in a variety of formats may have some costs. But costs will be minimal if training is by self-directed learning or is delivered remotely.

Improved training for practitioners should help identify people who have a right to advocacy under current legislation. This will increase the total number of people accessing advocacy services, leading to a greater resource impact than the training itself, at least in the short term. But the increased access will be from people who have a legal right to advocacy services, so resources should already be in place to meet this statutory requirement. Better access to advocacy should also lead to better outcomes and less risk of needs escalating, leading to lower downstream costs and higher quality of life.

There may be some costs associated with ensuring that knowledge gained through training is applied in practice, for example from changing approaches to enable effective supervision, although these should be small and short term. But increased use of knowledge in practice should lead to improvements in the quality of service and a reduction in complaints and adverse outcomes, resulting in cost savings.

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## Monitoring services and collecting data for quality improvement

Recommendations 1.11.1 to 1.11.18

#### Why the committee made the recommendations

For more information about how these recommendations were developed, see the <u>section</u> <u>on developing the recommendations</u>.

#### Agreeing outcomes

In the committee's experience, advocacy providers need to have defined, service-level outcomes that can be measured to ensure that they are delivering an effective, highquality service. Many providers currently report key performance indicators as part of contracts and commissioning arrangements. But in the committee's view, these servicelevel outcomes should include more person-centred metrics (for example, whether people's voices are heard and the effect on empowerment). Input from people who use advocacy services and other stakeholders would help to achieve this. The committee also noted that collaboration between commissioners and advocacy providers when agreeing outcomes would reduce the likelihood of gaps occurring between geographical areas or people falling between different parts of the health and social care system.

The committee agreed it was important to be clear about how outcomes will be reported. This enables data to be analysed for protected characteristics or other disadvantaged groups, such as those experiencing health inequalities.

Currently, advocacy services tend to collect data on the impact of advocacy at an individual level. In the committee's experience, collecting data that also enables an understanding of population-level needs would assist the commissioning of more effective services and would align with developments in Health and Social Care services such as the move to Integrated Care Systems. Based on the evidence, they agreed areas for data collection that would help this.

#### What data to collect

The committee were aware that advocates sometimes face pressure from other services or commissioners to prioritise certain outcomes or not to raise concerns. Advocates are also sometimes asked for unnecessary information that could identify individual people, potentially breaching the Data Protection Act 2018 and damaging relationships between the advocate and the person they support. The committee agreed that commissioners need to be alert to these issues when collecting data.

In the committee's experience, there is variation in what information is collected about people using advocacy services, and information about the impact of advocacy services is not routinely collected in a standardised format. Collecting data in a standardised format makes it easier to evaluate, so that gaps in service provision can be identified and it can be seen whether services are meeting local needs. It also makes it easier to share key information with other organisations.

Based on the evidence, the committee agreed some important standard types of data to collect and suggested formats for doing so. The committee agreed that including protected characteristics would help identify whether there are particular groups that are not receiving services they would benefit from and help to reduce health and other

inequalities.

In the committee's experience, information about advocacy services is not provided consistently. Monitoring whether health and social care providers are doing this should help drive improvements in access to advocacy for those who need it. The committee were aware of wide discrepancies in how advocacy is commissioned in different areas, with some areas only commissioning statutory services rather than being responsive to local needs. Monitoring access to advocacy and take up of it would help to identify any groups who would benefit from advocacy services but are not currently using them. This could help address inequalities in access.

Because advocacy is an emerging field relative to other areas of health and social care, there are no evidence-based quality standards mandated for use. In the committee's experience, quality standards provide an important benchmark with which to measure performance. Having a robust method of quality assurance would help to promote a consistent, high-quality service and identify any improvements needed.

#### How to collect data

The information and data used by commissioners is diverse, and varies according to area and local need. The committee agreed that standardised data recording and collection methods, with the same type of information collected by different commissioners and in different areas, would produce data that is consistent and transparent. This would allow data to be compared across services, which may in turn help improve the quality of services.

In the committee's experience, getting feedback from the full range of people using advocacy services is necessary to ensure that services are responsive to the needs of the local population. They agreed that it may be necessary to support individual preferences and communication needs to get this feedback, but that doing so should give a better view of whether services are meeting needs and any necessary improvements. The committee also noted that the provider of the service is typically the point of contact for feedback and were keen to facilitate anonymous feedback to prevent any barriers to receiving feedback.

#### Evaluating and sharing data

In the committee's view, the monitoring data collected needs to be evaluated and used to

generate continuous improvement in services. From their knowledge and experience, the committee were aware that commissioners do not always use information gathered from advocacy services to inform improvements in practice. The committee also agreed that sharing this information with other organisations would help highlight gaps in provision, areas for improvement, trends and themes for service change. All of these would help to improve the quality of advocacy services.

#### Monitoring advocacy in safeguarding

There is a statutory requirement to involve an independent advocate to support people who are subject to a safeguarding enquiry or safeguarding adult review, as outlined in the statutory guidance to the Care Act 2014. In the committee's experience, advocates are not always informed about safeguarding concerns in a timely manner. The committee agreed that it is important to monitor the involvement of advocates to ensure that the legal duty is being upheld, and that processes are in place to do this. They also agreed that advocates are in a good position to recognise and report when this is not being done so that steps can be taken to address problems.

#### Adhering to statutory duties

From their knowledge and experience, the committee were aware that there is a longstanding issue of referrals for advocacy not being made when needed. They discussed that complying with statutory duties is essential to ensure that a person's rights are upheld. The committee agreed that commissioners have the power to help enforce this compliance, given that they are the ones responsible for funding and contracts.

#### **Recommendation for research**

Based on the evidence, and their knowledge about gaps in evidence and about the factors that make an advocacy service effective, the committee agreed that more information is needed about the effectiveness of advocacy delivered through different approaches. For example, advocacy delivered by an advocate with lived experience, or by an advocate with the same ethnicity as the person being supported (see the <u>recommendation for research on ways of providing advocacy services</u>).

#### How the recommendations might affect practice or services

Collecting data is not expected to lead to any long-term increase in resource use. Most

centres already have data collection and monitoring processes in place. There will be some short-term costs for services whose monitoring, data collection or quality assurance systems are not in line with the recommendations.

There will also be some upfront costs from initial meetings between advocacy services and commissioners to develop protocols or operating procedures.

Better and standardised monitoring, data collection and quality assurance should lead to more effective and efficient advocacy services with potentially large cost savings.

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# Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the <u>NICE</u> topic page on patient and service user care.

## Developing the recommendations

The recommendations were not developed by the usual NICE guideline systematic review process because it was not anticipated that evidence reviews would identify significant new published research on advocacy beyond that which has been identified in previous NICE guidelines. The committee used the nominal group technique to vote on statements relating to each area of the scope. The statements were based on documents received in response to a call for evidence and additional documents identified by the guideline committee, which underwent critical appraisal. The committee based the recommendations on these statements, recommendations from existing NICE guidelines, and their knowledge and experience.

For full details of the evidence and the guideline committee's discussions, see the <u>evidence reviews</u>. You can also find information about <u>how the guideline was developed</u>, including <u>details of the committee</u>.

## Putting the guideline into practice

NICE has produced <u>tools and resources to help you put this guideline into practice</u>. For general help and advice on putting our guidelines into practice, see <u>resources to help you</u> <u>put NICE guidance into practice</u>.

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## Accreditation

