1 2	NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE
3	Guideline
4	Advocacy services for adults with health and
5	social care needs
6	Draft for consultation, June 2022
7	

This guideline covers advocacy for people using health and social care services in all adult settings (including for young people under 18 if they are using adult services). The guideline describes how to commission and deliver effective advocacy, including identifying who should be offered advocacy (including who is legally entitled to it), providing good advocacy, monitoring and improving advocacy services, and training and skills in advocacy.

Who is it for?

- · Commissioners of health and social care services
- · Providers of health and social care services
- Providers of advocacy services
- 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

What does it include?

- the recommendations
- recommendations for research

- rationale and impact sections that explain why the committee made the recommendations and how they might affect services
- the guideline context.

Information about how the guideline was developed is on the <u>guideline's</u> <u>webpage</u>. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

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Context

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- 2 Advocacy helps to ensure that people's voices, wishes and preferences are heard;
- 3 their rights are upheld and their needs are met, particularly when they have difficulty
- 4 in speaking up for themselves or are concerned that they are not being heard.
- 5 An advocate helps someone with health and social care needs to express their
- 6 needs and wishes, and to weigh up and take decisions about options available to
- 7 them. Advocates can help people find services, make sure correct procedures are
- 8 followed and challenge decisions made by councils or other organisations. The
- 9 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 Think Local, Act Personal Care
- 12 <u>and Support Jargon Buster</u>.)
- 13 This guideline covers advocacy delivered by a trained person whose sole
- 14 engagement is to support the person and help ensure that their voice, needs and
- preferences are heard (referred to in law as 'independent advocacy').
- 16 Several Acts of Parliament specify the local authority's responsibility to ensure the
- 17 provision of independent advocates and the situations in which they must make an
- 18 advocate available. But many more people at certain points in their lives could
- 19 benefit from access to the services of a trained advocate.
- 20 Little information is available about how many people access independent advocacy
- 21 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
- 25 Advocacy is widely recognised.
- 26 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
- 28 who interact with them, by setting out key aspects of service quality. It will also be of
- 29 interest to people who use advocacy services and their families and carers.

Recommendations 1

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

Making decisions using NICE guidelines 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.

This guideline applies to England.

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- 3 The recommendations in this guideline apply to both instructed and non-instructed
- 4 advocacy. When providing non-instructed advocacy, advocates will need to take
- 5 additional steps to determine as far as possible what the person's wishes, feelings
- 6 and desired outcomes are likely to be, to best represent the person.
- 7 If the person lacks the capacity to instruct an advocate, advocates will need to act
- 8 based on the person's likely wishes, feelings and desired outcomes.

1.1 9 Legal right to advocacy

- 1.1.1 10 Advocacy must be offered according to the relevant legislation. The
- 11 criteria for when and to whom to offer it are described in the:
- 12 Care Act 2014 and the Care and Support statutory guidance for 13 independent advocates for people using social care services
 - Mental Capacity Act 2005 and its Code of Practice for independent mental capacity advocates
 - Mental Health Act 1983 and its Code of Practice for independent mental health advocates.
- 18 1.1.2 Local authorities must make appropriate arrangements for independent 19 advocacy services to provide assistance to people making or intending to make complaints as described in the Health and Social Care Act 2012. 20

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2	For a summary, see box 1 on the legal entitlement to advocacy, as well as
3	supporting information and resources on the Social Care Institute for
4	Excellence's information on advocacy.
5	
6	For more guidance on helping people to make complaints, see the <u>NICE</u>
7	guidelines on patient experience in adult NHS services and service user
8	experience in adult mental health.

9 Box 1 Legal entitlement to advocacy

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

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The 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).

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.

The 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.

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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</u> to advocacy.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

<u>A: legal right to advocacy; evidence review E: enabling and supporting effective</u>

<u>advocacy.</u>

1 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 wellbeing 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 this might affect practice or services, see the <u>rationale and impact section on who</u> <u>else may benefit from advocacy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>
B: who else may benefit from advocacy.

7 1.3 Information about effective advocacy and signposting to services

- 9 1.3.1 Local authorities must meet the requirement of the Care Act 2014 to make 10 information and advice publicly available about care and support services 11 for adults in their area. This should include advocacy services.
- 12 1.3.2 Local authorities, health authorities, NHS trusts, health and social care
 13 providers and advocacy services should provide everyone legally entitled
 14 to advocacy (including young people who are using adult services) with
 15 information about their entitlement to advocacy and what this means.

2 3 4	1.3.3	providers and advocacy services should provide everyone who would benefit from advocacy (whether or not they are legally entitled to it) with information about:
5		what advocacy services are available to them
6		how an advocate could help them
7		how to access and contact advocacy services.
8	1.3.4	Make all information about advocacy available in a variety of ways to suit
9		people's needs, both verbally and in writing. For example, provide
10		interpreters, sign language and accessible versions such as Easy Read,
11		large print and braille. For more guidance on communicating and
12		providing information, see the NICE guideline on patient experience in
13		adult NHS services and the NHS Accessible Information Standard.
14	1.3.5	Local authorities, health authorities, NHS trusts, health and social care
15		providers and advocacy services should repeat information about
16		advocacy and how to access it at each key point in the person's
17		interaction with health and social care.
18	1.3.6	If a person is offered an out-of-area placement, the organisation arranging
19		the placement should give them (and their family or carers, as
20		appropriate) information about the advocacy support available to help
21		them.

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 information about effective advocacy and signposting to services</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

C: information about effective advocacy and signposting to services; evidence

review F: effective advocacy.

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1	1.4	Improving access to advocacy
2	This sect	ion should be read alongside the <u>section on training and skills for health</u>
3	and socia	al care practitioners who work with advocates.
4	1.4.1	Health and social care providers should ensure that advocates can meet
5		people in person to support them to make initial contact with advocacy
6		services.
7 8 9	1.4.2	Health and social care providers in all settings, including hospitals, care homes and prisons, should help people to access an advocate regardless of blanket restrictions or policies that might prevent this.
10 11	1.4.3	Mental health services must continue to facilitate access to independent mental health advocacy (IMHA) support if a person has been detained
12		under the Mental Health Act 1983 and has legal representation, because
13		they still have a legal right to advocacy. See the <u>section on legal right to</u>
14		advocacy.
15	1.4.4	Commissioners and advocacy providers should make it easy for people to

16 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).
- 21 1.4.5 Advocacy providers should aim to support continuity by offering people
 22 the same advocate for different types of advocacy (for example, statutory
 23 advocacy in line with the <u>Care Act 2014</u>, IMHA and non-statutory
 24 advocacy). If this is not possible, they should ensure that systems for
 25 handover are in place that do not need 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. This
 includes people who would be unable to instruct an advocate and could
 potentially miss out on statutory advocacy services.

1 1.4.7 Advocacy providers should offer IMHA on an opt-out basis so that 2 everyone who is eligible meets an advocate and is offered the service. 3 1.4.8 Advocacy organisations should ensure that IMHA is offered at the earliest 4 opportunity and then regularly afterwards to people who are eligible, 5 including people who have initially declined support. 6 1.4.9 IMHA services should raise awareness of service user groups and 7 promote peer and self-advocacy options. 1.4.10 8 Advocacy organisations should have a plan for how to ensure that their 9 services are taken up by the people with the greatest need, who may not be able to ask for them. 10 1.4.11 11 Local authorities and advocacy providers should collaborate to make it 12 clear to people how they can access advocacy if they: 13 • are placed outside of their home area or 14 are carers who care for someone outside their area. 15 1.4.12 Health and social care practitioners should ensure that people who are 16 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 improving access to advocacy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

D: improving access to advocacy; evidence review E: enabling and supporting

effective advocacy; evidence review G: partnership working; evidence review H:

planning and commissioning services for advocacy.

17 1.5 Enabling and supporting effective advocacy

- 18 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	1.5.2	When the need for advocacy is identified, allow enough time:
2		to appoint an advocate if the person does not have one
3 4		 to make any other arrangements, for example if the person needs an interpreter
5		 for the advocate to help the person prepare before any meetings or
6		discussions, and to ensure they understand the outcome afterwards.
7	1.5.3	Service providers should take into account the availability of the advocate
8 9		when planning and scheduling meetings, ward rounds or other situations where decisions are being made.
10	1.5.4	If people have not had enough time to prepare with their advocate before
11		a meeting, their advocate should support them in requesting to rearrange
12		the meeting.
13	1.5.5	Advocacy organisations should ensure that there is adequate time for the
14		advocate and person to build relationships and trust according to their
15		individual needs.
16	1.5.6	Health and social care practitioners should involve a person's advocate in
17		all discussions with the person until a decision has been made and
18		explained to the person, and they have had a chance to challenge the
19		decision if they want to.
20	1.5.7	Health and social care practitioners should facilitate advocacy, for
21		example by:
22		respecting the advocate's independence
23		 sharing information appropriately with advocates and anyone else
24		supporting the person and building good working relationships with
25		them
26		encouraging and supporting ongoing contact between the person and
27		their advocate
28		giving the person privacy to talk to their advocate

1 2 3		 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
4		responding to advocates in a timely manner
5		 supporting any communication needs, such as arranging an interpreter
6	1.5.8	Service providers should ensure that people can have discussions with
7		their advocates in a private area where they can talk in confidence without
8		being overheard.
9	1.5.9	Health and social care providers should offer practical support to help
10		people to communicate with their advocate remotely. This may include
11		providing:
12		access to computers, the internet and phones
13		support to use technology
14		help to schedule and remember meeting times.
15	1.5.10	Advocacy providers should use digital platforms (for example, social
16		media) to communicate with the person when it is effective and safe and
17		when necessary or the person prefers it.
18	1.5.11	Health and social care practitioners responsible for decisions should
19		ensure that all concerns that are raised, either by the person or the
20		advocate on their behalf, are understood, responded to and recorded.
21	1.5.12	Health and social care providers should periodically audit cases to assess
22		whether referrals have been made to advocacy services in line with
23		statutory duties.
24	1.5.13	If gaps in compliance (for example, people not being informed of their
25		right to an advocate) are identified by audits, or otherwise, health and
26		social care providers should develop action plans to improve compliance.
27	1.5.14	Local authorities and health and social care providers should consider
28		including the numbers of referrals they make to advocacy services as a
29		part of their corporate performance information.

1	1.5.15	Advocacy services should ensure that advocacy staff know when and how
2		to report and act on safeguarding concerns.
3	1.5.16	Advocacy services should ensure that their advocacy staff are delivering
4		effective safeguarding by:
5		having robust internal guidance
6		 keeping detailed, accurate records that are written at the time of the
7		discussion or event
8		appointing a safeguarding lead
9		 developing systems for tracking and monitoring concerns
10		• training, supervision and reflective practice
11		forming links to local Safeguarding Adults Boards
12		learning from adverse events
13		 continuing to advocate for the person throughout the process.
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15		For more guidance on communicating and discussing complex
16		information, see the NICE guidelines on people's experience in adult
17		social care services, patient experience in adult NHS services and
18		shared decision making.

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 enabling and supporting effective advocacy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

D: improving access to advocacy; evidence review E: enabling and supporting

effective advocacy; evidence review F: effective advocacy.

19 **1.6 Effective advocacy**

- 20 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

1		 operating outside normal working hours if possible as well as during
2		them
3		 making referral processes simple, flexible and clear
4		making referral forms easily available online
5		 ensuring that meeting places are physically accessible
6		clearly describing available services
7		 producing policies, procedures and publicity materials in accessible
8		formats, including Easy Read
9		meeting people's communication needs
0		 providing advocacy free of charge for people who are eligible
11		 making efforts (directly and indirectly through other organisations) to
12		reach under-represented and underserved communities
13		 providing <u>non-instructed advocacy</u>.
14	1.6.2	Advocacy providers should ensure that their advocacy service is person
15		centred, for example by:
16		ensuring that advocates are directed by the wishes and interests of the
17		person they are advocating for
8		• being non-judgemental and respectful of the person's needs, views,
9		values, culture and experiences
20		avoiding and challenging stereotyping
21		 supporting and helping the person to self-advocate as much as
22		possible
23		• supporting the person to choose their own level of involvement and the
24		way they and their advocate work together to progress matters
25		 enabling the person to lead and be involved in addressing the
26		advocacy issue or decision-making processes
27		 clearly agreeing with the person their advocacy needs, their impact and
28		desired outcomes
29		only consulting, meeting or accepting information and documentation
30		from third parties with the consent of the person, or if the person is
31		unable to consent and it is in their best interests

2		people seeking support.
3 4 5 6 7	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.
8 9 10	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 2 3	1.6.5	Advocacy providers should include people with lived experience of health and social care or advocacy services in their organisation. For example, as paid advocates, or as part of management committees or boards.
15 16	1.6.6	Advocacy providers must promote equality throughout their services for everyone with protected characteristics under the Equality Act 2010 .
17 18	1.6.7	Advocacy providers should deliver effective advocacy in relation to safeguarding by supporting their advocates to:
19 20 21		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 respend to concerns about peer practice that fall below the threshold.
23 24		 respond to concerns about poor practice that fall below the threshold for safeguarding challenge decisions if safeguarding concerns have been raised but the
25 26 27		 local authority has decided they do not meet the threshold for action continue to advocate for a person throughout any safeguarding processes
28 29 30		 take action if they observe other safeguarding issues while they are advocating for a person provide non-instructed advocacy.
JU		▼ provide non-instructed advocacy.

1	1.6.8	Advocacy providers should ensure that the same advocate works with a person throughout the advocacy process, if possible and the person
3		prefers it.
4 5 6	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:
7 8 9 10 11 12 13 14 15 16 17 18 19 20 21		 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.
24 25 26	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.
27 28	1.6.11	Advocacy services should ensure that they can provide access to interpretation and translation services when the person needs them.
29 30	1.6.12	Advocacy services should ensure that advocacy is culturally appropriate by respecting and taking into account the person's cultural needs,

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1		preferences, customs or religious beliefs and experience of <u>health</u>
2		<u>inequalities</u> .
3	1.6.13	Advocacy services should support their staff to develop cultural
4		competence to meet the needs of the populations in their local areas. For
5		example, by training, supervision and reflective practice.
6	1.6.14	Advocates should maintain confidentiality, and explain the principles and
7		the limitations of confidentiality in advance to people they are supporting.
8		This should include:
9		what information will be shared, who with, and when and
10		• when confidentiality may need to be breached – for example, to make a
11		child or adult safeguarding alert or when required by law.
12	1.6.15	Advocacy providers should work together to promote best practice and
13		consistency. This could be done, for example, by sharing learning, insight
14		and tools, and developing joint publications, guidance and resources.
	For a sho	ort explanation of why the committee made these recommendations and
	how they	y might affect practice or services, see the <u>rationale and impact section on</u>
	effective	advocacy.
	Full deta	ails of the evidence and the committee's discussion are in evidence review
	F: effecti	ive advocacy.

15 1.7 Partnership working and relationships with families and 16 carers, commissioners and providers

- 17 1.7.1 Advocates should liaise with family members 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 might include, for example:
 - seeking information from family members and carers to help understand the person's circumstance, views and wishes
 - sharing information with family members and carers about the work that they are doing on the person's behalf.

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1	1.7.2	Advocacy providers should be familiar with local support services, such as
2		health, social care, education, employment support and community action,
3		and what these services offer so that they can give up-to-date and
4		accurate information to people accessing advocacy.
5	1.7.3	Safeguarding adult boards should think about ways of working with
6		advocacy providers to inform their strategic plan and annual report. For
7		example, by having them as board members, or giving advocacy
8		providers the opportunity to give feedback about services.
9	1.7.4	Commissioners should support advocacy providers to ensure that
10		information is available to people who may use advocacy services. For
11		example, ensuring there is enough time in contracts to provide the
12		information.
13	1.7.5	Advocacy providers should work with commissioners and service
14		providers to develop protocols that facilitate effective advocacy (for
15		example referrals, engagement and dispute resolution).
16	1.7.6	Commissioners of advocacy services should work with other local
17		commissioners and commissioning bodies, and those in other
18		geographical areas, to:
19		identify and address any current gaps in services
20		 develop a long-term view of what advocacy services are needed and
21		plan how to achieve this.
22	1.7.7	Practitioners should share relevant elements of individual risk
23		assessments and safety plans with advocates to ensure their safety, and
24		the safety of the people they support.
25	1.7.8	Health and social care providers and advocacy providers should ensure
26		their staff understand when and how advocates are able to access a
27		person's records, in line with legislation.

2	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.
4	1.7.10	Advocacy providers should work in partnership with other organisations to
5		ensure culturally appropriate advocacy that meets local needs. For
6		example, by:
7		providing mental health advocacy as an integral part of wider Black
8		community and voluntary sector mental health service
9		 providing mental health advocacy as a discrete casework advocacy
10		service managed by a Black community and voluntary sector service
11		increasing the diversity of staff within advocacy services to reflect the
12		local population
13		 co-locating different types of advocacy services, for example, an
14		African and Caribbean advocacy service located in the same
15		community centre as a mental health advocacy service.

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 partnership working and relationships with families and carers, commissioners and providers.</u>

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

<u>G: partnership working and relationships with families and carers, commissioners</u>

and providers.

16 1.8 Planning and commissioning services for advocacy

17 1.8.1 Commission advocacy services based on an assessment of local need,
18 building on the Joint Strategic Needs Assessment and taking into account
19 the effects of structural, systemic and <u>health inequalities</u> on the
20 population, in co-production with people who use health and social care
21 services.

1 2	1.8.2	Consider commissioning advocacy services that can also be used by people who do not meet the criteria for statutory advocacy but could
3		benefit from using them (see the section on who else would benefit from
4		advocacy).
5	1.8.3	Consider taking into account wider public policies, strategy, legislation and
6		guidance to inform advocacy commissioning decisions.
7	1.8.4	Local authorities and commissioners should engage with health and social
8		care service providers and community stakeholders to help them
9		understand and address gaps in advocacy provision, including their duty
10		to develop the market under the <u>Care Act 2014</u> .
11	1.8.5	Commissioners and local authorities should involve people who use
12		advocacy services in planning and designing advocacy services, including
13		in monitoring contracts. For more guidance on involving people who use
14		services, see the NICE guideline on community engagement.
15	1.8.6	Commissioners should ensure that contracts support advocacy providers
16		to maintain their independence and operate in line with advocacy
17		principles. For example, by avoiding caps on the number of hours an
18		advocate can spend supporting someone.
19	1.8.7	Include time allowances in contracts and specifications when
20		commissioning advocacy, so providers allow enough time for advocates to
21		undertake continuing professional development and training.
22	1.8.8	Consider the benefits of advocacy providers having an external quality
23		accreditation, such as the Quality Performance Mark.
24	1.8.9	Commissioners should ensure that service specifications, service costs
25		and contracts with advocacy service providers specify that the service
26		should be person centred and based on the relationship between the
27		person and their advocate. For example, specify that advocacy services:
28		allow the person to receive advocacy on issues that have a major
29		impact on their health and social care needs

1		 ensure adequate and long-term support for people in situations that
2		place them at high risk (for example, of exclusion or abuse).
3	1.8.10	When planning and providing support, commissioners and advocacy
4		providers should consider whether reasonable adjustments can be made
5		to protect against or help the person deal with discrimination or
6		inequalities arising from a person's protected characteristics as defined by
7		the Equality Act 2010, or from other life circumstance and experiences
8		such as <u>health inequalities</u> (see <u>box 2</u>).
9	Box 2 Ch	naracteristics, life circumstances or life experiences relating to
		·
10	inequalit	ties

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 circumstance 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

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- 2 1.8.11 Commissioners and advocacy providers should consider working with
 3 local organisations that have the skills, knowledge and networks to help
 4 promote access to advocacy for underserved groups (for example, people
 5 with refugee status and people from Gypsy, Roma and Traveller
 6 communities).
- 7 1.8.12 When commissioning advocacy services, consider commissioning 8 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 non-statutory advocacy.
- 14 1.8.13 Commissioners should ensure that the role of advocates in safeguarding 15 is included in specifications when commissioning, developing policy and 16 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 planning and commissioning</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

H: planning and commissioning services, evidence review D: evidence review F:

effective advocacy, evidence review I: training, skills and support for advocates;

evidence review K: monitoring services and collecting data for quality improvement.

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2	1.9	Training, skills and support for advocates
3	1.9.1	Commissioners and advocacy providers should work with public bodies
4		and providers to increase investment in training for advocates so that they
5		are trained and competent to support people from a variety of
6		backgrounds and with a variety of needs.
7	1.9.2	Advocacy providers should ensure that training for advocates covers the
8		health, social care, housing, welfare and justice processes that are
9		relevant to their role, so they can support people to navigate these
10		services. These could include:
11		NHS continuing healthcare and other health-funded support
12		adult social care
13		personal budgets
14		personal independence payments
15		mental health services
16		section 117 aftercare
17		safeguarding procedures.
18	1.9.3	Advocacy services should provide training, including induction training, to
19		their advocacy staff. Training could cover:
20		core advocacy principles, for example those laid out in the Advocacy
21		charter
22		anti-oppressive practice
23		• communication
24		identifying abuse or neglect
25		 understanding human rights and how to promote them
26		health inequalities
27		making information available to people about how to make complaints,
28		for example about health and social care services or local authorities

1 social skills, for example being approachable and building rapport 2 perseverance and tenacity 3 time management 4 managing expectations 5 confidence to challenge decisions 6 consistency 7 maintaining GDPR compliance, report writing and record keeping 8 understanding structural inequalities and intersectionality 9 equal opportunities and diversity. 1.9.4 10 Advocates should complete the National Qualification in Independent 11 Advocacy. 12 1.9.5 Advocacy organisations should ensure arrangements are in place for the 13 regular support and supervision of all advocates. 1.9.6 14 Training for advocacy staff should include when and how to use 15 non-instructed advocacy 16 1.9.7 Advocates delivering non-instructed advocacy may benefit from increased 17 access to support, supervision and reflective practice to ensure their 18 advocacy remains person led, independent and outcome focused. 19 1.9.8 Advocacy services should ensure any volunteer advocates are trained 20 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> training, skills and support for advocates.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

<u>I: training, skills and support for advocates; evidence review J: training and skills</u>

<u>for practitioners who work with advocates; evidence review K: monitoring services</u>

and collecting data for quality improvement.

1	1.10	Training and skills for health and social care practitioners
2		who work with advocates
3 4	1.10.1	Providers and commissioners should ensure that information about advocacy is included in training for all health and social care practitioners
5 6		at induction, with refresher training every 2 to 3 years or as needed, so that they understand:
7		who is entitled to advocacy support under current legislation
8 9		 what advocacy support services are available locally in addition to those required by law
10		when and how to request advocacy
11		how to facilitate advocacy
12		the role of the advocate in different settings and situations.
13 14 15 16	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:
17 18		 who is entitled to advocacy support under current legislation when and how to request advocacy.
19 20 21 22 23	1.10.3	Providers and commissioners should ensure that staff in organisations working with advocacy services (including social workers, members of Safeguarding Adult Board members and commissioners of advocacy) have training in the role and function of advocates. This includes understanding that advocates:
24		 help people to get the support they need from services, for example by
25		offering to attend meetings, writing letters and emails and making
26		phone calls
27		 support the person to make decisions, for example by providing
28		information about available support services, making sure people
29		understand their options and exploring the potential outcomes of the
30		possible options

1		 represent only the views of the person they are supporting
2		ensure the person's voice is heard and their rights are respected in all
3		discussions
4		• aim to empower the person to develop personal agency, self-advocacy
5		and confidence
6		are independent of any provider service
7		share information they receive with the person they are supporting
8		challenge decisions and poor practice
9		know what to do about safeguarding
10		 have a role in protecting a person's rights and promoting <u>wellbeing</u>
11		• are involved in <u>non-instructed advocacy</u> , and what this is.
12	1.10.4	Providers of training on advocacy should:
13		tailor training to practitioners' roles and responsibilities
14		include people with lived experience of using advocacy services when
15		designing and delivering training
16		• be able to deliver training in different formats, including face to face,
17		digitally (for example as e-modules) and self-paced.
18	1.10.5	Health and social care providers should check that practitioners are using
19		the knowledge and understanding of advocacy obtained through training,
20		in their day-to-day practice, for example through supervision and reflective
21		practice.

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> training and skills for practitioners who work with advocates.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

J: training and skills for practitioners who work with advocates; evidence review D:

improving access to advocacy; evidence review F: effective advocacy.

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improvement 2 3 Agreeing outcomes 4 1.11.1 Advocacy service providers, commissioners, people who use advocacy services, and other stakeholders should work together to agree: 5 6 what service-level outcomes should be achieved (for example making 7 sure people's voices are heard, improving people's experience of 8 safeguarding, empowerment and reducing health inequalities) • how these outcomes will be reported (for example, information on 9 10 outcomes could be separated out based on protected characteristics or 11 other disadvantaged groups, such as those experiencing health 12 inequalities). 13 1.11.2 Advocacy service providers and commissioners should work together to 14 agree how they will record their progress against the service-level 15 outcomes. 16 1.11.3 When monitoring advocacy services, advocacy providers and 17 commissioners should measure outcomes that show the impact of 18 advocacy on: 19 • people using an advocate (for example to what extent they feel, or are, 20 protected from harm, and the effects on: their voice being heard; 21 personal control and independence; their opportunities; and challenging 22 injustice, and having their rights upheld) 23 • the health and care system (for example the effects on: the quality of 24 service response and experience of people using it, person-led 25 decision making and health inequalities) 26 • communities (for example the effects on: social inclusion; access to 27 community services; and opportunities for people to contribute 28 positively to society and get involved in their local community and 29 engage with local forums, such as partnership boards and safeguarding

Monitoring services and collecting data for quality

adult boards)

1		 the way advocacy services are run (for example the effects on: access
2		to advocacy, governance and best practice; co-production; and how
3		advocacy is delivered).
4	What da	ata to collect
5	1.11.4	Commissioners should ensure that measuring outcomes or monitoring
6		activity do not compromise the independence or integrity of the advocacy
7		provider, or individual privacy.
8	1.11.5	Advocacy providers, in partnership with commissioners, should record
9		anonymised information on people who use advocacy services, including
10		 protected characteristics in the <u>Equality Act 2010</u>
11		the main subject of advocacy support
12		identified <u>health inequalities</u>
13		communication need and preferences
14		reasons for referral
15		 type of location or residence (such as urban, rural, care home or
16		independent accommodation)
17		whether the advocacy provided is instructed or non-instructed.
18	1.11.6	Advocacy providers should collect information on the impact that their
19		services have on society. Types of information could include:
20		survey data (such as satisfaction with the service provided)
21		 examples or short case studies describing how outcomes have
22		changed as a result of advocacy
23		• the number of people reporting a particular outcome or the proportion
24		of people who achieved a particular outcome
25		 the experiences and views of people using advocacy services.
26	1.11.7	Local authorities and commissioners should monitor:
27		whether health and social care providers are telling people about
28		advocacy and the criteria for accessing it

1 2		 access to advocacy and take up of it by different populations in the local community.
3 4	1.11.8	Commissioners should check that advocacy providers have a robust method of quality assurance that monitors and reports on their quality of
5		service.
6	How to	collect data
7	1.11.9	Advocacy providers, in partnership with commissioners, should develop
8 9		shared, consistent, practical and robust methods to record and collect information and data.
10	1.11.10	Advocacy providers, in partnership with commissioners, should tailor the
11		formats and methods of seeking feedback about advocacy support to the
12		person's communication needs and preferences.
13	1.11.11	Advocacy providers should find ways of gathering feedback that maximise
14		the person's ability to provide that feedback anonymously and without the
15		input of the advocacy provider.
16	Evaluat	ing and sharing data
17	1.11.12	Commissioners should use the outcomes, data and information on user
18		demographics and the impact of advocacy services to evaluate the
19		effectiveness and quality of current advocacy services and to plan future
20		services.
21	1.11.13	Commissioners, advocacy providers and health and social care providers
22		should work together to evaluate data they have collected on advocacy
23		services. They should use this to make any changes that are needed to
24		health, social care or advocacy services so that they meet the needs of all
25		communities within the local population, including under-represented
26		groups, those with protected characteristics or those experiencing health
27		or other inequalities.
28	1.11.14	Commissioners and advocacy providers should share insights and key
29		information on common trends and themes from data they have collected

1		on advocacy services and issues affecting people using advocacy
2		services with relevant stakeholders such as health and social care
3		providers, voluntary and community sector organisations, the Care Quality
4		Commission and Safeguarding Adult Boards.
5	Monitor	ing advocacy in safeguarding
6	1.11.15	Local authorities and commissioners should monitor how advocates are
7		involved in supporting people experiencing safeguarding concerns.
8	1.11.16	Safeguarding Adults Boards should be assured that local authorities have
9		auditing processes in place to monitor how people and their advocates
10		are included in safeguarding processes.
11	1.11.17	Advocacy providers should report to Safeguarding Adults Boards on the
12		extent to which partner organisations fulfil statutory duties for advocacy
13		and safeguarding.
14	Adherin	g to statutory duties
15	1.11.18	Commissioners should ensure that:
16		statutory duties on public bodies to refer to and involve advocacy are
17		consistently adhered to and monitored
18		failures in the duty to refer to statutory advocacy are addressed.
	For a sh	ort explanation of why the committee made these recommendations and

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 monitoring services and collecting data for quality improvement</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

F: effective advocacy; evidence review G: partnership working; evidence review K:

monitoring services and collecting data for quality improvement.

19

1 Terms used in this guideline

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

5 Anti-oppressive practice

- 6 The phrase describes a critical examination of the impact of power, inequality and
- 7 oppression on people. This could include examining an organisational structure while
- 8 taking into account the wider social, cultural and political context. Anti-oppressive
- 9 practice seeks to lessen the exclusion of certain social groups from social equality,
- 10 rights and social justice.
- 11 Anti-oppressive practice may include:
- recognising the barriers that people might face, such as personal, cultural or
- 13 structural barriers
- recognising a person's place in a structure or culture and how this might affect
- 15 other people
- working to understand people's experience of oppression
- recognising people's attributes and contribution
- 18 empowering people to realise their rights.

19 **Health inequalities**

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

24 Intersectionality

- 25 The interconnected nature 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
- 28 box 2, regarded as creating overlapping and interdependent systems of
- 29 discrimination or disadvantage.

Advocacy services: NICE guideline DRAFT (June 2022)

Non-instructed advocacy

1

- 2 When a person cannot communicate their views or wishes in a way that can be
- 3 understood by other people, then advocates may use recognised approaches to
- 4 ensure that what may matter most to the person is represented. Advocates will need
- 5 to take additional steps to determine as far as possible what the person's likely
- 6 wishes, feelings and desired outcomes are likely to be, to best represent the person.
- 7 The advocate's role in non-instructed advocacy may include: upholding the person's
- 8 rights; making sure that their likely concerns are recognised and responded to;
- 9 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
- 11 to communicate what is important to them might fluctuate and advocates may move
- between using non-instructed advocacy and using instructed advocacy.

13 **Reflective practice**

- 14 A process for staff to:
- reflect on previous practice
- talk about why they made the decisions they made, and why they acted or
- 17 behaved in particular ways
- talk about their emotional responses to their actions and the actions of others
- engage in continuous learning.
- 20 Reflective practice may also provide insight into personal values and beliefs, and
- 21 help staff understand how these influence action and decision making.

22 Structural inequalities

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

Wellbeing

28

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

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- 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
- 5 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

11 Recommendations for research

12 The guideline committee has made the following recommendation for research.

13 1 Ways of providing advocacy services

- 14 What is the effectiveness and acceptability of providing advocacy through different
- 15 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> quality improvement.

Full details of the evidence and the committee's discussion are in <u>evidence review</u>

K: monitoring services and collecting data for quality improvement.

16 Rationale and impact

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

19 Developing the recommendations

- 20 The recommendations were not developed by the usual NICE guideline systematic
- 21 review process because it was not anticipated that evidence reviews would identify
- 22 significant new published research on advocacy beyond that which has been

- 1 identified in previous NICE guidelines. The committee used the nominal group
- 2 technique to vote on statements relating to each area of the scope. The statements
- 3 were based on documents received in response to a call for evidence and additional
- 4 documents identified by the guideline committee, which underwent critical appraisal.
- 5 The committee based the recommendations on these statements, recommendations
- 6 from existing NICE guidelines, and their knowledge and experience.

7 Legal right to advocacy

- 8 Recommendations 1.1.1 to 1.1.2
- 9 Why the committee made the recommendations
- 10 For more information about how these recommendations were developed, see
- 11 developing the recommendations.
- 12 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
- 16 they are legally required to offer advocacy.
- 17 How the recommendations might affect practice
- 18 The recommendations bring together statutory guidance. Any change in practice
- 19 would be a result of becoming compliant with current legal requirements.
- 20 Return to recommendations
- 21 Who else may benefit from advocacy
- 22 Recommendation 1.2.1
- 23 Why the committee made the recommendation
- 24 For more information about how this recommendation was developed, see
- 25 developing the recommendations.
- 26 The committee noted that advocacy was often mentioned in NICE guidance.

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

4 How the recommendation might affect practice or services

- 5 The provision of non-statutory advocacy services varies widely across areas and
- 6 service providers. Many areas have little or no provision beyond what is legally
- 7 required. Therefore, investment is needed to expand the scope and range of
- 8 services.
- 9 Although there was no economic evidence identified for this topic, several published
- 10 NICE guidelines recommended the use of non-statutory advocacy as it was
- 11 considered both effective and cost effective in the populations they covered,
- 12 because it reduced or prevented the need for medical or other interventions. The
- populations considered in those guidelines had a substantial overlap with the
- 14 population covered here, so the results are likely to be generalisable to this
- 15 guideline.
- 16 If people who would benefit from non-statutory advocacy do not receive it, their
- 17 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
- 19 new costs, but rather costs incurred sooner. Given the lower level of need for this
- 20 group, the time needed for advocacy is likely to be substantially lower than for
- 21 statutory advocacy. It is likely to reduce unplanned hospital admissions and the need
- 22 for residential care. This should also lead to a higher quality of life by addressing
- 23 needs earlier and preventing escalation. This reduction in time needed should also
- 24 free up capacity in the statutory advocacy system, although this may take a few
- 25 years. This will reduce or remove the need for longer-term investment in services,
- 26 especially in employing new advocates.
- 27 Return to recommendations
- 28 Information about effective advocacy and signposting to services
- 29 Recommendations 1.3.1 to 1.3.6

1 Why the committee made the recommendations

- 2 For more information about how these recommendations were developed, see
- 3 <u>developing the recommendations</u>.
- 4 Local authorities have a legal duty to make information available about the care and
- 5 support services in their area, but the committee were aware that this does not
- 6 always happen.
- 7 In the committee's experience, advocacy services are not widely known about and
- 8 people are often unaware of their entitlement to advocacy. So, they do not access
- 9 services. The committee agreed that providing this information should help to ensure
- 10 that those with a legal entitlement to advocacy know about these services and can
- 11 access them.
- 12 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
- 14 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
- 16 access it. The committee agreed that providing information about non-statutory
- 17 advocacy would increase knowledge and uptake.
- 18 The Accessible Information Standard requires information to be given in accessible
- 19 formats. The committee's experience is that this often does not happen for
- 20 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
- 22 difficulties might be less able to access services.
- 23 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
- 25 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
- 27 information about advocacy services if someone is offered an out-of-area placement.
- 28 They agreed that this responsibility needs to be clear.

1 How the recommendations might affect practice or services

- 2 There is a legal requirement for all advocacy services to provide information and
- 3 signposting. But there are inconsistencies in how well this is met in different areas.
- 4 There may be some change in practice for those not fully compliant with statutory
- 5 requirements. For example, information is not always given in a range of formats, so
- 6 there will be a cost for areas not currently adhering to this requirement.
- 7 Providing information and signposting to people using out-of-area services will be a
- 8 change in practice, because there is currently variation and confusion about who
- 9 should do this. But implementing this recommendation is not expected to need extra
- 10 resources.
- 11 Providing information about non-statutory advocacy services is currently not a legal
- 12 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
- 15 services.
- 16 Return to recommendations
- 17 Improving access to advocacy
- 18 Recommendations 1.4.1 to 1.4.12
- 19 Why the committee made the recommendations
- 20 For more information about how these recommendations were developed, see
- 21 developing the recommendations.
- In the committee's experience, meeting in person was routine practice before the
- 23 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 can speed up the
- 28 process of developing trust. This is particularly important when people are accessing
- 29 advocacy services for the first time. They agreed that in-person meetings for the first

- 1 contact would improve access for people who would otherwise be unwilling to use
- 2 advocacy services. But they also noted that although in-person meetings were
- 3 optimal, there are situations for which remote meetings using digital platforms could
- 4 still be effective and some people may prefer them.
- 5 The committee were aware that advocates experienced difficulties accessing certain
- 6 settings due to blanket restrictions. These increased during the COVID-19 pandemic
- 7 (for example, limits on hospital and care home visiting). The committee agreed that
- 8 access to an advocate was an essential part of upholding people's rights.
- 9 Having legal representation does not fulfil, or negate, the legal entitlement to
- advocacy. But in the committee's experience, there are often misconceptions that
- 11 people do not need an independent mental health advocate if they have legal
- 12 representation.
- 13 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
- 16 evidence and their experience, the committee agreed that making access easier may
- 17 help hard-to-reach groups and improve empowerment and self-advocacy.
- 18 The evidence indicated that there can be problems with continuity and access when
- 19 people transition between different types of advocacy. Effective advocacy depends
- 20 on developing trust and mutual understanding between the advocate and the person
- 21 receiving support, so keeping the same advocate (for example, by having multi-
- 22 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.
- 24 Healthcare practitioners should refer people for non-instructed advocacy if they need
- 25 it, but in the committee's experience this does not routinely happen. If independent
- 26 mental health advocates are regularly present in inpatient settings, people are less
- 27 likely to miss out on their statutory right to advocacy. The committee agreed that this
- 28 could also have an important safeguarding effect, because it will give the advocates
- a comprehensive view of people's circumstances and environment.

- 1 The expert testimony highlighted barriers to access, such as lack of awareness or
- 2 understanding and negative attitudes, and stated that an opt-out system for IMHA
- 3 could help to overcome these barriers. Based on their experience, the committee
- 4 agreed that referrals are not always made when they should be and that offering
- 5 advocacy on an opt-out basis is an effective way of ensuring access to statutory
- 6 advocacy.
- 7 In the committee's experience, late referrals to IMHA services do not give people
- 8 enough time to arrange advocacy support or meet their advocates before key
- 9 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.
- 11 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
- 14 was first offered or people whose circumstances changed.
- 15 Based on their own experience and evidence from the expert testimony, the
- 16 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
- 18 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
- 20 also help the person to develop skills such as communication or decision making.
- 21 This is in line with the advocacy ethos of supporting independence.
- In the committee's experience, people with the greatest need for advocacy services
- 23 may not be able to ask for them, and so they do not get the support they are entitled
- to. Based on the evidence, they agreed it was therefore important for advocacy
- organisations to have a plan to proactively offer support to people who may want to
- 26 use the service.
- 27 Based on the evidence and the committee's experience, it is often unclear who is
- 28 responsible for providing advocacy services when someone is placed out of area.
- 29 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

8

- 1 advocacy services. The committee agreed that, as part of this, it would be sensible
- 2 to provide information about access to advocacy for people placed out of area. This
- 3 would need collaboration with advocacy providers.
- 4 In the committee's experience, people who are unable to ask for an advocate often
- 5 are not offered advocacy services, despite being entitled to them. They agreed that it
- 6 was the responsibility of healthcare practitioners to ensure that advocacy is provided
- 7 for everyone who needs it, even if they are not able to ask.

How the recommendations might affect practice or services

- 9 During the COVID-19 pandemic most meetings with advocates were by phone or
- 10 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
- 12 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
- 14 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
- 16 earlier. This would avoid costly medical interventions, such as unplanned admissions
- to hospital, and prevent duplicate or inappropriate referrals.
- 18 Remote meetings are likely to be less expensive, but if the added convenience
- 19 increases uptake those cost savings will be reduced.
- 20 The removal of blanket restrictions should not increase resource use, apart from the
- 21 effect of in-person meetings restarting. Most new places advocates would visit would
- 22 not need substantially more travel or time than existing venues. Although extra time
- 23 may be needed for visiting prisons, to clear security protocols, this will only be
- 24 relevant to a small percentage of visits.
- 25 Providing a simple process to access advocacy services will need some resources.
- 26 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
- 28 scale of having fewer access points, and a reduction in repeated or inappropriate
- 29 referrals. Regular visits to inpatient settings by independent mental health advocates
- 30 will be a change in practice in most places.

- 1 The committee agreed that providing continuity of access could have some upfront
- 2 costs to employ multi-skilled advocates where these are not currently used, but this
- 3 should be offset in part through more effective use of resources.
- 4 There is likely to be an increase in resource use from IMHA services making regular
- 5 visits to hospital wards both from the visits and from an increase in people using
- 6 the service. Healthcare practitioners should already be making referrals for non-
- 7 instructed advocacy, but in many places this does not happen. Although it is likely to
- 8 increase costs, savings are also likely to be made through improved safeguarding
- 9 practices and through advocates obtaining a better understanding of peoples' needs.
- 10 This should allow for better management of needs, improving quality of life and
- 11 preventing costly unplanned hospitalisations.
- 12 Providing an independent mental health advocate 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
- 16 negative attitudes) will be substantially reduced. This is likely to increase access to
- 17 those most in need of IMHA services, who may have had difficulty opting-in, and to
- 18 increase the number of meetings between advocates and people using their service.
- 19 Although there is likely to be a significant resource impact in the short term it will lead
- 20 to improved access to advocacy services, and the benefits of these could offset
- 21 costs in the longer term.
- 22 Return to recommendations
- 23 Enabling and supporting effective advocacy
- 24 Recommendations 1.5.1 to 1.5.16
- 25 Why the committee made the recommendations
- 26 For more information about how these recommendations were developed, see
- 27 developing the recommendations.
- 28 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
- 30 the committee's experience, referrals to advocacy services are often made too late.

- 1 This can mean the service does not have time to tailor meetings to the person's
- 2 needs, for example communication needs. The committee also agreed that timely
- 3 appointments means the advocate can help the person prepare for meetings. They
- 4 noted that delays to this would have a detrimental effect on the outcomes because
- 5 advocacy helps people to take part effectively in decision making. From their
- 6 knowledge and experience, the committee were aware that the inconsistency is
- 7 partly because it is difficult to specify how much time is needed. This depends on the
- 8 person's individual circumstances and needs, for example if they need an interpreter.
- 9 Many people who use an advocate have a statutory right to be represented at
- 10 meetings. This is also crucial for non-statutory advocacy, so that people have their
- 11 voices heard when decisions are being made. But in the committee's experience the
- 12 availability of the advocate is often not taken into account when arranging meetings.
- 13 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.
- 16 From their knowledge and experience, the committee were aware that delays in
- 17 appointing advocates or not checking the availability of the advocate also put the
- 18 person under time pressure. Lack of preparation time has a negative impact on the
- 19 outcomes of meetings. So, the committee agreed it was important to give people the
- 20 chance to rearrange meetings if they think that the time with their advocate was
- 21 insufficient.
- The committee agreed that building relationships and trust is a fundamental aspect
- of advocacy services. In the committee's experience, effective advocacy is only
- 24 possible when advocates have adequate time to build this relationship, so people
- 25 feel comfortable sharing personal information and what is important to them. The
- 26 committee were aware that the time it can take to build a trusting relationship could
- 27 vary greatly based on individual needs, communication styles and personalities.
- 28 Their experience was that this is often not factored in sufficiently when advocacy
- 29 services are arranged.
- The committee discussed involving advocates in all discussions with the person.
- 31 This promotes continuity of care, allowing the person using advocacy services to feel

- 1 supported throughout the process. In the committee's experience advocates are
- 2 often only used during the decision-making process and less so after decisions have
- 3 been made. But they noted that the discussions in meetings may sometimes be hard
- 4 for the person to take in. This means that they may misinterpret what they have
- 5 agreed to. The committee therefore decided that an advocate should be involved in
- 6 all discussions (before and after meetings) to ensure that the person has understood
- 7 fully what decisions have been made and the impact they may have, so that they
- 8 have opportunities to challenge decisions and to raise any concerns.
- 9 The committee agreed that health and social care practitioners need to work
- 10 collaboratively with advocacy services. This could facilitate decision making with the
- 11 person in many ways. In the committee's experience, health and social care
- 12 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
- 14 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
- 16 encourage practitioners and advocates to build good relationships from the start so
- that they can work together effectively and in the best interest of the person.
- 18 The committee agreed on the importance of privacy and ensuring that people can
- 19 talk with their advocate in private spaces, without being overheard. This promotes a
- 20 trusting relationship and allows people to talk frankly about their goals, wishes, and
- 21 needs.
- 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
- 24 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
- 27 remotely with their advocate or help them access virtual meetings that may
- 28 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
- 30 meetings. The committee discussed that digital platforms could help advocacy
- 31 services to engage with people and therefore ensure they are regularly contacted,
- 32 get timely updates and are informed and empowered.

- 1 The committee agreed on the vital role of advocates in supporting a person to have
- 2 their voice heard. This includes ensuring that concerns raised by the person (or on
- 3 their behalf) are not only listened to but are also interpreted in the way they are
- 4 intended, are acted on and are noted in records. This can then be referred to in any
- 5 future meetings and followed up for a response if necessary.
- 6 In the committee's experience, there is wide variation in referrals for statutory
- 7 advocacy, and non-compliance with legal duties is common. They highlighted the
- 8 need to audit and monitor advocacy services to identify gaps in service delivery. The
- 9 committee recognised that if health and social care practitioners developed action
- 10 plans this would help to improve compliance, by having clear steps that need to be
- 11 taken to bring advocacy services up to the standard required by the legislation. The
- 12 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.
- 15 The committee noted that advocacy services commonly deal with vulnerable people
- 16 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
- 18 neglect, they must follow local safeguarding policies as set out in the Care Act
- 19 (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
- 21 safeguarding processes could have serious consequences.
- The committee agreed that in their experience, the quality of safeguarding from
- 23 advocacy providers varies and guidance is needed to ensure that safeguarding is
- 24 effective, consistent and in line with legislation. They agreed that robust internal
- 25 guidance would ensure providers consistently work to the required standard. Having
- 26 effective governance, leadership, lines of communication and responsibilities also
- 27 ensures that these processes are followed. The committee were aware that a
- 28 safeguarding lead is already part of many local safeguarding policies but
- 29 emphasised the need for this role to maintain good practice. The committee agreed
- 30 on other examples that would ensure that staff know the relevant actions to take, so
- 31 that they can prove that concerns have been raised and that actions have been
- 32 taken. The committee also noted that safeguarding situations and related legislation

- 1 are complex and that training and supervision can help advocates feel confident in
- 2 what to do if issues arise.
- 3 The committee noted that guidance on communicating and discussing complex
- 4 information is covered by the NICE guidelines on people's experience in adult social
- 5 <u>care services, patient experience in adult NHS services</u> and <u>service user experience</u>
- 6 in adult mental health.

7

How the recommendations might affect practice or services

- 8 There is variation in how effectively advocacy is enabled and supported in different
- 9 areas, so the impact on practice will vary. More advocacy hours will be needed to
- 10 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.
- 12 Services may need to employ additional advocates. It may be possible to reallocate
- 13 staff from other roles as services are streamlined and fewer meetings are repeated
- 14 or decisions challenged.
- 15 Involving advocates until decisions have been communicated will need a
- 16 reorganisation of resources but is not expected to lead to additional cost or need for
- 17 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
- 19 fewer decisions being challenged and resources being used more efficiently.
- 20 Having the same advocate throughout the process will need multi-skilled advocates
- 21 to be available at the start of a person's contact with advocacy. This may mean
- 22 moving or employing multi-skilled workers, resulting in upfront costs. There may be
- 23 less need for multi-skilled advocates later in the process if duplication of meetings
- and the need for handovers are reduced.
- 25 The type of information that gets audited may change, but this is not expected to
- 26 need additional time or costs and will make data collection compliant with statutory
- 27 requirements.
- 28 The guideline will reinforce best practice for health and social care workers
- 29 facilitating advocacy and ensuring that advocates know how and when to act on
- 30 safeguarding concerns.

- 1 Digital platforms are already in almost universal use since COVID-19. It is unlikely
- 2 that further changes would be needed to this part of the service.
- 3 Return to recommendations
- 4 Effective advocacy
- 5 Recommendations 1.6.1 to 1.6.15
- 6 Why the committee made the recommendations
- 7 For more information about how these recommendations were developed, see
- 8 <u>developing the recommendations</u>.
- 9 The committee agreed that people were more likely to access advocacy if
- 10 organisations provided accessible services. Based on their knowledge and
- 11 experience they agreed on ways that advocacy providers could make their services
- more accessible, for example by making efforts to reach underserved communities.
- 13 They also drew on their knowledge of the advocacy charter and Quality Performance
- 14 Mark, 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.
- 17 The committee noted that providing person-centred services that adapt to each
- 18 person's needs and circumstances is essential to effective advocacy. The committee
- 19 agreed on specific suggestions for ensuring this, based on the QPM and their
- 20 knowledge and experience. These included taking account of the person's views.
- 21 values, culture and other experiences. The committee agreed that this individualised
- 22 approach is vital to ensure that the person is comfortable and to help establish trust.
- 23 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
- 25 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
- 28 using services what effective advocacy looks like, and what to expect from the
- 29 service.

1 The committee agreed that a fundamental element of advocacy support is a shared 2 understanding about what the person's optimal result would be. This allows the 3 success of the advocacy to be assessed. But the committee were aware of variation 4 in practice and the need to standardise good practice. They discussed the 5 importance of advocates continually discussing and assessing goals and desired 6 outcomes with the person, and agreed that everyone involved with advocacy needs 7 to work together. They discussed that goals are recorded in initial meetings, but it is 8 also important to discuss them each time and record any changes. Based on their 9 experience, the committee acknowledged the challenges of such ongoing 10 discussions if people lack capacity. But they agreed it is vital to make all possible 11 efforts to establish the person's wishes and preferred outcomes. To ensure that the 12 service is in the person's best interest, the committee agreed that it is important to 13 involve other people who have an understanding of what the person would want (for 14 example, family members or carers). 15 The committee discussed the benefits of actively involving people with lived 16 experience of health inequalities or using health and social care or advocacy in 17 designing and developing advocacy services. Having had the experience of using 18 services could give them an understanding of what works and what the person 19 needs from an advocate. This can ensure that services are more relevant and that 20 they address needs sensitively and comprehensively. The committee agreed on the 21 need to encourage services to get people with lived experience involved or to help 22 them become advocates themselves. 23 The committee agreed it is essential to promote equality, equity of access, social 24 inclusion and justice, and culturally relevant advocacy for all. Despite this being a 25 legal requirement covered by the Equality Act 2010, the committee were aware of 26 variations in service provision. 27 Based on knowledge of the Care Act 2014, the committee discussed the importance 28 of providers supporting advocates to identify and raise safeguarding concerns. They 29 stated that not carrying out advocacy effectively and in line with safeguarding 30 policies would potentially expose the person to discrimination, abuse or neglect, but 31 the role of advocacy in safeguarding is often not well understood. Based on the 32 committee's expertise and experience of safeguarding, they agreed on suggested

- 1 ways in which providers can achieve effective advocacy that meets their legal
- 2 safeguarding duties. Despite the Care Act 2014 specifying that local authorities must
- 3 appoint an independent advocate to support someone through a Safeguarding
- 4 Adults Review, the committee were aware this does not always happen.
- 5 The committee discussed that people value continuity and consistency in their
- 6 advocacy services. Effective advocacy depends on developing trust and a mutual
- 7 understanding of the issues that are important to the person. The committee agreed
- 8 that this takes time to develop. So, to help this, the committee decided that the
- 9 advocate ought to remain constant for as long as the person needs advocacy
- 10 (unless the person using the advocate wishes to change).
- 11 The committee agreed on the importance of people being confident that their
- 12 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
- 14 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,
- 17 are valuable when supporting a diverse range of clients. Some people may have
- 18 needs in many areas and need support in multiple issues. Having a single advocate
- 19 able to provide several types of advocacy can be more effective and promote
- 20 continuity of care. This could help with consistency and improving the overall quality
- of their advocacy. The committee conceded that sometimes specialist advocates are
- 22 needed for more specific support (for example, a specialist in supporting people who
- 23 lack capacity). The committee also acknowledged that it may not always be possible
- 24 for all advocacy providers to provide advocates with mixed skillsets.
- 25 Advocacy services need to address inequalities in access to services and in service
- 26 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
- 28 experience inequalities, such as taking into account a person's cultural needs and
- 29 preferences.
- 30 Effective and accessible communication and language is essential for an advocate to
- 31 gain an in-depth understanding of a person's wishes and preferences. Interpreters

- 1 are important if the advocate does not share the person's same first language. A lack
- 2 of interpreting and translation services often poses as a barrier when using advocacy
- 3 services.
- 4 The committee also noted expert testimony on the importance of culturally
- 5 appropriate advocacy, which extends beyond language. They discussed that
- 6 culturally appropriate advocacy is critical to achieve equity and social justice, and to
- 7 reach people who are already disadvantaged and underserved by services. But
- 8 there is a lack of provision for people from minority cultural backgrounds. The
- 9 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.
- 13 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.
- 16 The committee agreed this could be facilitated by supporting staff to develop cultural
- 17 competence through training, supervision and reflective practice so that they are
- 18 confident in speaking to people about preferences related to culture.
- 19 Based on the committee's knowledge of the UK General Data Protection
- 20 Regulation of the Data Protection Act 2018 as well as legal requirements related to
- 21 safeguarding, they highlighted the importance of confidentiality and privacy in
- 22 person-centred advocacy. These are requirements of advocacy and fundamental to
- 23 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.
- 30 In the committee's experience, important aspects of professional relationships are
- 31 sharing learning, insights and tools; and developing joint publications, guidance and

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- 1 resources. They agreed this improves collective effectiveness in the advocacy sector
- 2 and helps to improve standards, provide consistency, and sustain a drive towards
- 3 best practice. It also encourages innovation and helps services develop new tools
- 4 and techniques. Based on their experience the committee agreed that smaller
- 5 providers may have less capacity for this work, and competition for funding could act
- 6 as a disincentive to share best practice. But they agreed it was still important to
- 7 promote this joint learning and sharing.

8 How the recommendations might affect practice or services

- 9 The largest change in practice is likely to be in translation services and culturally
- 10 appropriate advocacy. There may need to be investment in translation services, co-
- 11 location of services and culturally appropriate advocacy. This will increase access for
- 12 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
- 14 inequality and unfairness in accessing advocacy services and will increase their
- 15 overall uptake.
- 16 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
- 20 providers who may not have the advocate levels or facilities to produce such tools.
- 21 But sharing best practice and promoting joint learning would lead to better advocacy
- 22 with less repetition, challenges to decisions or need to repeat meetings. Such tools
- 23 could also be used to promote cost-effective or cost-saving practices, leading to
- 24 more efficient use of limited resources.
- 25 Providing a greater range of venues for in-person meetings may mean that
- 26 advocates need to travel further and may increase hosting costs. Using digital
- 27 platforms for remote meetings has become common practice since COVID-19.
- 28 Organisations may need to build extra capacity in services so that advocates have
- 29 flexibility to work with different people according to a person's choice of advocate.

- 1 The recommendations will lead to changes in the number and range of people
- 2 involved in designing advocacy services, and to changes in the information given to
- 3 people about availability of and access to services. The way that goals are recorded
- 4 and updated will also be a change in practice in some areas. All of these can be
- 5 achieved by reallocating existing resources and are not expected to need additional
- 6 investment.
- 7 Return to recommendations
- 8 Partnership working and relationships with families and carers,
- 9 commissioners and providers
- 10 Recommendations 1.7.1 to 1.7.10
- 11 Why the committee made the recommendations
- 12 For more information about how these recommendations were developed, see
- developing the recommendations.
- 14 In the committee's experience, families and carers commonly report that advocacy
- services do not work collaboratively with them, when this could be in the person's
- best interests. Such cooperation could be beneficial to the person and their care, for
- 17 example to gain an understanding of the persons' views, preferences, and desired
- outcomes. This is particularly important when people may not be able to
- 19 communicate this effectively themselves, for example people with learning
- 20 disabilities and communication challenges or when people lack capacity.
- 21 The committee discussed the importance of advocates being aware of support
- 22 services that are available in their area. This is to 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.
- 25 They highlighted that it would usually be on council websites because the Care Act
- 26 2014 requires local authorities to make information about care and support services,
- 27 including advocacy services, publicly available.
- 28 In the committee's experience, advocates could help raise awareness of issues,
- 29 such as problems with referrals and difficulties people may have in accessing

- 1 services, and the extent of such issues. They noted that safeguarding boards might
- 2 be unaware of all issues on the front line of services, and that raising awareness
- 3 could improve services and safeguarding. Safeguarding boards engaging with
- 4 advocacy providers could also raise the profile of advocacy, lead to less variation,
- 5 and support effective advocacy.
- 6 The committee acknowledged that people in need of advocacy services would not
- 7 always know how to go about finding such services. They agreed on the need for
- 8 commissioners to support advocacy providers giving this information. This could
- 9 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
- 11 delivering advocacy.
- 12 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
- 15 effective services. They discussed that procedures or protocols could provide clarity,
- including for service referrals and dispute resolution. They particularly note the need
- 17 for jointly developed protocols to facilitate positive and consistent working
- 18 relationships between services. The committee were aware that that this is
- 19 consistent with the Advocacy Quality Performance Mark, which also highlights the
- 20 need for protocols for promoting services.
- 21 The committee discussed the benefits of commissioners collaborating with other
- 22 commissioners and commissioning bodies, locally and in other areas. In their
- 23 experience, working together is important for effective commissioning. It also
- 24 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
- 27 geographical areas or between different parts of the health and social care system.
- 28 This would also help address geographical inequalities in access to services.
- 29 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

- 1 support does not feel safe. But in their experience, risks are not always clearly
- 2 communicated and shared between advocacy services and care providers.
- 3 In their experience, advocates do not always know whether they can access a
- 4 person's notes and what the legislation is in relation to information sharing. Health
- 5 and social care providers may not routinely share information, so there is
- 6 inconsistency in what is made available. The committee noted the legislation on
- 7 sharing information, such as the Data Protection Act 2018 is complex, and agreed on
- 8 the need for health, social care, and advocacy providers to ensure that their staff
- 9 understand when and how advocates may access a person's records in line with
- 10 legislation.
- 11 The committee discussed that commissioners of independent mental health
- 12 advocate services and mental health services working in partnership would help
- 13 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.
- 17 The committee discussed the importance of all organisations working together to
- 18 provide culturally appropriate advocacy that meets local needs. From their
- 19 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
- 22 committee noted that these issues include social disadvantage, lack of equality and
- 23 diversity within the workforce, and inequalities in access to services and service
- 24 provision.
- 25 The expert testimony specifically highlighted support for integrating or co-locating
- 26 advocacy in other Black community and voluntary sector services. The committee
- agreed that these organisations could play a critical role in building relationships and
- 28 partnerships and addressing social disadvantage. The testimony also supported
- 29 increasing the diversity of staff in advocacy services if people express a preference
- 30 for advocates who share their gender, language, and culture. The committee agreed

- 1 that this is important to break down barriers to accessing services and building
- 2 trusting relationships, which improve the effectiveness of advocacy.

3 How the recommendations might affect practice or services

- 4 The level of partnership working and relationships with families and carers,
- 5 commissioners and providers varies. But many of the recommendations reinforce
- 6 legal requirements, so services in almost all areas already comply.
- 7 More effective partnership working would lead to cost savings from improving
- 8 services, reducing repetition and complaints, and making services more efficient.
- 9 There would be some initial costs to establish collaborative services where these are
- 10 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
- 12 not happen consistently. This may need a reorganisation of resources in some areas
- 13 but it is not expected to increase costs.
- 14 Having correct and up-to-date information on advocacy services will speed up
- access to advocacy, avoid duplication, and avoid people losing contact with
- 16 advocacy services if their needs escalate. Ensuring that service providers consider
- 17 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
- 19 to cost savings or free up resources.
- 20 Making sure the correct and up-to-date information is used should prevent people
- 21 trying to contact disbanded services or trying to contact them outside operating
- 22 hours, and should reduce costs even if initial upfront investment is needed.
- 23 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
- 25 actions may not be cost effective in all areas, so it would be up to individual service
- 26 providers to decide how best to achieve the overall objectives.
- 27 Return to recommendations

Planning and commissioning

2 Recommendations 1.8.1 to 1.8.13

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3	Why the	committee	made the	recommend	dations
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- 4 For more information about how these recommendations were developed, see
- 5 developing the recommendations.
- 6 The evidence highlighted the need to improve the commissioning of advocacy
- 7 services and suggested ways that this could be done. In the committee's experience,
- 8 understanding the needs of the local population is essential when commissioning
- 9 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
- 11 committee highlighted that it is not mandated, so they wanted to place a greater
- 12 emphasis on this approach to standardise effective, evidence-informed
- 13 commissioning. Furthermore, this approach would help to ensure that advocacy
- services are commissioned in a way that would avoid the effects of structural,
- 15 systemic and health inequalities, which result in unequal status, treatment and
- 16 opportunities among population groups.
- 17 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
- 19 advocacy but fall outside the statutory requirements may have difficulty accessing it.
- 20 In the committee's experience, commissioning advocacy services that can be used
- 21 by people who do not meet the criteria for statutory advocacy would help to close the
- 22 gap in provision, ensuring more people benefit. The committee also agreed this
- would facilitate earlier intervention at a lower level of need, which could prevent an
- 24 escalation to situations in which statutory advocacy might be needed.
- 25 Based on their experience, the committee agreed that commissioners need to be
- aware of policies, legislation and guidance beyond those that explicitly address
- 27 statutory requirement for advocacy (for example, the Equality Act 2010). Advocacy
- 28 services may need to change so that services are compliant with these wider
- 29 requirements. The committee agreed that this would ensure that commissioning
- decisions create advocacy services that are as comprehensive as possible,
- 31 compliant with all legislation, meet a diverse range of needs and promote equality.

- 1 The Care Act 2014 and statutory guidance require local authorities to ensure
- 2 adequate high-quality care and support is provided that meets the needs of the local
- 3 population. The Care Act 2014 also includes the concept of market development,
- 4 which means the local authority has a responsibility to ensure there are sufficient,
- 5 good quality services available in their area. In the committee's experience, closer
- 6 collaboration between local authorities, commissioners, health and social care
- 7 service providers and community stakeholders would help to establish a clear picture
- 8 of whether or not existing services are meeting local population needs, to ensure
- 9 these requirements are fulfilled.
- 10 The evidence highlighted the need to involve people who use or are likely to use
- 11 advocacy services in planning, designing and monitoring services. In the
- 12 committee's experience, service user involvement happens in some areas but not
- 13 consistently. The committee agreed that involving service users in planning,
- designing and monitoring helps ensure services are relevant and suited to people's
- 15 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
- 17 implementation of this practice.
- 18 In the committee's experience, people have different needs and therefore need
- 19 different amounts of advocacy. Having overly restrictive contracts that specify what
- 20 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
- 22 to work in line with the principles of advocacy and reduces the quality and
- 23 effectiveness of the advocacy they provide.
- 24 The committee agreed that advocates need to undertake training and continuing
- 25 professional development to be able to provide high-quality, effective advocacy.
- 26 Contracts and specifications for advocacy providers need to include time allowances
- to make this possible but not all of them currently do so.
- 28 In the committee's experience, quality standards provide an important benchmark to
- 29 measure performance against. This helps to promote a consistent, high-quality
- 30 service and identify any improvements needed. The committee were aware that the
- 31 Advocacy Quality Performance Mark (QPM) is a widely used quality assurance

- 1 assessment. The QPM is given to organisations demonstrating excellent service
- 2 provision in line with QPM standards, the Advocacy Charter and the Advocacy Code
- 3 of Practice. The effectiveness of the QPM was not reviewed as part of this guideline
- 4 so the committee did not recommend its use. But they agreed with the benefits of
- 5 external quality accreditation.
- 6 In the committee's view, taking a person-centred approach is a key tenet of
- 7 advocacy. Embedding this in contracts and service specifications is essential in
- 8 enabling advocacy services to be truly person centred. Based on the expert
- 9 testimony and a report from the Care Quality Commission (recommending a level of
- 10 personalised care that equated to intensive and long-term support), the committee
- 11 gave examples of steps commissioners could take to ensure services are person
- 12 centred.
- 13 In the committee's experience, it is not possible to specify a particular way of
- 14 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
- 16 for reasonable adjustments that promote equality and avoid disadvantaging
- 17 particular people. Doing this alongside the recommendations on training (see
- 18 sections 1.9 and 1.10), will ensure advocates have the dedicated time and space to
- deliver a person-centred service and to continuously enhance their skills, all of which
- 20 is essential for maintaining quality and standards.
- In the committee's experience, people are most comfortable with advocates they can
- 22 relate to and trust, and this tends to lead to more effective advocacy. The expert
- 23 testimony highlighted that a lack of diversity and understanding of equality and
- 24 issues relevant to minority communities can form a barrier to people accessing, or
- 25 taking up, advocacy services. The evidence highlighted that local organisations can
- 26 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 that could help remove barriers

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- 29 to access for underserved groups, such as those with refugee status and people
- 30 from Gypsy, Roma and Traveller communities).

- 1 The evidence highlighted the lack of suitable advocacy for people with complex
- 2 needs, such as learning disabilities. The committee agreed that people's different
- 3 advocacy needs can be best met by offering a variety of advocacy models and
- 4 commissioning services tailored to the local population. This includes commissioning
- 5 services with advocates specialising in different types of advocacy and multi-skilled
- 6 advocates.
- 7 The evidence highlighted the need to establish consistent good practice in
- 8 safeguarding as part of the advocacy role. Advocacy is important in safeguarding
- 9 because it supports people's involvement and decision making when there are
- 10 safeguarding concerns, safeguarding enquiries or safeguarding adult's reviews.
- 11 Involving someone independent from other services, who is representing the
- 12 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
- 14 quality to be raised before they become a safeguarding issue. But in the committee's
- 15 experience advocates are not consistently involved in safeguarding processes.

16 How the recommendations might affect practice or services

- 17 There is already a statutory duty to make information about advocacy services
- 18 available. This will remind services to comply if they do not already.
- 19 Active analysis of public policies, legislation and guidance may initially have a
- 20 resource impact but will lead to more effective, efficient practice and will potentially
- 21 save costs in the longer term. Changes in practice may also occur as a result of
- 22 commissioning different or modified services in line with statutory requirements and
- 23 lessons from shared learning.
- 24 There may be some upfront costs associated with involving people who use
- 25 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
- 27 them actively participate. But this should lead to services being more responsive and
- 28 efficient, and avoid wastage. This would lead to cost savings. It is also in line with the
- 29 general move towards shared decision making in health and social care.

- 1 Supporting advocacy providers to maintain their independence will lead to better
- 2 quality service, reducing complaints and needs for judicial reviews, therefore saving
- 3 costs in the long term. There may be some resource impact associated with
- 4 engaging with the community and carrying out local needs assessments on which to
- 5 base commissioning of advocacy services. But in the vast majority of areas this is
- 6 already happening.
- 7 Not all contracts and specification for advocacy include time allowances for training
- 8 and continuing professional development so some change in practice may be
- 9 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
- 11 escalate.
- 12 Ensuring that advocacy services are person centred is not expected to have a
- 13 resource impact. All health and social care services should already personalise care
- or treatment specifically for the person who uses the service.
- 15 Return to recommendations
- 16 Training, skills and support for advocates
- 17 Recommendations 1.9.1 to 1.9.8
- 18 Why the committee made the recommendations
- 19 For more information about how these recommendations were developed, see
- 20 developing the recommendations.
- 21 In the committee's view, advocacy is still establishing itself in the consciousness of
- 22 both the people who would benefit from using it and the practitioners who can make
- 23 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
- 27 and consistent training is the most effective way to achieve this. But there is variation
- in the current content and availability of training.

- 1 The committee agreed with evidence from NICE's guideline on decision-making and
- 2 mental capacity that an increase in investment in training for advocates would
- 3 improve the availability and quality of advocacy.
- 4 The evidence highlighted several areas that advocates need to be trained in. In the
- 5 committee's experience, advocates need knowledge and skills in these processes
- 6 and areas to undertake their role effectively. In their experience, training for
- 7 advocates is inconsistent, and the committee agreed that all training needs to be
- 8 brought up to an agreed standard.
- 9 Statutory guidance to the Care Act (7.43) states that 'Once appointed, all
- 10 independent advocates should be expected to work towards the National
- 11 Qualification in Independent Advocacy within a year of being appointed, and to
- 12 achieve it in a reasonable amount of time.' The committee noted that the statutory
- 13 guidance is vague about the timeframe for achieving this qualification and in their
- 14 experience, 'a reasonable amount of time' is interpreted very differently. The
- 15 committee agreed that the quality of advocacy services would improve if all
- 16 advocates achieved this qualification, although they could not recommend a specific
- timeframe because the statutory guidance does not stipulate one.
- 18 The committee agreed that supervision of advocates is crucial. It ensures
- 19 consistency across services and that advocates are meeting the necessary
- 20 standards. It also provides an opportunity for all advocates to develop skills and
- 21 learn from others.
- In the committee's experience, people who cannot instruct an advocate are less
- 23 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
- 26 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.
- 28 Extra steps may be needed to determine the person's likely wishes, feelings and
- 29 desired outcomes in the absence of instruction. The committee agreed that providing
- 30 extra training and support for non-instructed advocates would improve practice in
- 31 this area.

- 1 The committee agreed it is essential that volunteer advocates receive the same
- 2 support and supervision as paid advocates. This ensures that the services provided
- 3 by volunteer advocates meet the necessary standard.

4 How the recommendations might affect practice or services

- 5 There are currently variations in the training advocates are given on health and
- 6 social care, justice, legal processes, and skills needed for effective advocacy. The
- 7 bespoke economic model for the guideline estimated that there would be an initial
- 8 resource impact from improving training, especially when training takes advocates
- 9 away from core duties for a long time. But there would be cost savings in future from
- 10 advocates working more efficiently and a reduction in complaints and repeated
- 11 meetings. Better training for advocates would also lead to a higher quality of service.
- 12 This would improve people's outcomes and quality of life, while reducing the number
- of expensive interventions such as unplanned admissions to hospital.
- 14 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
- 17 responsibility of individual advocates and the needs of the population in their local
- area. There is already a requirement for all independent advocates to work towards
- the National Qualification in Independent Advocacy, so this should not need
- 20 additional resources.
- 21 Training in non-instructed advocacy is in line with the Care Act (2014) requirement
- for advocates to have appropriate training, so should not have additional resource
- 23 requirements.
- 24 Currently there are inconsistencies in the amount of training provided for volunteer
- 25 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
- 27 the needs of the population in their local area. It is not anticipated that all volunteer
- 28 advocates will need training in all the processes and areas. Training volunteer
- 29 advocates will ensure that the required service standard is met, and there might also
- 30 be improvements from reduced complaints.

- 1 Return to recommendations
- 2 Training and skills for health and social care practitioners who
- 3 work with advocates
- 4 Recommendations 1.10.1 to 1.10.5
- 5 Why the committee made the recommendations
- 6 For more information about how these recommendations were developed, see
- 7 <u>developing the recommendations</u>.
- 8 It is a legal duty for an advocacy referral to be made when people are entitled to
- 9 advocacy support, and people who cannot self-refer to advocacy rely on these
- 10 referrals. In the committee's experience, the different statutory duties and eligibility
- 11 criteria for advocacy are complex and difficult to understand, making it hard for
- 12 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
- 14 entitlement to advocacy support, so that they could comply with the legal
- 15 requirements on referral.
- 16 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
- 19 consistent practice and referrals and increase effective practice. Refresher training
- 20 every 2 to 3 years achieves a balance between the need to keep knowledge current
- 21 and the time needed to attend training. The committee used the evidence to decide
- 22 on the most important elements of training.
- 23 The committee agreed that staff who may be the first point of contact in health and
- 24 social care services need to understand who is entitled to advocacy and when and
- 25 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.
- 27 Health and social care practitioners should already receive training on the role and
- 28 function of advocacy as part of induction training. But in the committee's experience
- this is not consistent, which can lead to misunderstandings about advocacy, poor

- 1 practice and negative working relationships. Having better knowledge would enable
- 2 practitioners to facilitate advocacy more effectively and improve working
- 3 relationships. The committee used their experience of common misunderstandings
- 4 about the role of advocacy to decide on what this training should cover.
- 5 Different health and social care practitioners will need different levels of training in
- 6 advocacy, depending on their role. In the committee's experience, tailored training is
- 7 more cost effective than providing the same for everyone. The committee also
- 8 agreed that delivering training in flexible formats should maximise its effectiveness.
- 9 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
- 11 sessions.
- 12 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
- 15 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
- 17 practice.

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

How the recommendations might affect practice or services

- 22 Some changes in practice or services may be needed. Health and social care
- 23 practitioners should already be receiving training in legislation and the role of
- 24 advocates but this is delivered inconsistently. Refresher training is not routine and
- 25 there is variation across regions in how much training is tailored. Although there may
- 26 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
- 28 training where previous training materials can be reused and costs should be
- 29 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.

- 1 Training does not consistently include people with lived experience. For
- 2 organisations that are not currently doing this, there is likely to be a change in
- 3 practice. And there will be some costs from providing to support to enable people
- 4 with lived experience to take part in in the training and share their experiences. This
- 5 would improve the overall quality of training, making it more relevant and meaningful
- 6 and help to improve practitioners' understanding of advocacy. This can help the right
- 7 people access advocacy at the right time, and in the long term could improve
- 8 services.
- 9 Delivering training in a variety of formats may have some costs. But costs will be
- 10 minimal if training is by self-directed learning or is delivered remotely.
- 11 Improved training for practitioners should help identify people who have a right to
- 12 advocacy under current legislation. This will increase the total number of people
- 13 accessing advocacy services, leading to a greater resource impact than the training
- 14 itself, at least in the short term. But the increased access will be from people who
- 15 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 a less risk of needs escalating, leading to lower downstream costs
- 18 and higher quality of life.
- 19 There may be some costs associated with ensuring that knowledge gained through
- training is applied in practice, for example from changing approaches to enable
- 21 effective supervision, although these should be small and short term. But increased
- 22 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.
- 24 Return to recommendations
- 25 Monitoring services and collecting data for quality improvement
- 26 Recommendations 1.11.1 to 1.11.18
- 27 Why the committee made the recommendations
- 28 For more information about how these recommendations were developed, see
- 29 developing the recommendations.

1 Agreeing outcomes

- 2 In the committee's experience, advocacy providers need to have defined, service-
- 3 level outcomes that can be measured to ensure that they are delivering an effective,
- 4 high-quality service. Many providers currently report key performance indicators as
- 5 part of contracts and commissioning arrangements. But in the committee's view
- 6 these service-level outcomes should include more person-centred metrics (for
- 7 example whether people's voices are heard and the effect on empowerment). Input
- 8 from people who use advocacy services and other stakeholders would help to
- 9 achieve this. The committee also noted that collaboration between commissioners
- and advocacy providers when agreed outcomes would reduce the likelihood of gaps
- occurring between geographical areas or people falling between different parts of the
- 12 health and social care system.
- 13 The committee agreed it was important to be clear about how outcomes will be
- 14 reported. This enables data to be analysed for protected characteristics or other
- disadvantaged groups, such as those experiencing health inequalities.
- 16 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
- 18 understanding of population-level needs would assist the commissioning of more
- 19 effective services and would align with developments in Health and Social Care
- 20 services such as the move to Integrated Care Systems. Based on the evidence, they
- 21 agreed areas for data collection that would help this.

What data to collect

22

- 23 The committee were aware that advocates sometimes face pressure from other
- 24 services or commissioners to prioritise certain outcomes or not to raise concerns.
- 25 Advocates are also sometimes asked for unnecessary information that could identify
- 26 individual people, potentially breaching the Data Protection Act 2018 and damaging
- 27 relationships between the advocate and the person they support. The committee
- agreed that commissioners need to be alert to these issues when collecting data.
- 29 In the committee's experience, there is variation in what information is collected
- 30 about people using advocacy services, and information about the impact of
- 31 advocacy services is not routinely collected in a standardised format. Collecting data

- 1 in a standardised format makes it easier to evaluate, so that gaps in service
- 2 provision can be identified and it can be seen whether services are meeting local
- 3 needs. It also makes it easier to share key information with other organisations.
- 4 Based on the evidence the committee agreed some important standard types of data
- 5 to collect and suggested formats for doing so. The committee agreed that including
- 6 protected characteristics would help identify whether there are particular groups that
- 7 are not receiving services they would benefit from and help to reduce health and
- 8 other inequalities.
- 9 The committee's experience was that information about advocacy services is not
- 10 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.
- 12 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 and take up of advocacy
- would help to identify any groups who would benefit from advocacy services but are
- not currently using them, so could help address inequalities in access
- 17 Because advocacy is an emerging field relative to other areas of health and social
- 18 care, there are no evidence-based quality standards mandated for use. In the
- 19 committee's experience quality standards provide an important benchmark with
- which to measure performance. This would help to promote a consistent, high-quality
- 21 service and identify any improvements needed.

How to collect data

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- 23 The information and data used by commissioners is diverse, and varies according to
- 24 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
- 28 turn help improve the quality of services.
- 29 In the committee's experience getting feedback from the full range of people using
- 30 advocacy services in necessary to ensure that services are responsive to the needs

- 1 of the local population. They agreed that it may be necessary to support individual
- 2 preferences and communication needs to get this feedback, but that doing so should
- 3 give a better view of whether services are meeting needs and any necessary
- 4 improvements. The committee also noted that the provider of the service is typically
- 5 the point of contact for feedback and were keen to facilitate anonymous feedback to
- 6 prevent any barriers to receiving feedback.

7 Evaluating and sharing data

- 8 In the committee's view, the monitoring data collected needs to be evaluated and
- 9 used to generate continuous improvement in services. From their knowledge and
- 10 experience, the committee were aware that commissioners do not always use
- 11 information gathered from advocacy services to inform improvements in practice.
- 12 The committee also agreed that sharing this information with other organisations
- helps 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

- 16 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
- 19 experience advocates are sometimes not 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
- 22 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
- 24 problems.

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Adhering to statutory duties

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

1 Research recommendation

- 2 Based on the evidence, and their knowledge about gaps in evidence and about the
- 3 factors that make an advocacy service effective, the committee agreed that more
- 4 information is needed about the effectiveness of advocacy delivered through
- 5 different approaches. For example, advocacy delivered by an advocate with lived
- 6 experience, or by an advocate with the same ethnicity as the person being supported
- 7 (see research recommendation 1).

8 How the recommendations might affect practice or services

- 9 Collecting data is not expected to lead to any long-term increase in resource use.
- 10 The vast majority of centres already have data collection and monitoring processes
- in place. There will be some short-term costs for services whose monitoring, data
- 12 collection or quality assurance systems are not in line with the recommendations.
- 13 There will also be some upfront costs from initial meetings between advocacy
- 14 services and commissioners to develop protocols or operating procedures.
- 15 Better and standardised monitoring, data collection and quality assurance should
- 16 lead to more effective and efficient advocacy services with potentially large cost
- 17 savings.
- 18 Return to recommendations

19 Finding more information and committee details

- 20 To find NICE guidance on related topics, including guidance in development, see the
- 21 NICE webpage on patient and service user care.
- 22 For details of the guideline committee see the committee member list.
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