

Advocacy services for adults with health and social care needs

[F] What does effective advocacy look like?

NICE guideline number tbc

Evidence reviews underpinning recommendations 1.3.1, 1.5.8, 1.6.1 to 1.6.16, 1.8.12, 1.10.3, and 1.11.1 to 1.11.2 in the NICE guideline

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These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists

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1 What does effective advocacy look like?

2 Key theme

- 3 • What does effective advocacy look like?

4 Introduction

5 The aim of this review is to identify what effective advocacy looks like.

6 Recommendations about advocacy have been made in a number of existing NICE
7 guidelines. However, these have identified a lack of evidence relating to advocacy that would
8 meet inclusion criteria for standard evidence reviews. Therefore, it was agreed that
9 recommendations for this guideline would be developed by adopting and adapting advocacy-
10 related recommendations from existing NICE guidelines, using a formal consensus based on
11 statements generated from a call for evidence, and documents identified by the guideline
12 committee, and informal consensus methods to address any areas of the guideline scope
13 that are not covered by the existing NICE guidelines or the formal consensus process.

14 Summary of the inclusion criteria

15 Please see Table 1 for a summary of the inclusion criteria applied to evidence received in
16 response to the call for evidence and identified by the guideline committee.

17 **Table 1: Summary of the inclusion criteria**

Country	UK
Geographical level	National* *For policy or guidance documents, this means, the policies and recommendations apply nationally. For original research, this means the studies have been conducted in the national policy and practice context of our scope, i.e., the English health and social care system
Publication date	2011 onwards
Study design	Primary qualitative or quantitative studies (including unpublished research), excluding case-studies Systematic reviews of qualitative or quantitative studies, excluding case-studies Guidelines or policy documents that are based on qualitative or quantitative evidence, excluding case-studies
Topic areas	What does effective advocacy look like?

18 Methods and process

19 The process for identifying, adopting and adapting recommendations from existing NICE
20 guidelines, the call for evidence and formal consensus methods are described in
21 supplementary material 1.

22 Declarations of interest were recorded according to [NICE's 2019 conflicts of interest policy](#)
23 [\(see Register of Interests\)](#).

1 **Effectiveness evidence**

2 **Included studies**

3 ***Existing NICE guidelines***

4 No existing NICE recommendations were identified for this scope area.

5 ***Formal consensus***

6 A single call for evidence was undertaken for all topics included in the scope of this guideline.
7 Additional documents were identified by the guideline committee. See the study selection
8 flow chart in appendix A.

9 Ten documents were identified for this review (National Development Team for Inclusion
10 NDTi 2014b, NDTi 2016a, NDTi 2020a, NDTi 2020b, Newbigging 2011, Newbigging 2012,
11 Lawson 2017, Lawson 2020, Roberts 2012, SERIO 2021).

12 One document each focused on people living with learning disabilities, (Roberts 2012),
13 African and Caribbean men using mental health services and providers of mental health
14 advocacy services (Newbigging 2011), providers and commissioners of independent
15 Advocacy (NDTi 2016a), Veterans and their families (SERIO 2021), patients detained under
16 the amended Mental Health Act 1983 (Newbigging 2012), and people living with disabilities
17 (NDTi 2014b). Two documents focused on those who have duties to commission and
18 arrange advocacy services (Lawson 2017 and 2020), and 2 documents focused on
19 advocates (NDTi 2020a and NDTi 2020b).

20 **Expert witness**

21 One important area of inequalities highlighted in the equality impact assessment was that
22 people from Black, Asian and Minority Ethnic communities can face disparity in access and
23 discrimination in health and social care services, and are underrepresented in those
24 accessing advocacy services. The committee highlighted early on in committee meetings
25 that this was a key area for the guideline to cover as advocacy services, as well as mental
26 health services more broadly, have a poor track record when it comes to overcoming
27 discrimination within services and disparity in access to advocacy.

28 There was a paucity of information about advocacy services for Black, Asian and Minority
29 Ethnic communities in the documents received in response to the call for evidence and
30 additional documents identified by the guideline committee and no recommendations on this
31 topic in existing NICE guidelines.

32 Therefore, the committee decided to invite expert witnesses, who were independent and
33 peer researchers from Oxford University, to provide testimony to supplement the formal
34 consensus process. The testimony covered evidence of inequalities and differential
35 treatment for people from Black, Asian and Minority Ethnic communities in health and social
36 care and proposed: positive practices to promote equality of access, investing in community
37 based advocacy, developing the advocacy workforce and steps to increase accountability for
38 the provision of culturally appropriate advocacy.

39 A copy of the expert testimony form is provided in appendix H.

40 **Excluded studies**

41 ***Formal consensus***

42 Documents not included in this review are listed, and reasons for their exclusions are
43 provided in appendix D.

1 **Summary of included studies**

2 Summaries of the documents included in the formal consensus process for this review are
3 presented in Table 2.

4 **Table 2: Summary of documents included in the formal consensus process**

Document	Population	Evidence base
Lawson 2017 Report National	Those who have duties to commission and arrange advocacy services for safeguarding adults	Briefing including qualitative discussions with advocates from across England to determine the enablers and barriers to involvement of advocacy in safeguarding adults
Lawson 2020 Briefing Multiple areas	Those who have duties to commission and arrange advocacy services for safeguarding adults	Briefing including qualitative discussions with advocates from across England to determine the enablers and barriers to involvement of advocacy in safeguarding adults
NDTi 2014b Report of an evidence review International	People living with disabilities	Report describing the findings of an evidence review on independent advocacy for: Young disabled people at transition; Disabled parents whose children are subject to safeguarding procedures; Disabled people when entry to residential care is a possibility; Disabled people are victims or alleged perpetrators of anti-social behaviour.
NDTi 2016a Framework England	Providers and commissioners of independent advocacy	Literature review (no details reported) and consultation with two self-advocacy groups
NDTi 2020a Report on survey findings England & Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 435 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides recommendations for government, local authorities, and care providers
NDTi 2020b Report on survey findings Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 72 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides recommendations for government, local authorities, and care providers

Document	Population	Evidence base
Newbigging 2011 Systematic Review National (England, Wales, and Northern Ireland)	African and Caribbean men using mental health services; providers of mental health advocacy services for adults that either targeted African and/or African and Caribbean men, BME communities or provided a service for the whole population in a locality	Systematic literature review, a national survey on the provision of advocacy (n=391 providers of mental health advocacy services), focus groups with African and Caribbean men (n=25), and case studies (22 people including 7 service users, 6 commissioners, 4 mental health service providers and 5 experts in the field).
Newbigging 2012 Mixed methods: literature review, qualitative research (focus groups and interviews), case studies England	Patients detained under the amended Mental Health Act 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	Multiple methods (including literature review, 11 focus groups, shadow visits with IMHAs, expert panel review) to obtain information on IMHA services to develop draft quality indicators for IMHA services. Data from 8 case studies (NHS Trust areas) to understand experiences of qualifying service users and the commissioning and delivery of IMHA services and their relationship with mental health services
Roberts 2012 Survey England	People living with learning disabilities	3 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies; provides information on, for example, funding and also discusses gaps in advocacy provision and barriers to accessing services
SERIO 2021 Service evaluation England	Veterans and their families	Report of an independent three-year evaluation of The Veterans' Advocacy People, a service targeted at veterans, and their families from each of the service arms, which aims to provide open and flexible advocacy support. Includes qualitative interviews

1 *IMHA: Independent Mental Health Advocate; NDTi: National Development Team for Inclusion; NHS: National*
 2 *Health Service.*

3 See the full evidence tables for documents included in the formal consensus process in
 4 appendix B and a summary of the quality assessment of these documents in appendix C.

5 **Summary of the evidence**

6 ***Existing NICE guidelines***

7 No existing NICE recommendations were identified for this scope area.

8 ***Formal consensus round 1***

9 Two documents (Lawson, 2017; NDTi, 2016a) were assessed using the Appraisal of
 10 Guidelines for Research & Evaluation Instrument (AGREE II) tool, 1 document (Newbigging,
 11 2011) was assessed using both the Risk of Bias in Systematic reviews (ROBIS) checklist
 12 and the Critical Appraisal Skills Programme (CASP) tool for qualitative research as it
 13 included both a systematic literature review and a survey with qualitative components, and 7

1 included documents (Lawson, 2020; NDTi, 2014b; NDTi, 2020a; NDTi, 2020b; Newbigging,
2 2012; Roberts, 2012; SERIO, 2021) were assessed using the CASP tool for qualitative
3 research. See the results of the quality assessment in the evidence tables in appendix B and
4 quality assessment tables in appendix C.

5 The committee were presented with 74 statements in round 1 of the formal consensus
6 exercise; responses were received from 12 of 13 committee members. Sixty-two of these
7 statements reached $\geq 80\%$ agreement in round 1 and were included for the discussion with
8 the committee. Eleven statements had between 60% and 80% agreement; 10 of these were
9 redrafted for round 2 and one was discarded because the source material for the statement
10 was published before the 2014 Care Act which the committee agreed addressed the issue in
11 the statement. One statement had $< 60\%$ agreement and was redrafted for round 2 because
12 the comments raised addressable issues and suggestions for revision.

13 See appendix G for the statements that were rated by the committee and results of round 1,
14 which are provided in Table 11.

15 ***Formal consensus round 2***

16 The committee were presented with 11 statements in round 2 of the formal consensus
17 exercise; responses were received from 12 of 13 committee members. Six of these
18 statements reached $\geq 80\%$ agreement and were carried forward to the committee discussion.
19 Three statements were between 60% and 80% agreement and 2 statements received less
20 than 60% agreement; these statements were discarded.

21 **Economic evidence**

22 Economic considerations will be taken into account together with resource impact.

23 **The committee's discussion and interpretation of the evidence**

24 **The outcomes that matter most**

25 In the methods used for this guideline (adopting and adapting existing recommendations and
26 formal consensus) no outcomes were considered formally by the committee; therefore, the
27 committee were not required to determine which outcomes were critical or important.

28 **The quality of the evidence**

29 The quality of some of the documents identified by the committee and through the call for
30 evidence was assessed using ROBIS and the AGREE II tool, which is explained in detail in
31 the methods supplement for this guideline. ROBIS is intended for use in assessing the
32 quality of systematic reviews but was also used for the purpose of this guideline to assess a
33 number of reviews that were not intended by the authors to be systematic as it was the best
34 available tool. The AGREE II instrument is intended for use assessing the quality of
35 systematically developed clinical practice guidelines, including assessments of
36 methodological rigour and transparency. Therefore, some domains of ROBIS and the
37 AGREE II tool may be less relevant for these documents and they would not have followed
38 reporting guidelines for systematic reviews. All supporting material published with documents
39 was reviewed to inform quality assessment, however it was not feasible to contact the
40 authors of each document. Therefore it is plausible that the documents may have scored
41 lower on quality assessments than the underlying methodology would warrant had authors
42 made their full methodology available or if more appropriate tools were available. The
43 committee were aware of this in their discussions of the existing recommendations and
44 statements extracted from documents identified from the call for evidence. Where
45 shortcomings in the quality of documents impacted the committee's opinions about using the
46 statements, this is described in the benefits and harms section below. On the whole

1 however, where there was full committee support for a statement extracted from a lower
2 quality document, the committee made the recommendation because their experiential
3 knowledge corroborated the statement and strengthened the argument to use it as the basis
4 for a recommendation.

5 ***Existing NICE guidelines***

6 No existing NICE recommendations were identified for this scope area.

7 ***Formal consensus***

8 The quality of two documents (Lawson, 2017; NDTi, 2016a) were assessed using the
9 AGREE II tool. High quality documents were defined as those where any two domains
10 scored $\geq 70\%$. The documents scored an overall rating of 29% and 34% and were therefore
11 not deemed to be high quality. The included documents scored 22% and 28% for
12 stakeholder involvement; both scored 4% for applicability; 8% and 10% for rigour of
13 development and 0% and 17% for editorial independence. Overall, the documents did not
14 provide sufficient information on the stakeholder involvement in the development of the
15 document. It was unclear whether the likely barriers and facilitators to implementation,
16 strategies to improve uptake, and resource implications of applying the document were
17 considered. The methods used to formulate and update the recommendations, and details
18 on whether a systematic process had been used to gather and synthesise the evidence,
19 were not clearly described. Declaration of any bias or competing interests from the document
20 development group members were not reported.

21 The quality of 1 document (Newbigging, 2011) was assessed using the ROBIS checklist and
22 the CASP tool for qualitative research as it included both a systematic literature review and a
23 survey with qualitative components. The document was judged to have unclear risk of bias
24 according to the ROBIS checklist for systematic reviews because insufficient details were
25 provided to enable a judgement to be made. The document had no or very minor
26 methodological limitations according to the CASP tool for qualitative research.

27 The quality of 7 documents (Lawson, 2020; NDTi, 2014b; NDTi, 2020a; NDTi, 2020b;
28 Newbigging, 2012; Roberts, 2012; SERIO, 2021) were assessed using the CASP checklist
29 for qualitative research. One document (Newbigging, 2012) was judged to have minor
30 methodological limitations. Six Documents (Lawson, 2020; NDTi, 2014b; NDTi, 2020a; NDTi,
31 2020b; Roberts, 2012; SERIO, 2021) were judged to have serious limitations. Methodological
32 limitations included a lack of reporting in regards to data analysis, data collection,
33 recruitment, and research design. Furthermore, ethical issues had not been taken into
34 consideration, and there was a lack of discussion of relationship between researcher and
35 participants.

36 ***Benefits and harms***

37 The committee acknowledged that the majority of statements had been extracted from a
38 documents judged to be of lower. However they were in full agreement with these statements
39 and because their own knowledge and experience chimed with the point being made they
40 concluded it would be important to make recommendations on that basis and that the
41 benefits of doing so outweighed any risks of excluding these statements altogether.

42 ***Communication, confidentiality, and privacy***

43 Statement 7 highlighted the importance of effective communication to achieve effective
44 advocacy. The concept of how to communicate effectively is already covered by other NICE
45 guidelines. Therefore, the committee agreed to cross-refer to the following existing NICE
46 guidelines rather than making new recommendations on communicating and discussing
47 complex information: the NICE guideline on babies, children and young people's experience
48 of healthcare [NG204], the NICE guideline on patient experience in adult NHS services

1 [CG138], and the NICE guideline [NG86] on people’s experience in adult social care services
2 [NG86]. The committee agreed that this recommendation was more about enabling and
3 supporting effective advocacy, therefore decided to move this recommendation to the area of
4 enabling and supporting effective advocacy (see evidence review E).

5 Statement 8 highlighted the importance of confidentiality and privacy when delivering person-
6 centred advocacy. There was strong agreement with this statement among the committee
7 but they discussed that in practice, there are some complications, particularly around the
8 principle of confidentiality. Privacy and confidentiality are core principles of advocacy and
9 fundamental to building trusting relationships. At the same time, in the committee’s
10 experience there are circumstances in which an advocate must breach a person’s
11 confidence, for example where there are safeguarding concerns or where it appears a law
12 has been broken. The committee agreed the key was for advocates to be open about this,
13 maintaining confidentiality and assuring people but also explaining the circumstances or
14 conditions under which confidentiality may need to be breached. It is also important for
15 advocates to be open with the person about the fact that sharing information in certain
16 circumstances, for example professional supervision, is not considered a breach of
17 confidentiality. In the committee’s experience, this is considered vital so that people can
18 make a choice about what information they can share. Furthermore, this will help to promote
19 trust, as relationships could be damaged if information is being shared without people’s
20 knowledge. In some instances people might not be aware of the circumstance under which
21 information is shared.

22 The committee also agreed to use statement 8 to make a recommendation specifically about
23 privacy, ensuring that providers enable people to have discussions with their advocate in
24 private spaces, without being overheard. The benefit of this would be to promote a trusting
25 relationship and allow people to open up and talk frankly about their goals, wishes and
26 needs. The committee agreed to place the recommendation in the section of the guideline
27 about enabling and supporting effective advocacy (see evidence review E) because it was
28 more relevant to those recommendations than the ones about effective advocacy.

29 ***Promoting best practice and consistency***

30 Statements 9 and 10 highlighted the importance of sharing learning, insight, and tools and
31 developing joint publications, guidance and resources to ensure continued collective
32 effectiveness across the advocacy sector. In the committee’s experience this is an important
33 aspect of professional relationships and sharing best practice and learning should improve
34 the standards of advocacy. Therefore, the committee agreed to combine these statements so
35 that advocacy services should work with each other to promote best practice and
36 consistency. This should help to provide consistency and sustain a drive towards best
37 practice across the advocacy sector, as well as encouraging innovation as advocacy
38 services develop new tools and techniques. However on the basis of their experience the
39 committee agreed that the recommendation might be challenging for smaller providers to
40 follow because they may have less capacity and the competition for funding could act as a
41 disincentive to share best practice. They nevertheless agreed it was important to promote
42 this joint learning and sharing through making the recommendation.

43 ***Information about local services***

44 Statement 12 covered the importance of advocacy services ensuring that their services are
45 known about. The committee agreed that increasing awareness about available services is
46 key to improving access but they highlighted that the responsibility for this falls on local
47 authorities rather than individual advocacy services. They therefore used the statement to
48 make a recommendation and they directed it at local authorities. Given that it is a duty set
49 out in the Care Act 2014, for local authorities to make information available about local
50 services they were able to make the recommendation in the strongest terms. The committee
51 also built on this legal duty to say that information about local services should specifically
52 include advocacy services, with the intention that this should improve awareness,

1 signposting and ultimately access to advocacy. The committee agreed to place this
2 recommendation in the section of the guideline about information about effective advocacy
3 and signposting to services (see evidence review C) because it was more relevant to those
4 recommendation than the ones about effective advocacy.

5 ***Making advocacy services accessible***

6 Statement 13 covered the importance of advocacy organisations making sure that their
7 advocacy services are accessible. The committee all agreed with this as a means of
8 ensuring that people can access effective advocacy but to make a meaningful, useful
9 recommendation they concurred that specific examples about ensuring accessibility should
10 be given. Aware that the advocacy charter and Quality Performance Mark (QPM 2018)
11 cover accessibility, they used these to make suggestions such as ensuring meeting places
12 are accessible and communication needs are met. However, they also agreed that
13 accessibility to services is broader than just physical access so they also included examples
14 for improving access to advocacy through offering remote meetings and making efforts to
15 reach underserved communities. The committee acknowledged that for some organisations
16 there may be resource requirements involved in following this recommendation but that on
17 the whole these actions are already legally required. Specifically, the Mental Health Act
18 1983: Code of Practice (2015) says that patients should have access to a telephone they can
19 use to contact IMHA services and that IMHAs should be able to access wards where people
20 are resident. The committee agreed that it was important to make face-to-face advocacy
21 available whenever needed, as this is considered the gold standard to ensure effective
22 communication. Furthermore, safeguarding concerns could be picked up more easily when
23 the advocate is able to arrange face-to-face advocacy. However, the committee
24 acknowledges that there may be times where face-to-face meetings are not possible for
25 example due to an infectious outbreak or violent incident. In the committee's experience it
26 was also important that advocacy services are offered outside of standard "office" hours, if
27 possible. Advocacy services are generally offered during office hours but some people might
28 not be able to see an advocate during these hours, therefore the committee agreed that
29 offering some flexibility in working hours where possible could help to meet people's needs.
30 However, it is important to note that advocacy services are not funded to operate as an
31 emergency service so this will occur on an individual basis. In the committee's experience it
32 was also important to ensure that advocacy services are accessible by providing non-
33 instructed advocacy. The committee agreed that someone who is unable to instruct will not
34 seek help and that advocates need to be more proactive to ensure that people who are
35 unable to instruct are not excluded from receiving advocacy services. The committee agreed
36 the recommendation would help to improve consistency in the provision of accessible
37 services and the promotion of equality as more people will be encouraged to make use of
38 advocacy services with these provisions in place.

39 ***Ensuring advocacy service is person centred***

40 Statement 14 highlighted the importance of advocacy organisations, for example
41 Independent Mental Health Advocates (IMHAs), ensuring their services are person-centred.
42 There was strong support for this statement with the committee agreeing that delivering a
43 person-centred service is essential to providing effective advocacy. They agreed to use the
44 statement as a basis for two separate recommendations, starting with a list of specific
45 suggestions for ensuring advocacy services are person-centred. The first two suggestions
46 that the committee agreed were similar to those set out in the QPM (2018), so to avoid
47 confusion they agreed to align the wording with the QPM. For one of the other suggestions,
48 the committee drew on statement 30, about offering a choice of delivery for individuals
49 seeking support. In the committee's experience there are a variety of reasons why a person
50 might prefer an advocate of a certain gender, ethnicity, or age. This might not be possible in
51 every situation, however they agreed it is important that advocacy services make every
52 attempt to match an advocate to these preferences to ensure that the person receiving
53 advocacy is comfortable and to help to establish trust with the advocate. The committee

1 agreed that this might not be possible for all organisations, particularly smaller organisations,
2 but this should be done wherever possible. The committee suggested other ways of ensuring
3 a person-centred service on the basis of their own expertise and experience and they agreed
4 they are important across independent advocacy so they did not retain the specific reference
5 in the statement to IMHAs. On the basis of their experience the committee agreed this
6 recommendation, with its list of suggestions, will achieve benefits beyond the effectiveness of
7 the service, as it also informs other professionals and people using services, educating them
8 about what effective advocacy looks like and what can be expected from the service.
9 Stemming from discussions about this recommendation, the committee agreed to add a
10 recommendation that for people assessed as lacking capacity to instruct their advocate,
11 providers need to pay particular attention to ensure that the service is delivered in a person
12 centred way. In part this means involving people with an interest in the person's welfare and
13 it is something the committee agreed they had to emphasise because in their experience
14 involving other appropriate people does not happen consistently.

15 ***Including people with lived experience***

16 Statement 19 covered advocacy organisations fully including people with learning disabilities
17 within the advocacy organisations (sometimes as paid self-advocates, sometimes as part of
18 management committees or boards, thus giving people with learning disabilities a say in the
19 direction of the organisation). The committee all agreed with this statement but they thought
20 it should be extended beyond learning disabilities to include a broader representation of
21 people, such as people living with dementia, mental health issues and brain injuries as well
22 as people on the autistic spectrum. They therefore expanded on the statement to
23 recommend the active involvement in advocacy organisations of people with lived experience
24 of health and social care or advocacy. They agreed that the benefit of the recommendation
25 would be ensuring the views of people with lived experience influence the design and
26 development of services, so they are far more relevant and address advocacy needs
27 sensitively and comprehensively (which is particularly relevant for those people who have
28 experienced health inequalities). In the committee's experience this does not happen
29 consistently, and where this does happen, the range of advocacy service users may not be
30 as inclusive as it could be.

31 ***Advocates working with the person they are supporting***

32 Statement 22 covered advocacy services identifying and recording what the advocate is
33 working with a person to achieve in terms of outcomes. The committee agreed with the
34 statement in principle but they also discussed that using the precise wording to make a
35 recommendation could lead to situations in which goals are recorded in initial meetings and
36 then assumed to be fixed. In their experience, an advocacy service is most successful when
37 goals are discussed and recorded on an ongoing basis. They therefore reflected this need for
38 flexibility in the recommendation but also used wording to ensure there is a shared
39 understanding and clarity about what the person wants to achieve. The committee agreed
40 this was essential to being able to judge the success of the advocacy provided and to other
41 health and social care services being able to respond and plan appropriately. Despite being
42 seen as a fundamental element of advocacy support, in the committee's experience this is
43 not happening consistently and the recommendation would help to standardise good practice
44 in this area. Statement 5 about everyone involved with advocacy working in partnership
45 when implementing an outcome system was also used to inform this recommendation. The
46 committee acknowledged the challenges of such ongoing discussions in situations where
47 people who lack capacity but agreed that all efforts have to be made to establish the
48 person's wishes and preferred outcomes. To ensure that the service is in the person's best
49 interest the committee recommended that other people could be involved who would have an
50 understanding of what the person would want to achieve (for example family members or
51 carers).

52

1 ***Promoting equality through advocacy services***

2 Statements 24 and 46 highlighted the importance of advocacy services ensuring that there is
3 a tangible commitment from advocacy services to promote equality, equity of access, social
4 inclusion and justice and providing a culturally relevant approach. There was strong
5 agreement for both statements and because they are overlapping, the committee agreed to
6 use them to make a single recommendation for advocacy services to promote equality
7 through their services. The committee agreed this is essential to ensure equality for all in
8 terms of the provision of advocacy services but despite being a legal requirement covered by
9 the Equality Act (2010), in the committee's experience, this does not happen consistently.
10 The committee agreed to therefore make this recommendation in the strongest terms, using
11 the wording 'must' on the basis of being required by law.

12 ***Effective advocacy in the context of safeguarding***

13 Statement 28 highlighted the importance of identifying key local issues to ensure an effective
14 role for advocacy including IMHAs in making safeguarding personal. There was agreement
15 for this statement not least because the committee acknowledged that the role of advocacy
16 in safeguarding is not generally very well understood. They therefore used the statement to
17 make a recommendation but because they felt it was generally applicable they did not
18 include the specific reference to IMHA. The committee also agreed to add a range of
19 suggestions for ways in which advocacy providers can achieve effective advocacy in the
20 context of safeguarding. These were based on the committee's own expertise and
21 experience of safeguarding which suggested that advocacy is not consistently well provided
22 in the context of safeguarding, despite the Care Act (2014) specifying that local authorities
23 must appoint an independent advocate to support someone through a Safeguarding Adults
24 Review.

25 ***Agreeing on service level outcomes***

26 Statement 33 covered that advocacy outcomes need to be identified and recorded for
27 services. There was agreement for this statement so the committee agreed to use it as a
28 basis for a recommendation although they reworded it to make it clearer and more action
29 orientated. In the committee's experience in addition to knowing whether a person's
30 outcomes and goals have been achieved through advocacy, it is also important to know that
31 service providers are delivering an effective service to the local population. This is largely
32 measured through reporting on key performance indicators as part of contracts and
33 commissioning arrangements. However, the committee agreed that all service providers
34 have a responsibility for evaluating their service beyond the requirements of formal contracts,
35 for example in terms of whether people's voices are heard through the service (i.e., if their
36 views are listened to, understood and considered by others) or whether they are being
37 empowered to have greater control over choices about the care and services they use. The
38 committee also agreed it was important to have clarity about how outcomes will be reported
39 as this could enable data to be separated out based on protected characteristics or other
40 disadvantaged groups such as those facing health inequalities. On this basis the committee
41 made recommendations 1.11.1 and 1.11.2, which they agreed were more relevant to the
42 section on monitoring (see evidence review K). They also agreed that 2 partnership working
43 statements provided further support for this recommendation and the reasons for this are
44 explained in evidence review G.

45 ***The same advocate working with a person throughout the advocacy process***

46 Statement 34 highlighted the importance of advocacy providers offering consistency to
47 people. In the committee's experience, effective advocacy depends on the development of
48 trust and a mutual understanding of the issues that are important to the individual. The
49 committee agreed that this trust and understanding takes time to develop so it is easier if the
50 advocate remains constant for as long as the person needs advocacy. The increased trust
51 and understanding that continuity would likely afford may lead to better outcomes for the

1 individual, thus improving the overall quality of advocacy services. This is not happening
2 consistently and not always possible. The committee agreed that there might be cases where
3 a person does not want the same advocate. Therefore, the committee agreed to reword this
4 statement to improve clarity so that advocacy providers should, where possible and in
5 agreement with the person, keep the same advocate for each person. Statement 44
6 highlighted the importance of service users and carers being confident that IMHA is
7 independent. There was complete agreement with this and the committee discussed that it is
8 crucially important for people using advocacy and their carers to know they have their
9 advocate's full support and loyalty. The committee thought this was generally relevant to
10 advocacy so they did not include the specific reference to IMHA in the recommendation.
11 They also agreed it would be useful to add specific ways in which advocacy services can
12 demonstrate their independence from other organisations because an obvious separation
13 from other services communicates a clear message about their independence and ultimately
14 gives people greater confidence when using advocacy services. In the committee's
15 experience this does not happen consistently and there needs to be clear protocols in place
16 to ensure advocacy services maintain their independence.

17 ***Specialised and multi-skilled advocates***

18 Statement 47 highlighted the importance of advocates having mixed skills-sets to offer
19 support to a diverse range of clients who may be facing multiple issues. Some people may
20 have needs in numerous areas, so the committee agreed with the point that the advocacy
21 service could be more effective if one person delivers different types of advocacy, supporting
22 the person holistically. In the committee's experience this would help to achieve person led
23 continuity of care, which could help with consistency and improving the overall quality of
24 advocacy services. Furthermore, advocacy services could be more effective if advocacy is
25 delivered by one person, as it would help to build a trusting relationship between the
26 advocate and the person. However, in the committee's experience it was equally important to
27 also have specialist advocates available where more specialist knowledge is needed. For
28 example, some people might prefer advocates with lived experience, but there might be
29 cases where the advocate only has lived experience in one area and not all situations where
30 the person may need advocacy. The committee also acknowledged that it may not always be
31 possible for all advocacy providers to provide advocates with this breadth of skills. Therefore,
32 the committee agreed that the recommendation should cover having specialised as well as
33 multi-skilled advocates available, where possible, to offer a flexible and integrated service.

34 ***Interpretation and translation services and culturally appropriate advocacy***

35 Statement 64 emphasised that advocacy services should provide interpretation and
36 translation services for African and Caribbean men. In the committee's experience, effective
37 communication is essential to ensure effective advocacy. It is difficult to advocate for
38 someone if communication is not possible, as effective advocacy requires an in-depth
39 understanding of a person's wishes and needs, which in turn can help to build a trusting
40 relationship between the advocate and the person. Interpretation is important when the
41 advocate and the person receiving advocacy do not share the same first language. This
42 might not be provided consistently, as it depends on the availability of interpreting services
43 and it is important that a lack of interpreters for certain languages or forms of communication
44 does not form a barrier to effective advocacy. The committee tried to address this
45 inconsistency through their recommendation for advocacy providers to ensure access to
46 interpretation and translation services. Stemming from these discussions and in light of the
47 expert testimony described in this evidence review (review F), the committee agreed to also
48 include a recommendation to ensure that advocacy is culturally appropriate. Although they
49 agreed that the recommendation for interpretation and translation services would help to
50 ensure advocacy is culturally appropriate, the committee agreed the issue extends beyond
51 language and communication and should be explicitly stated. This was supported by the
52 expert testimony which stated that culturally appropriate advocacy is critical to achieve equity
53 and social justice, however there is currently a lack of appropriate provision for people from

1 Black, Asian and Minority Ethnic communities. The testimony highlighted that when people
2 perceive that services, in this case advocacy, are culturally relevant, in terms of their own
3 ethnic identity, this can create a sense of shared understanding and encourage access to
4 that service.

5 ***Developing cultural competence***

6 Also stemming from statement 64, the committee discussed how in their experience
7 advocacy requires an in-depth understanding of a person's wishes, needs and preferences,
8 many of which will be influenced by their cultural or ethnic identity and experience of health
9 inequalities. Advocates need to be sensitive to this to ensure effective advocacy. Although
10 this is integral to good practice, in the committee's experience this is not happening
11 consistently. The committee therefore agreed to also add a recommendation to ensure
12 advocacy services support their staff to develop cultural competence through means of
13 training, supervision and reflective practice.

14 ***Training Health and Social Care practitioners***

15 Statement 2 covered advocacy services providing engagement with an appropriate
16 organisation that meets people's needs. Statement 3 highlighted the importance of advocacy
17 services 'providing' discussions around access to other services, as this could lead to the
18 person having a greater sense of control over their life course. Statement 5 covered the
19 importance of advocacy services including IMHAs ensuring that people are heard and their
20 rights are respected. Statements 37, 39, 40, 41, and 42 covered that IMHA should be
21 effective by ensuring that service user's confidence is increased, providing support and a
22 sense of there being someone on the side of the service user, providing information to
23 increase understanding and awareness of people's rights, assisting service users to regain a
24 sense of personal agency and recover, and providing a supportive and empowering
25 approach. The committee agreed that all of these statements are core parts of the advocacy
26 role that advocates will be doing routinely. In the committee's experience recommendations
27 about these statements targeted at advocates were not necessary, but instead it would be
28 more useful if Health and Social Care practitioners received training about these aspects of
29 the advocacy role to improve their understanding of the role and to better facilitate advocacy.
30 Therefore, the committee agreed to use these statements to inform recommendation 1.10.3
31 about providers and commissioners ensuring that staff in agencies working with advocacy
32 services have training in the role and function of advocates, which is in the section on
33 training for practitioners (see evidence review J).

34 ***Parts of the expert witness testimony that were not used in this review***

35 The committee agreed with the conclusions drawn from the expert witness testimony and
36 considered the inclusion of culturally appropriate and relevant services as integral to
37 advocacy services. However, some points from the expert witness testimony were not used
38 to support recommendations because the committee agreed that they fell outside the remit of
39 NICE guidelines, such as advocacy providers to evidence that they are taking appropriate
40 measures in line with the Public Sector Equality Duty, and relevant good practice frameworks
41 (for example, the Patient Carer Race Equality Framework); investment in culturally specific
42 advocacy to reflect the local demography; mainstream providers to evidence that they are
43 working in partnership with community and voluntary sector organisations to upskill, as
44 necessary, in statutory advocacy; developing a set of indicators to benchmark culturally
45 appropriate advocacy that are sensitive to addressing racialised differences in service
46 access, experiences of advocacy support, and attention to racialised issues at statutory
47 service delivery level; and evidence provided to racialised communities of the commitment to
48 address inequalities in advocacy provision through investment in and supporting community
49 organisations to deliver culturally appropriate advocacy.

1 **Future research recommendation**

2 The committee also made a recommendation for future research to address the existing gap
3 in evidence about the factors that make an advocacy service effective. The research
4 recommendation was also informed by several statements from the area of monitoring so the
5 recommended research, an explanation about why it is important and an outline of the
6 proposed research design are described in evidence review K, monitoring services and
7 collecting data for quality improvement.

8 **Statements that were not used in this review**

9 There were a number of statements carried forward to committee discussions that were not
10 used to inform recommendations. The issues addressed in statements 6, 16, 18, 21, 23, 27,
11 31, 32, 35, 45, 51, 61, 63, 68 and 72 are covered in other recommendations in this guideline.
12 Statements 16, 21, and 31 are covered by recommendation 1.6.2 under this review about
13 advocacy being person centred. Statement 6 is covered by recommendation 1.6.1 in this
14 review about advocacy services being accessible. Statement 35 is covered by
15 recommendation 1.6.9 under this review about advocacy providers maintaining
16 independence. Statement 18 is covered by recommendation 1.10.3 under the area of training
17 practitioners (see evidence review J) about advocates ensuring that people's voices are
18 heard. Statement 23 is covered by recommendations 1.11.6 and 1.11.10 under the area of
19 monitoring services (see evidence review K) about collecting information on the impact of
20 services and about advocacy providers seeking feedback about advocacy support.
21 Statement 27 is covered in the recommendation about improving consistency and advocacy
22 in safeguarding is covered by the Care Act (2014). Statement 32 and 45 are covered in the
23 recommendation about finding out the views, needs, and goals of the person. Statement 26
24 was not used to inform a recommendation as the recommendations in monitoring provide
25 more detail about what information should be collected. Statement 35 is covered by
26 recommendation 1.7.2 under the area of partnership working (see evidence review G) about
27 advocacy providers being familiar with local support services. Statement 51 is covered by the
28 recommendation about good communication which cross references to existing NICE
29 guidelines. Statement 61 is covered by the recommendation about presenting the persons'
30 needs and preferences. The committee agreed that statement 63 was not just specific to
31 African and Caribbean men and ensuring that people are receiving advocacy when legally
32 entitled to is covered by the recommendation under legal right to advocacy (see evidence
33 review A), recommendation 1.4.14 under improving access (see evidence review D) and
34 recommendation 1.10.1 under training practitioners (see evidence review J). The committee
35 agreed that the need for cultural sensitivity in statement 68 is covered by recommendation
36 1.6.12 about providing culturally appropriate advocacy but having principles and standards
37 for services was broader than cultural sensitivity which would be a routine part of planning
38 and commissioning services. Statements 50, 52, 53, 54, 56, 58, 60, 62, 63, and 65 were not
39 used to form recommendations as these statements are all part of the job description of an
40 advocate. Statements 4, 11, 15, 17, and 25 were not used to form recommendations as they
41 did not provide enough detail on how to provide effective advocacy. Statements 73 and 74
42 were not used to inform recommendations as these were statements about the impact of
43 advocacy and did not provide enough detail to inform an action but the wider impact of
44 advocacy services was considered in the recommendations in the monitoring section, such
45 as recommendation 1.11.3 about advocacy providers and commissioners measuring the
46 outcomes that show the impact of advocacy (see evidence review K). Statements 69, 70,
47 and 71 were not used to inform recommendations as advocacy cannot directly transform
48 mental health services or increase choice. Statement 20 was not used to inform
49 recommendations because it did not provide enough detail to say how to achieve good
50 outcomes. Furthermore, other statements already provide this detail. Statement 43 was not
51 used to inform recommendations as it is a statutory requirement that advocates are
52 independent. Statement 49 was not used to inform recommendations because advocacy
53 services are unable to directly affect the overrepresentation of African and Caribbean men in
54 mental health services, therefore this cannot be made into an action. Furthermore, the

1 committee agreed that the recommendations made by this guideline as a whole should help
2 to address the problems this statement highlights, by improving the effectiveness of
3 advocacy resulting in people being listened to properly and potentially minimising
4 inappropriate detention. Statement 55 was not used to inform recommendations as the
5 committee agreed that advocates do not have the power to affect improvements in economic
6 and political power. Statement 59 was not used to inform recommendations because acting
7 as an appropriate adult is not the role of advocate. There is free legal Aid to have a solicitor
8 to represent a person at Mental Health Tribunals, so the added value of an advocate in these
9 situations is not clear. Statement 38 was not used to inform recommendations as this is not
10 something advocates specifically have controlled over and the committee pointed out that a
11 person may have a good sense of wellbeing yet still be in need of advocacy support.
12 Statement 48 was not used to inform recommendations as this is not about advocacy and
13 outside of the scope of this guideline.

14 **Cost effectiveness and resource use**

15 Recommendations around shared learning and the development of joint documents,
16 guidance and resources may have a resource impact in terms of time needed to develop,
17 quality assure and promote such tools. This may also require time from advocates to share
18 their experiences and knowledge with others either in writing or through other mediums. This
19 may be particularly difficult for smaller providers who may not have the advocate levels or
20 facilities to produce such tools. Although not an overall resource impact for the NHS and
21 personal social services or for third sector and voluntary organisations, sharing such
22 knowledge may not be desirable for some organisations, especially smaller ones, as it may
23 increase and improve competition for limited funding. The committee however agreed it was
24 important to share best practice and promote joint learning and that it would lead to better
25 advocacy with less repetition, challenges to decisions or need to repeat meetings. Such tools
26 could also be used to promote cost effective or cost saving practices leading to more efficient
27 use of limited resources.

28 Improving awareness about available services may increase uptake of some of the less well
29 promoted ones. This should lead to a redistribution of resources rather than an increase in
30 cost however if either total numbers increases or more costly services are used more
31 frequently there would be an overall resource impact. It should be noted that there is a duty
32 set out in the Care Act 2014 to provide such information about what local services are
33 available and should be current practice in a large number of areas.

34 There may be some increase in resource use from making sure that effective advocacy can
35 be accessed by all people. Resource use may come from having to provide a larger range of
36 venues for in-person meetings or allowing remote meetings where this is beneficial to all
37 parties. However, accessibility is already a legal requirement and investment in remote
38 meetings happened during COVID-19 so large investment will not be needed by all
39 organisations. Providing some flexibility for meeting outside usual working hours will increase
40 costs if overtime or additional hours are required to achieve this. The committee
41 acknowledged though that advocacy is not intended to run as an emergency service so
42 organisations will have discretion on how to implement this.

43 Allowing a person-centred approach to advocacy services especially around allowing a
44 choice of advocate may require the need to have a greater number of advocates.
45 Organisations may need to build extra capacity in their services so that advocates have
46 flexibility to work with different people when such a need arises. The committee acknowledge
47 this may not be possible in smaller or medium sized organisations but were keen to highlight
48 that this should be considered if possible. For such organisations there is unlikely to be any
49 resource impact with advocacy resources being reorganised where possible rather than
50 capacity increasing. Person centred care is important for advocacy as well as health and
51 social care generally and the committee thought such an approach in advocacy would
52 improve advocacy meetings reducing the need to replicate meetings or the times decisions

1 are challenged reducing downstream costs. It is also possible it could reduce expensive
2 healthcare interventions such as unplanned admission to hospital. The recommendations are
3 also in line with moves within health and social care towards a more person centred
4 approach to health and care.

5 Having the same advocate throughout will require specialist and multi-skilled advocates to be
6 available at the start of a person's contact with advocacy. This may require moving or
7 employing such multi-skilled workers resulting in upfront costs. There may be less need for
8 multi-skilled advocates downstream as duplication of meetings and the need for handovers
9 are both reduced.

10 Providing translation services and culturally appropriate advocacy will lead to an increase in
11 resource use. This additional resource use is through ensuring that translation services can
12 be accessed when needed, collocating advocacy services in more culturally appropriate
13 places (such as community centres) and ensuring that other cultural needs are met. Such
14 needs are currently not being met in a large number of areas and resource implications could
15 be significant. The committee agreed strongly that effective communication and people
16 feeling comfortable and confident in their settings will lead to better advocacy. Lack of an
17 appropriate interpreter for some languages or other forms of communication is a barrier to
18 effective advocacy. The committee after hearing expert testimony agreed strongly that this
19 needed to be implemented but also acknowledged that such recommendations could have a
20 significant resource impact and that economic evidence on the topic had not been identified.
21 The committee however highlighted NICE Principles 9 and 10 which discuss some examples
22 of when recommendations can be made outside usual practice around evidence of
23 effectiveness and cost effectiveness. Principle 9 that NICE guidance should support
24 strategies that improve population health as a whole, while offering particular benefit to the
25 most disadvantaged especially protected characteristics under the Equality Act of 2010.
26 Principle 10 highlights that again recommendations can go against usual decision rules when
27 the fairness of society can be improved. Whilst the committee accepted that there was no
28 evidence around cost effectiveness, there was strong evidence of unfairness and inequality
29 when it came to accessing effective advocacy. The committee therefore considered that any
30 decrease in the efficient use of resources would be more than compensated by the reduction
31 in inequality and increase in the fairness of society.

32 **Other factors the committee took into account**

33 The committee considered the NICE '[Our Principles](#)' in particular principles 9 and 10 when
34 considering cost effectiveness and resource use for recommendations about culturally
35 appropriate advocacy.

36 **Recommendations supported by this evidence review**

37 This evidence review supports recommendations 1.3.1, 1.5.8, 1.6.1 to 1.6.16, 1.8.12, 1.10.3,
38 and 1.11.1 to 1.11.2. Other evidence supporting these recommendations can be found in the
39 evidence reviews on partnership working (see evidence review G).

40 **References – included studies**

41 **Formal consensus**

42 **Lawson 2017**

43 Lawson, J. (2017). Making Safeguarding Personal. What might 'good' look like for advocacy?
44 Local Government Association. Available at:
45 [https://www.local.gov.uk/sites/default/files/documents/25.30%20-
46 %20Chip_MSP%20Advocacy_WEB_2.pdf](https://www.local.gov.uk/sites/default/files/documents/25.30%20-%20Chip_MSP%20Advocacy_WEB_2.pdf) [Accessed 07/04/2021]

1 **Lawson 2020**

2 Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding
3 Personal, Local Government Association. Available at:
4 [https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20r
5 ole%20of%20advocacy%20in%20MSP_04.pdf](https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf) [Accessed 07/04/2021]

6 **Newbigging 2011**

7 Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and
8 Caribbean men: Good practice principles and organizational models for delivery. *Health
9 Expectations*, 16(1), 80-104.

10 **Newbigging 2012**

11 Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012).
12 The Right to Be Heard: Review of the Quality of Independent mental Health Advocate
13 (IMHA) Services in England, University of Central Lancashire. Available at:
14 <https://www.firah.org/upload/notices3/2012/uclan.pdf> [Accessed 13/05/2021]

15 **National Development Team for Inclusion 2014b**

16 National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to
17 Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished

18 **National Development Team for Inclusion 2016a**

19 National Development Team for Inclusion (2016a). Advocacy Outcomes Framework:
20 Measuring the impact of independent advocacy. Available at:
21 https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021]

22 **National Development Team for Inclusion 2020a**

23 National Development Team for Inclusion (2020a). Valuing voices: Protecting rights through
24 the pandemic and beyond. Available at: [https://www.ndti.org.uk/assets/files/Valuing_voices_
25 _Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf](https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf) [Accessed
26 07/04/2021]

27 **National Development Team for Inclusion 2020b**

28 National Development Team for Inclusion (2020b). Valuing voices in Wales: Protecting rights
29 through the pandemic and beyond. Available at: [https://www.dewiscil.org.uk/news/valuing-
30 voices-in-wales-report](https://www.dewiscil.org.uk/news/valuing-voices-in-wales-report) [Accessed 07/04/2021]

31 **Roberts 2012**

32 Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with
33 learning disabilities in England, Improving Health and Lives: Learning Disabilities
34 Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf
35 [Accessed 06/04/2021]

36 **SERIO 2021**

37 SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return
38 on Investment Analysis, The Advocacy People. Available at: [https://www.vfrhub.com/wp-
39 content/uploads/2021/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf](https://www.vfrhub.com/wp-content/uploads/2021/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf) [Accessed
40 06/04/2021]

1 **Other**

2 **Care Act 2014**

3 Care Act, 2014 (c. 23). Available at:

4 <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted> [Accessed 21/09/2021]

5 **Equality Act 2010**

6 Equality Act, 2010 (c.15). Available at: <https://www.legislation.gov.uk/ukpga/2010/15>

7 [Accessed 29/04/2021]

8 **Quality Performance Charter 2018**

9 Quality Performance Charter (QPM), 2018. Available at: [https://qualityadvocacy.org.uk/wp-](https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf)
10 [content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf](https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf)

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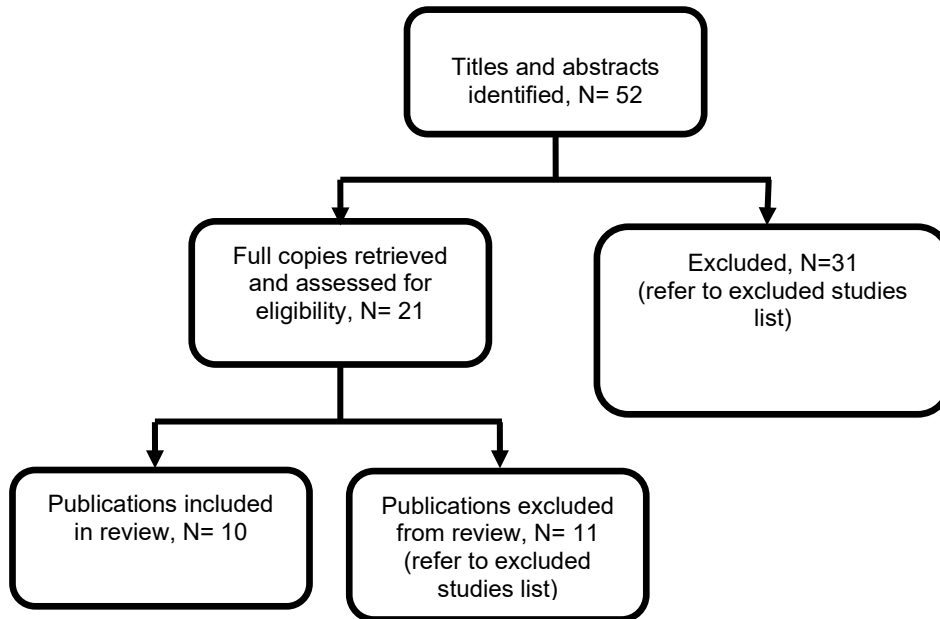
1 **Appendices**

2 **Appendix A Study selection for formal consensus process**

3 **Study selection for scope area: What does effective advocacy look like?**

4 **Figure 1: Study selection flow chart**

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1 Appendix B Evidence tables

2 Evidence tables for scope area: What does effective advocacy look like?

3 Table 3: Evidence tables

Study details	Population	Recommendations/key findings	Quality assessment
<p>Full citation Lawson, J. (2017). Making Safeguarding Personal. What might 'good' look like for advocacy? Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.30%20-%20Chip_MSP%20Advocacy_WEB_2.pdf [Accessed 07/04/2021]</p> <p>Country/ies where the study was carried out England</p> <p>Study type Report/Review</p> <p>Study dates 2017</p> <p>Source of funding No sources of funding reported.</p>	<p>Those who have duties to commission and arrange advocacy services</p>	<p>Key findings in relation to what does effective advocacy look like? (Delivering Advocacy)</p> <ul style="list-style-type: none"> Commissioners involve people who use or are likely to use advocacy to inform their understanding of advocacy, embracing the range of view from all sections of the community. 	<p>Quality assessment using AGREE II</p> <p>1) Scope and Purpose 61% Overall objective and population are described. Health question is not specifically described but alluded to</p> <p>2) Stakeholder involvement 22% Target users are defined but not information on guideline development group and views and preferences from population has been included.</p> <p>3) Rigour of development 8% Health benefits when describing recommendations have been considered. No information on systematic methods, criteria selection, strengths and limitations, and methods for formulating recommendations have been provided. Link between recommendations and supporting evidence not clear. No information on external reviewing, and procedure for updating have been provided.</p> <p>4) Clarity of presentation 22% Recommendations are not always specific and easily identifiable. No mentioning of different options for management.</p> <p>5) Applicability 4%</p>

Study details	Population	Recommendations/key findings	Quality assessment
			<p>Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource implications, and auditing criteria provided.</p> <p>6) Editorial independence 0.0% No funding body and competing interest have been identified.</p> <p>Overall rating 29%</p>
<p>Full citation Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding Personal, Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf [Accessed 07/04/2021]</p> <p>Country/ies where the study was carried out England</p> <p>Study type Qualitative (Focus group discussions)</p> <p>Study dates 2020</p> <p>Source of funding No sources of funding reported</p>	<p>Those who have duties to commission and arrange advocacy services</p>	<p>Recommendations in relation to what does effective advocacy look like (Delivering advocacy)</p> <ul style="list-style-type: none"> • There is a need of identifying what needs to be done and by whom to ensure a more effective role for advocacy in MSP, (Making Safeguarding Personal) including identification of: <ul style="list-style-type: none"> ○ national steps that can be taken to enhance consistency of approach and effectiveness. ○ key local issues. Planning and carrying out local actions accordingly across stakeholders 	<p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No) Yes – to support strengthening the role of all types of advocacy in safeguarding adults, specifically in Making Safeguarding Personal by generating multi-agency conversations based on the briefing and stimulating local action to address some of the core messages that emerge from this.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can't tell/No) Yes.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No) Yes.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No) Can't tell - insufficient detail provided on recruitment strategy.</p> <p>5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No) Yes. Semi-structured focus group discussions on teleconference calls were held with 28 advocates from 18</p>

Study details	Population	Recommendations/key findings	Quality assessment
			<p>advocacy providers across England, covering 33 Local Authority areas.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can't tell/No) No - ethical issues and approval for the study were not discussed.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No) Can't tell – no details provided.</p> <p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings.</p> <p>10. How valuable is the research? Valuable - the authors discuss issues arising in relation to providing advocacy services in relation to safeguarding adults, and provide suggestions on how to address the key issues.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Serious limitations.</p>
<p>Full citation National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project:</p>	<p>People living with disabilities</p>	<p>Key findings in relation to what does effective advocacy look like (Delivering advocacy)</p>	<p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)</p>

Study details	Population	Recommendations/key findings	Quality assessment
<p>Summary Findings Minister’s Briefing Note. Unpublished</p> <p>Country/ies where the study was carried out England</p> <p>Study type Briefing Note/Survey</p> <p>Study dates 2014</p> <p>Source of funding No sources of funding reported</p>		<ul style="list-style-type: none"> Choice of delivery for individuals seeking support determines effectiveness. Important to tailor local delivery to fit local needs. Using a “whole-life” approach that doesn’t just focus on “the presenting issue”. This approach is likely to lead to better outcomes for individuals, efficiencies for advocacy providers and savings for commissioners. Outcomes are identified and recorded (not just for clients but for services too) Advocacy providers are viable and offer consistency to their clients (most often associated with providers having more than one funding source and being well networked within their locality) The research identified characteristics reflecting effective, holistic advocacy: <ul style="list-style-type: none"> The importance of advocates having mixed skills-sets to offer support to a diverse range of clients, many with multiple issues People living with disabilities being offered and experiencing person-centred support with a choice of 	<p>Yes – to summarise the findings of the survey to highlight what good advocacy for disabled people should look like.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No) Can’t tell – Survey included over 200 advocacy providers but no more information was included.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No) Can’t tell – Insufficient information regarding the survey.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No) Can’t tell - insufficient detail provided on recruitment strategy.</p> <p>5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No) Can’t tell – insufficient detail on data collection</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No) No - ethical issues and approval for the study were not discussed.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No) Can’t tell – no details provided.</p> <p>9. Is there a clear statement of findings? (Yes/Can’t tell/No)</p>

Study details	Population	Recommendations/key findings	Quality assessment
		different ways of receiving that support.	<p>Yes – to some extent. Findings are clearly discussed but researchers do not discuss credibility of their findings.</p> <p>10. How valuable is the research? Valuable - the authors discuss issues in delivering advocacy for disabled people and highlight key areas to improve on as well as providing a summary as to what 'good' advocacy should look like.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Serious limitations.</p>
<p>Full citation National Development Team for Inclusion (2016a). Advocacy Outcomes Framework: Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021]</p> <p>Country/ies where the study was carried out England</p> <p>Study type Framework</p> <p>Study dates 2016</p> <p>Source of funding Esmee Fairbairn Foundation</p>	Providers, commissioners and users of independent Advocacy	<p>Key findings in relation to what does effective advocacy look like (Delivering advocacy)</p> <ul style="list-style-type: none"> • Effective advocacy is/means: <ul style="list-style-type: none"> ○ Delivering good outcomes for person receiving the advocacy support and most importantly supporting a person to achieve their goals. Clearly identify what advocate is working with a person to achieve. ○ Will lead to frequent changes and improvements in how health and social care services are planned, delivered, and evaluated. ○ Promoting social inclusion, equality and social justice and critical role in changing how communities are experienced and accessed by its members. 	<p>Quality assessment using AGREE II</p> <p>1) Scope and Purpose 22% Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided.</p> <p>2) Stakeholder involvement 28% Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear.</p> <p>3) Rigour of development 10% Health benefits have seemingly been considered when describing recommendations. No information regarding systematic methods, criteria for selection, strengths and limitations, and methods for formulating recommendations have been provided. Links between recommendations and evidence are not clear. No information on external reviews and no information on updating has been provided.</p> <p>4) Clarity of presentation 56%</p>

Study details	Population	Recommendations/key findings	Quality assessment
		<ul style="list-style-type: none"> Measuring what works or does not work is important way of improving impact of advocacy 	<p>Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to.</p> <p>5) Applicability 21% Advice on how to put recommendations into practice is alluded to but not clearly defined. No information facilitators and barriers, potential resource implications, auditing criteria are provided.</p> <p>6) Editorial independence 17% Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided.</p> <p>Overall rating 34%</p>
<p>Full citation National Development Team for Inclusion (2020a). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021]</p> <p>Country/ies where the study was carried out England and Wales</p> <p>Study type Survey (open and closed ended questions)</p> <p>Study dates</p>	<p>Advocates (across multiple areas of statutory and non-statutory advocacy)</p>	<p>Key findings in relation to what does effective advocacy look like? (Delivering Advocacy)</p> <ul style="list-style-type: none"> Three quarters (76%) of advocates reported that people’s human rights were not being fully upheld during the pandemic; health and social care services reduced, non-compliance with legal duties, severe ongoing restrictions on people’s liberty and private and family life. “Section 17 leave was withheld with a blanket approach being adopted, however staff could go out on the patients behalf. We challenged why staff couldn’t take the patient with them 	<p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No) Yes - to gather information on the accessibility and quality of advocacy and the Covid-19 pandemic's impact on people who are entitled to advocacy, along with the challenges and what was working well in response to the pandemic and the restrictions in place.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No) Yes.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No) Yes.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No) Can’t tell - insufficient detail provided on recruitment strategy.</p>

Study details	Population	Recommendations/key findings	Quality assessment
June 2020 Source of funding		<p>and the practice was reviewed and Section 17 leave was then granted following an individual risk assessment, as it should have been from the start.” (p.8)</p> <ul style="list-style-type: none"> • Advocacy principles for coronavirus and beyond <ul style="list-style-type: none"> ○ Make sure that people are heard and their rights are respected. ○ Communicate effectively, and safely meet with people in person. ○ Effective communication central to advocacy; many advocates support people who need additional support to communicate or who use non-verbal communication techniques. ○ In addition, confidentiality and privacy are crucial to deliver person-centred advocacy. ○ Sharing learning, insights, tools and developing joint publications, guidance, and resources, will ensure continued collective effectiveness across the advocacy sector. <p>Recommendations in relation to What does effective</p>	<p>5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No) Can't tell – limited information on methods of data collection and no other details provided.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can't tell/No) No - ethical issues and approval for the study were not discussed.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No) Can't tell – no details provided.</p> <p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.</p> <p>10. How valuable is the research? Valuable - the authors provide recommendations relating to responding to future waves of the pandemic and providing social care and support for people with long-term health conditions beyond the coronavirus pandemic.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Serious limitations.</p>

Study details	Population	Recommendations/key findings	Quality assessment
		<p>advocacy look like? (delivering advocacy)</p> <ul style="list-style-type: none"> • Shared commitments by advocacy organisations to ensure people’s access to effective advocacy. Advocacy organisations have committed to: <ul style="list-style-type: none"> ○ Make sure their advocacy services are known about, accessible, person-centred, and provide effective advocacy whether through remote tools or face to face meetings. 	
<p>Full citation National Development Team for Inclusion (2020b). Valuing voices in Wales: Protecting rights through the pandemic and beyond. Available at: https://www.dewiscil.org.uk/news/valuing-voices-in-wales-report [Accessed 07/04/2021]</p> <p>Country/ies where the study was carried out Wales</p> <p>Study type Survey (open and closed ended questions)</p> <p>Study dates June 2020</p>	<p>Advocates (across multiple areas of statutory and non-statutory advocacy)</p>	<p>Key findings in relation to what does effective advocacy look like? (Delivering Advocacy)</p> <ul style="list-style-type: none"> • 85% of advocates reported that people’s human rights were not being fully upheld during the pandemic; health and social care services reduced, non-compliance with legal duties, severe ongoing restrictions on people’s liberty and private and family life. • Reduced referral rates: “Referrals to advocacy are much lower and indicate rights to advocacy not observed.” (p.9) and “Lower admissions to wards. Some wards stopped referring for a while thinking, despite assurances 	<p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No) Yes - to gather information on the accessibility and quality of advocacy and the Covid-19 pandemic’s impact on people who are entitled to advocacy, along with the challenges and what was working well in response to the pandemic and the restrictions in place.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No) Yes.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No) Yes.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No) Can’t tell - insufficient detail provided on recruitment strategy.</p>

Study details	Population	Recommendations/key findings	Quality assessment
<p>Source of funding Age Cymru</p>		<p>to the contrary, that IMHA was suspended by the CA2020....” (p.9)</p>	<p>5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No) Can't tell – limited information on methods of data collection and no other details provided.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can't tell/No) No - ethical issues and approval for the study were not discussed.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No) Can't tell – no details provided.</p> <p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.</p> <p>10. How valuable is the research? Valuable - the authors provide recommendations relating to responding to future waves of the pandemic and providing social care and support for people with long-term health conditions beyond the coronavirus pandemic.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Serious limitations.</p>
<p>Full citation</p>	<p>African and Caribbean men</p>	<p>Key findings in relation to what does effective advocacy</p>	<p>Quality assessment using ROBIS <i>Phase two</i></p>

Study details	Population	Recommendations/key findings	Quality assessment
<p>Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and Caribbean men: Good practice principles and organizational models for delivery. <i>Health Expectations</i>, 16(1), 80-104.</p> <p>Country where the study was carried out UK (England, Wales, and Northern Ireland)</p> <p>Study type Systematic literature review and national survey</p> <p>Study dates 2011</p> <p>Source of funding Social Care Institute of Excellence (SCIE)</p>	<p>using mental health services; providers of mental health advocacy services for adults that either targeted African and/or African and Caribbean men, BME communities or provided a service for the whole population in a locality.</p>	<p>look like (Delivering Advocacy)</p> <ul style="list-style-type: none"> • Mainstream advocacy organisation do not meet needs for local African, Caribbean and South Asian communities. There is lack of resources for BME advocacy, an imbalance of power and a lack of understanding amongst mainstream mental health advocacy services of cultural issues. • Descriptions of advocacy services for African and Caribbean communities highlighted various negative issues facing African and Caribbean men which could be addressed by advocacy services: <ul style="list-style-type: none"> ○ Over representation in mental health services. ○ Access to appropriate and sufficient support in the community across statutory and voluntary sectors. ○ Good communication to reduce the risks of isolation and exclusion. ○ Improved access to housing. ○ Support around benefits. ○ Enabling issues and complaints about statutory services to be raised. 	<p>1.1 Did the review adhere to pre-defined objectives and eligibility criteria? Yes – There were a clear protocol and pre-specification of objectives the review are provided.</p> <p>1.2 Were the eligibility criteria appropriate for the review question? Yes – Eligibility criteria seem appropriate for review question</p> <p>1.3 Were eligibility criteria unambiguous? Yes – Eligibility criteria were clearly defined</p> <p>1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate? Yes - Restrictions seemed appropriate</p> <p>1.5 Were any restrictions in eligibility criteria based on sources of information appropriate? Yes - Restrictions applied on the basis of sources of information were clearly described.</p> <p>Concerns regarding specification of study eligibility criteria Low Concern - Considerable effort has been made to clearly specify the review question and objectives, and to pre-specify and justify appropriate and detailed eligibility criteria that have been adhered to during the review</p> <p>2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports? Yes – Direct databases are all clearly identified.</p> <p>2.2 Were methods additional to database searching used to identify relevant reports? Yes – secondary reference search was undertaken.</p>

Study details	Population	Recommendations/key findings	Quality assessment
		<ul style="list-style-type: none"> ○ Addressing the lack of economic and political power. ○ Medication issues. ○ Addressing drug abuse. ● All organisations described providing, or the potential for providing, the following services for African and Caribbean men: <ul style="list-style-type: none"> ○ Support in meetings with mental health services- ward rounds and CPA meetings. ○ Representation at Mental Health Tribunals or as an Appropriate Adult. ○ Negotiation with service providers particularly in respect of medication and leave. ○ Signposting and referral to other sources of specialist support and support navigating the mental health system. ○ Working in partnership to enable partners to speak for themselves. ○ Supporting people to make complaints or air grievances. ○ Supporting people to access rights and entitlements. ○ Interpreting and translating. ○ Help with housing and benefit issues. 	<p>2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible? No information</p> <p>2.4 Were restrictions based on date, publication format, or language appropriate? No – Search was restricted to English language publications.</p> <p>2.5 Were efforts made to minimise errors in selection of studies? Yes – Two authors independently screened and searched data.</p> <p>Concerns regarding methods used to identify and/or select studies Unclear concern – Some information regarding search strategy is missing</p> <p>3.1 Were efforts made to minimise error in data collection? Yes – 2 authors independently data extracted.</p> <p>3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results? Probably yes – Link to full study characteristics provided; however cannot access these.</p> <p>3.3 Were all relevant study results collected for use in the synthesis? Probably yes – Unclear whether all relevant study results were included</p> <p>3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria? Yes – TAPUPAS standard was used to critically assess included studies.</p>

Study details	Population	Recommendations/key findings	Quality assessment
		<ul style="list-style-type: none"> ○ Support for families. ○ Re-establishing social networks. ○ Befriending. ● There was a need for cultural sensitivity of services, which should be underpinned by a clear set of principles and standards to provide a framework for 	<p>3.5 Were efforts made to minimise error in risk of bias assessment? Yes – Two reviewers independently critically assessed included papers and a third reviewer was used where there were discrepancies.</p> <p>Concerns regarding methods used to collect data and appraise studies Low concern – Insufficient information about study characteristics but risk of bias as assessed accordingly.</p> <p>4.1 Did the synthesis include all studies that it should? No information</p> <p>4.2 Were all predefined analyses followed or departures explained? No information</p> <p>4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies? No information</p> <p>4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis? No information</p> <p>4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses? No information</p> <p>4.6 Were biases in primary studies minimal or addressed in the synthesis? No - The studies were evaluated for risk of bias but results were not incorporated into findings/conclusion</p> <p>Concerns regarding the synthesis and findings</p>

Study details	Population	Recommendations/key findings	Quality assessment
			<p>Unclear concern - There is insufficient information reported to make a judgement on risk of bias</p> <p>Phase three</p> <p>A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment? Yes</p> <p>B. Was the relevance of identified studies to the review's research question appropriately considered? Yes</p> <p>C. Did the reviewers avoid emphasizing results on the basis of their statistical significance? Yes</p> <p>Risk of bias – Unclear risk of bias</p> <p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No) Yes – Aims very clearly defined</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can't tell/No) Yes</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No) Yes</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No) Yes – Recruitment strategy clearly defined and deemed appropriate.</p>

Study details	Population	Recommendations/key findings	Quality assessment
			<p>5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No) Yes – Focus groups and national surveys were used.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) Can't tell – No information provided</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can't tell/No) Yes – Ethical issues were considered</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No) Yes – Thematic analysis was used and clearly defined.</p> <p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings</p> <p>10. How valuable is the research? Valuable- Researchers also highlight that there is further need for research on the impact of advocacy on the use of mental health services, satisfaction with care, and mental health and broader social outcomes for African and Caribbean men and the relationship between different organizational models for provision and this range of outcomes.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) No limitations</p>
<p>Full citation Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able,</p>	<p>Patients detained under the amended Mental Health</p>	<p>Recommendations in relation to what does effective advocacy look like (Delivering Advocacy)</p>	<p>Quality assessment using CASP qualitative studies checklist</p>

Study details	Population	Recommendations/key findings	Quality assessment
<p>L., et al. (2012). The Right to Be Heard: Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire. Available at: https://www.firah.org/upload/notices3/2012/uclan.pdf [Accessed 13/05/2021]</p> <p>Country/ies where the study was carried out England</p> <p>Study type Mixed methods: literature review, qualitative research (focus groups and interviews), case studies</p> <p>Study dates 2010 to 2012</p> <p>Source of funding Department of Health</p>	<p>Act 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)</p>	<ul style="list-style-type: none"> • The role of IMHAs in relation to the Safeguarding process needs further investigation and guidance. • Non-instructed advocacy appeared to many to go against the ethos of advocacy in terms of being person-centred and person-driven. One IMHA stated that “it does feel quite unnatural at first” [IMHA] (p.146), contrasting with generic advocacy when the advocate would not be asking questions of family or staff if the person had not asked them to. • Service users and mental health professionals recognised the main benefit from IMHAs was ensuring service users had a voice. For example, “The outcome is about ensuring that person’s voice is heard and that they understand what their rights are and that they’ve had an opportunity to exercise those rights. So it’s not necessarily about them getting what they want in the end of that, it’s about the process of supporting them, ensuring that they’re kept at the centre of the decisions that are being made about them, and that they could feel confident that 	<p>1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No) Yes - to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to people who qualify for these services under the MHA 1983. To identify the factors that affect the quality of IMHA services.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No) Yes.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No) Yes.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No) Yes - how IMHA services and service users were identified is explained, in addition to identification of carers and family members, mental health staff and commissioners.</p> <p>5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No) Yes - the methods used were explicitly described and justifications for their use were provided, although saturation of data was not discussed.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No) Yes - the authors acknowledged the potential for the quality of the data collection and analysis to be influenced by the researchers.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)</p>

Study details	Population	Recommendations/key findings	Quality assessment
		<p>they've been listened to and understood by services." [IMHA] (p.192)</p> <ul style="list-style-type: none"> • Increasing service users' confidence. • Increasing service users' sense of wellbeing. • Providing support and a sense of there being someone on the side of the service user. • Providing information to increase understanding and awareness, for example on rights and treatment. • Assisting service users to regain a sense of personal agency and recovery. • Supportive, empowering approach. • Providing an important safeguarding function. • IMHA Service Characteristics • Quality indicator 13 – Independence <ul style="list-style-type: none"> ○ IMHA services are independent organisations from statutory mental health service provision. ○ Mental health service users and their carers are confident that the IMHA service is independent from statutory provision. • Quality indicator 14 – Person-centred focus 	<p>Yes - ethical approval was received from the Cambridgeshire 3 Research Ethics Committee and the International School for Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No) Yes - the authors describe the analysis process and sufficient data are presented to support the findings.</p> <p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes.</p> <p>10. How valuable is the research? Valuable - the authors highlight gaps in the evidence, how the evidence relates to previous research, and implications for practice and policy and future research.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Minor limitations.</p>

Study details	Population	Recommendations/key findings	Quality assessment
		<ul style="list-style-type: none"> ○ IMHA services have a clear person-centred focus and the centrality of relationship to advocacy work is recognised in service specification and contracts. There is a tangible commitment to equality, equity of access and providing a culturally relevant approach. 	
<p>Full citation Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf [Accessed 06/04/2021]</p> <p>Country/ies where the study was carried out England</p> <p>Study type Survey (open and closed ended questions) and case studies</p> <p>Study dates December 2011 and January 2012</p> <p>Source of funding</p>	<p>A range of people including people living with learning disabilities</p>	<p>Key findings in relation to what does effective advocacy look like? (delivering advocacy)</p> <ul style="list-style-type: none"> • 54 advocacy organisations provided examples on what had been done well, with advocacy being user led as a major theme emerging from examples of good practice: • Supporting parents with learning disabilities, including child protection issues (8 organisations). Fully including people with learning disabilities within the advocacy organisations (sometimes as paid self-advocates, sometimes as part of management committees or boards, thus giving people with learning disabilities a say in the direction of the organisation). 	<p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No) Yes - to explore the nature and extent of advocacy services for people with learning disabilities in England, how funding changes affect these services, and the impact of advocacy on health and health services for people with learning disabilities.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can't tell/No) Yes.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No) Yes.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No) Yes - how advocacy organisations and commissioners of advocacy services were identified is explained to some extent.</p> <p>5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)</p>

Study details	Population	Recommendations/key findings	Quality assessment
Supported by the Department of Health.		<ul style="list-style-type: none"> 1-1 case advocacy, including crisis advocacy (7 organisations). 	<p>Can't tell – limited information on methods of data collection and no other details provided.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can't tell/No) No - ethical issues and approval for the study were not discussed.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No) Can't tell – no details provided.</p> <p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.</p> <p>10. How valuable is the research? Valuable - the authors provide evidence on gaps in the provision of advocacy services and areas for further research.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Serious limitations.</p>
<p>Full citation SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return on Investment Analysis, The Advocacy People. Available at:</p>	Military veterans and their families	<p>Key findings in relation to what does effective advocacy look like (Delivering Advocacy)</p> <ul style="list-style-type: none"> Benefits for many clients in terms of onward referral to, 	<p>Quality assessment using CASP qualitative studies checklist</p> <p>1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)</p>

Study details	Population	Recommendations/key findings	Quality assessment
<p>https://www.vfrhub.com/wp-content/uploads/221/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf [Accessed 06/04/2021]</p> <p>Country/ies where the study was carried out England</p> <p>Study type Mixed methods: literature review, qualitative research and social return on investment analysis</p> <p>Study dates 2018 to 2021</p> <p>Source of funding No sources of funding reported.</p>		<p>and engagement with, an appropriate organisation that met their needs (for example, organisations providing social activities, provision of access to education or employment), or discussed access to other services, led to a sense of greater control of their life course.</p> <ul style="list-style-type: none"> ○ “The Veterans’ Advocacy People is like a bridge between veterans and services; a voice for veterans who are unable, for whatever reason, to access the services of benefits they are entitled to, like mental health, physical health, etc.” (p.21) ● The knowledge that The Veterans’ Advocacy People was specifically focussed on supporting veterans was important. ○ “The Veterans’ Advocacy People gave me a voice. Someone was listening to me and offering the support that I was lacking. Before them, I had no knowledge of this type of service. I find that, in our group, it’s difficult to ask for help because if someone puts you down you shut down.” (p.21) 	<p>Yes - to assess the impact of advocacy on veterans and their families, and the wider social and financial impact. To enable a greater understanding within central and local government and across the military charity sector of any potential for investment in this area and lessons for practice in support for veterans and in the wider use of advocacy services.</p> <p>2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No) Yes.</p> <p>3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No) Yes.</p> <p>4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No) Can’t tell - insufficient detail provided on recruitment strategy.</p> <p>5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No) Can’t tell – limited information on methods of data collection.</p> <p>6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.</p> <p>7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No) No - ethical issues and approval for the study were not discussed.</p> <p>8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No) Can’t tell – no details provided.</p>

Study details	Population	Recommendations/key findings	Quality assessment
			<p>9. Is there a clear statement of findings? (Yes/Can't tell/No) Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.</p> <p>10. How valuable is the research? Valuable - the authors suggest strengths and limitations of the research and potential for unintended outcome consequences, and suggestions for further analysis relating to data monitoring.</p> <p>Overall methodological limitations (No or minor/Minor/Moderate/Serious) Serious limitations.</p>

- 1 AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; BME: Black and Minority Ethnic; CASP: Critical Appraisal Skills Programme; CPA: Care Programme
- 2 Approach; IMHA: Independent Mental Health Advocate; MHA: Mental Health Act; NDTi: National Development Team for Inclusion; ROBIS: Risk of Bias Assessment Tool for
- 3 Systematic Review; TAPUPAS: transferability, accessibility, propriety, utility, purposivity, accuracy and specificity; UCLAN: University of Central Lancashire

1 Appendix C Quality Assessment

2 Quality assessment tables for scope area: What does effective advocacy look like?

3 Formal consensus

4 **Table 6: AGREE II assessment of included guidelines**

Ratings								
Guideline	Year	Scope and Purpose	Stakeholder involvement	Rigour of development	Clarity of presentation	Applicability	Editorial independence	Overall rating
Lawson 2017	2017	61%	22%	8%	22%	4%	0%	29%
NDTi 2016a	2016	22%	28%	10%	56%	21%	17%	34%

5 *AGREE: Appraisal of Guidelines for Research & Evaluation Instrument*

6 **Table 4: ROBIS quality assessment of included systematic reviews**

Domains (Low concern/High concern/Unclear concern)						
Systematic review reference	Year	Study eligibility criteria	Identification and selection of studies	Data collection and study appraisal	Synthesis and findings	Overall risk of bias
Newbigging 2011	2011	Low concern	Unclear concern	Low concern	Unclear concern	Unclear concern

7 *ROBIS: Risk of Bias Assessment Tool for Systematic Reviews*

1 **Table 5: CASP quality assessment of included qualitative studies**

Screening questions (Yes/No/Can't tell)											
Qualitative study reference	Year	Clear statement of aims of research	Appropriate methodology	Research design appropriate to address aims	Appropriate recruitment strategy	Appropriate data collection methods	Relationship between researcher and participants adequately considered	Ethical issues taken into consideration	Data analysis sufficiently rigorous	Clear statement of findings	How valuable is the research
Lawson 2020	2020	Yes	Yes	Yes	Can't tell	Yes	No	No	Can't tell	Yes	Valuable
NDTi 2014b	2014	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
NDTi 2020a	2020	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
NDTi 2020b	2020	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
Newbigging 2011	2011	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable
Newbigging 2012	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Roberts 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable
SERIO 2021	2021	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable

2 *CASP: Critical Appraisal Skills Programme*

1 Appendix D Excluded studies

2 Excluded studies for scope area: What does effective advocacy look like?

3 Formal consensus (documents identified by the call for evidence and the guideline 4 committee)

5 Table 6: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Bauer, B., Wistow, G., Dixon, J., Knapp, M. (2013). Investing in Advocacy Interventions for Parents with Learning Disabilities: What is the Economic Argument? Personal Social Services Research Unit. Available at: http://eprints.lse.ac.uk/51114/1/Investing%20in%20advocay.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Chatfield, D., Lee, S., Cowley, J., Kitzinger, C., Kitzinger, J., Menon, D. (2018). Is there a broader role for independent mental capacity advocates in critical care? An exploratory study. <i>Nursing in Critical Care</i> , 23(2), 82-87.	No key findings or recommendations relevant to What does effective advocacy look like?
Davies, L., Townsley, R., Ward, L., Marriott A. (2009). A framework for research on costs and benefits of independent advocacy, Office for Disability Issues. Available at https://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/odiframework.pdf [Accessed 16/02/2022]	Publication has no evidence base
EY (2017). Society's return on investment (SROI) in older people's cancer advocacy services. Available at: https://opaal.org.uk/?s=Society%27s+return+on+investment+%28SROI%29+in+older+people%E2%80%99s+cancer+advocacy+services [Accessed 16/02/2022]	Publication has no evidence base
Feeney, M., Evers, C., Agpalo, D., Cone, L., Fleisher, J., Schroeder, K. (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. <i>Health Expectations</i> , 23, 722-730.	Non-UK based (International)
Harflett, N., Turner, S., Bown, H., National Development Team for Inclusion (2015). The impact of personalisation on the lives of the most isolated people with learning disabilities. A review of the evidence. Available at: https://www.ndti.org.uk/assets/files/Isolation_and_personalisation_evidence_review_final_02_06_15.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to What does effective advocacy look like?

Study	Reason for Exclusion
Healthwatch (2015). Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service. Available at: https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Kiliñç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. <i>Disability and Rehabilitation</i> , 44(2), 219-230.	Publication is based on case-studies
Macadam, A., Watts, R., Greig, R. (2013). The Impact of Advocacy for People who Use Social Care Services, NIHR School for Social Care Research Scoping Review. Available at: https://www.ndti.org.uk/assets/files/SSCR-scoping-review_SR007.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to What does effective advocacy look like?
Mercer, K., Petty, G. (2020). Scoping Exercise Report – An overview of advocacy delivery in relation to Personal Health Budgets and other health funded support. Available at: https://www.ndti.org.uk/assets/files/Advocacy-Health-Funded-Support-Report-pdf.pdf [Accessed 07/05/2021]	No key findings or recommendations relevant to What does effective advocacy look like?
National Development Team for Inclusion (2012). Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Available at: https://www.ndti.org.uk/assets/files/Reasonably-adjusted_2020-12-30-150637.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to What does effective advocacy look like?
National Development Team for Inclusion, Empowerment Matters (2014). Advocacy QPM: Advocacy Code of Practice, revised edition, 2014. Available at https://qualityadvocacy.org.uk/wp-content/uploads/2018/05/Code-of-Practice-1.pdf [Accessed 25/11/2021]	Publication has no evidence base
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished.	No key findings or recommendations relevant to What does effective advocacy look like?
National Development Team for Inclusion (2014). The impact of advocacy for people who use social care services: a review of the evidence, NDTi Insights. Available at: https://www.ndti.org.uk/assets/files/Insights_19_Impact_of_Advocacy_FINAL.pdf [Accessed 11/02/2022]	No key findings or recommendations relevant to any scope area

Study	Reason for Exclusion
National Development Team for Inclusion. (2015). The impact of personalisation on the lives of the most isolated people with learning disabilities. A review of the evidence	No key findings or recommendations relevant to What does effective advocacy look like?
National Development Team for Inclusion (2016b). Advocacy Outcomes Toolkit: An accompanying guide to the advocacy outcomes framework. Available at: https://www.ndti.org.uk/assets/files/Advocacy_Outcomes_Toolkit.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to What does effective advocacy look like?
National Development Team for Inclusion. (2018). The Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/Advocacy-Charter-A3.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). The Easy Read Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/The-Advocacy-Charter-Easy-Read.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). Advocacy QPM: Assessment Workbook. Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf [Accessed 16/02/2022]	Publication has no evidence base
Newbigging, K., Ridley, J., McKeown, M., Machin, K., Sadd, J., Machin, K., et al. (2015). Independent Mental Health Advocacy – The Right to Be Heard: Context, Values and Good Practice. Jessica Kingsley Publishers: London, UK.	Publication is based on book/book chapter
Older People’s Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer. available at: https://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Older People’s Advocacy Alliance (2016). Facing Cancer Together. Demonstrating the power of independent advocacy. Available at: https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	Publication is based on case-studies
Older People’s Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case-studies

Study	Reason for Exclusion
Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, <i>Mental Health Review Journal</i> , Vol. 23(4), 280-292.	No key findings or recommendations relevant to What does effective advocacy look like?
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services, easy read version. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/easy-read/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2014). At a glance 67: Understanding Independent Mental Health Advocacy (IMHA) for mental health staff. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). Commissioning Independent Mental Health Advocacy (IMHA) services in England: 10 top tips for commissioners. https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/10-top-tips.asp [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence and University of Central Lancashire (2015). Flowchart for Open Access IMHA. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving access to Independent Mental Health Advocacy for providers of mental health services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base

Study	Reason for Exclusion
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a briefing for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/briefing/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence and University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a report for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/report/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). Making a difference: measuring the impact of Independent Mental Health Advocacy (IMHA). Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/impact/ [Accessed 16/02/2022]	Publication is based on case-studies
Social Care Institute for Excellence, University of Central Lancashire (2015). What does a good IMHA service look like? (Self-assessment tool) Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/what-good-imha-service-looks-like/ [Accessed 16/02/2022]	Publication has no evidence base
Strong, S. (2012). User-led organisation leadership of support planning and brokerage. The International Journal of Leadership in Public Services, 8(2), 83-89.	Publication is based on case-studies
Taylor & Francis Production Disability and Rehabilitation (IDRE). My Life Tool (self-management tool): www.mylifetool.co.uk	Publication has no evidence base
Teeside University (2015/2016). UTREG Online Module Specification: Advocacy - Evolution, Equality and Equity. Unpublished.	Publication has no evidence base
Townsley, R., Marriott, A., Ward, L. (2009). Access to independent advocacy: an evidence review, Office for Disability Issues. Available at: http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-exec-summary-standard.pdf [Accessed 16/02/2022]	Not published in the last 10 years
Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory.	No key findings or recommendations relevant to What does effective advocacy look like?

Study	Reason for Exclusion
Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-2012-01.pdf [Accessed 06/04/2021]	
Turner, S. & Giraud-Saunders, A. (2014). Personal health budgets: Including people with learning disabilities	Publication is based on case-studies
VoiceAbility (2021). Preventing over-medication. STOMP top tips for advocates: How you can help to stop the over-medication of people with a learning disability, autism or both	Publication has no evidence base
VoiceAbility (2021). STOMP and STAMP: Stopping the over medication of children, young people and adults with a learning disability, autism or both.	Publication has no evidence base

1 **Excluded economic studies**

2 No economic evidence was considered for this scope area.

3

4

- 1 **Appendix E Research recommendations – full details**
- 2 **Research recommendations for scope area: What does effective advocacy look**
- 3 **like?**
- 4 No research recommendations were made for this scope area.

1 **Appendix F Existing NICE recommendations**

2 No existing NICE recommendations were identified for this scope area.

3

1 Appendix G Formal consensus

2 Additional information related to scope area: Enabling and supporting effective advocacy

3 **Table 7: Formal consensus round 1 statements and results for scope area: Enabling and supporting effective advocacy**

Statement no.	Statement	References	Percentage agreement	Action taken
1	Advocacy services should provide onward referral to an appropriate organisation that meet people's needs.	SERIO 2021	72.73%	Redrafted for round 2
2	Advocacy services should provide engagement with an appropriate organisation that meet people's needs.	SERIO 2021	100.00%	Carried forward to committee discussion
3	Advocacy services should provide discussions around access to other services, as this can lead to a sense of greater control of the person's life course.	SERIO 2021	100.00%	Carried forward to committee discussion
4	It is important that advocacy services are focused on supporting specific populations.	SERIO 2021	63.64%	Redrafted for round 2
5	Advocacy services including IMHAs should ensure that people are heard and their rights are respected.	National Development Team for Inclusion 2020a, Newbigging 2012	100.00%	Carried forward to committee discussion
6	Effective advocacy can be delivered using remote tools or face to face.	National Development Team for Inclusion 2020a	54.55%	Redrafted for round 2
7	Effective advocacy requires effective communication.	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
8	Delivering person-centred advocacy requires confidentiality and privacy.	National Development	100.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
		Team for Inclusion 2020a		
9	It is required to share learning, insights, and tools to ensure continued collective effectiveness across advocacy sector.	National Development Team for Inclusion 2020a	90.91%	Carried forward to committee discussion
10	It is required to develop joint publications, guidance, and resources to ensure continued collective effectiveness across advocacy sector.	National Development Team for Inclusion 2020a	90.00%	Carried forward to committee discussion
11	Advocacy organisations should commit to ensuring people's access to effective advocacy.	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
12	Advocacy organisations need to make sure that their services are known about.	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
13	Advocacy organisations need to make sure that their advocacy services are accessible.	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
14	Advocacy organisations, for example IMHAs, need to make sure that their services are person-centred.	National Development Team for Inclusion 2020a,	100.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
		Newbigging 2012		
15	Advocacy organisations need to make sure that they provide effective advocacy.	National Development Team for Inclusion 2020a	91.67%	Carried forward to committee discussion
16	Advocacy should be user led	Roberts 2012	83.33%	Carried forward to committee discussion
17	Advocacy organisations should fully support parents with learning disabilities.	Roberts 2012	83.33%	Carried forward to committee discussion
18	Advocacy organisations should fully support parents with child protection issues.	Roberts 2012	77.78%	Redrafted for round 2
19	Advocacy organisations should fully include people with learning disabilities within the advocacy organisations (sometimes as paid self-advocates, sometimes as part of management committees or boards, thus giving people with learning disabilities a say in the direction of the organisation).	Roberts 2012	100.00%	Carried forward to committee discussion
20	Advocacy should aim to deliver good outcomes for the person receiving advocacy support	NDTi 2016a	90.91%	Carried forward to committee discussion
21	Advocacy should support a person to achieve their goals.	NDTi 2016a	90.91%	Carried forward to committee discussion
22	Advocacy should clearly identify and record what the advocate is working with a person to achieve in terms of outcomes.	NDTi 2016a, NDTi 2014b	100.00%	Carried forward to committee discussion
23	Advocacy is effective if it involves frequent changes and improvements in how health and social care services are planned, delivered, and evaluated.	NDTi 2016a	60.00%	Redrafted for round 2
24	It is important that there is tangible commitment from advocacy services to promote equality, equity of access, social inclusion and justice.	NDTi 2016a, Newbigging 2012	100.00%	Carried forward to committee discussion
25	Effective advocacy should play a critical role in changing how communities are experiences and accessed by its members.	Newbigging 2012	90.00%	Carried forward to committee discussion
26	Effective advocacy should measure what works or does not work, as an important way of improving the impact of advocacy.	Newbigging 2012	90.91%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
27	National steps that can be taken to enhance consistency of approach and effectiveness need to be identified to ensure a more effective role for advocacy in making safeguarding personal.	Lawson 2020	100.00%	Carried forward to committee discussion
28	Key local issues need to be identified to ensure an effective role for advocacy including IMHAs in making safeguarding personal.	Lawson 2020, Newbigging 2012	90.00%	Carried forward to committee discussion
29	Local actions need to be planned and carried out accordingly across stakeholders.	Lawson 2020	70.00%	Redrafted for round 2
30	Advocacy should offer a choice of delivery for individuals seeking support.	NDTi 2014b	91.67%	Carried forward to committee discussion
31	Advocacy should tailor local delivery to fit local needs.	NDTi 2014b	90.91%	Carried forward to committee discussion
32	Advocacy should use a 'whole-life' approach that doesn't just focus on the 'presenting issue'.	NDTi 2014b	90.91%	Carried forward to committee discussion
33	Advocacy outcomes need to be identified and recorded - for services.	NDTi 2014b	90.91%	Carried forward to committee discussion
34	It is important that advocacy providers offer consistency to people.	NDTi 2014b	91.67%	Carried forward to committee discussion
35	It is important that advocacy providers are viable.	NDTi 2014b	70.00%	Redrafted for round 2
36	The role of independent mental health advocates in relation to the Safeguarding process needs further investigation and guidance.	Newbigging 2012	66.67%	Discarded
37	Effective IMHA should ensure that service user's confidence is increased.	Newbigging 2012	91.67%	Carried forward to committee discussion
38	Effective IMHA should ensure that service user's sense of wellbeing is increased.	Newbigging 2012	83.33%	Carried forward to committee discussion
39	Effective IMHA should ensure to provide support and a sense of there being someone on the side of the service user.	Newbigging 2012	100.00%	Carried forward to committee discussion
40	Effective IMHA should provide information to increase understanding and awareness of people's rights.	Newbigging 2012	100.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
41	Effective IMHA should ensure that service users are assisted to regain a sense of personal agency and recovery.	Newbigging 2012	91.67%	Carried forward to committee discussion
42	Effective IMHA should ensure to provide a supportive and empowering approach.	Newbigging 2012	100.00%	Carried forward to committee discussion
43	IMHA should be independent from statutory mental health provision.	Newbigging 2012	91.67%	Carried forward to committee discussion
44	It is important that service users and carers can be confident that IMHA is independent.	Newbigging 2012	100.00%	Carried forward to committee discussion
45	It is important that the centrality of relationship to advocacy work in IMHA services is recognised in service specification and contracts.	Newbigging 2012	100.00%	Carried forward to committee discussion
46	It is important that there is tangible commitment to equality, equity of access and providing a culturally relevant approach.	Newbigging 2012	100.00%	Carried forward to committee discussion
47	It is important that advocates have mixed skills-sets to offer support to a diverse range of clients, many with multiple issues.	NDTi 2014c	100.00%	Carried forward to committee discussion
48	People living with disabilities should be offered person-centred support with a choice of different ways of receiving that support.	NDTi 2014c	83.33%	Carried forward to committee discussion
49	Advocacy services should address negative issues facing African and Caribbean men, including their over representation in mental health services.	Newbigging 2011	90.91%	Carried forward to committee discussion
50	Advocacy services should address negative issues facing African and Caribbean men, including access to appropriate and sufficient support in the community across statutory and voluntary sectors.	Newbigging 2011	100.00%	Carried forward to committee discussion
51	Advocacy services should address negative issues facing African and Caribbean men, including good communication to reduce the risks of isolation and exclusion.	NDTi 2014c	90.00%	Carried forward to committee discussion
52	Advocacy services should address negative issues facing African and Caribbean men, including improved access to housing.	NDTi 2014c	100.00%	Carried forward to committee discussion
53	Advocacy services should address negative issues facing African and Caribbean men, including support around benefits.	NDTi 2014c	90.91%	Carried forward to committee discussion
54	Advocacy services should address negative issues facing African and Caribbean men, including enabling issues and complaints about statutory services to be raised.	NDTi 2014c	100.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
55	Advocacy services should address negative issues facing African and Caribbean men, including addressing the lack of economic and political power.	NDTi 2014c	81.82%	Carried forward to committee discussion
56	Advocacy services should address negative issues facing African and Caribbean men, including medication issues.	NDTi 2014c	100.00%	Carried forward to committee discussion
57	Advocacy services should address negative issues facing African and Caribbean men, including addressing drug abuse.	NDTi 2014c	72.73%	Redrafted for round 2
58	Advocacy services should provide support to African and Caribbean men in meetings with mental health services, including ward rounds and CPA meetings.	NDTi 2014c	100.00%	Carried forward to committee discussion
59	Advocacy services should aim to represent African and Caribbean men at Mental Health Tribunals or as an Appropriate Adult.	NDTi 2014c	90.91%	Carried forward to committee discussion
60	Advocacy services should provide services for African and Caribbean men to negotiate with other service providers particularly in respect of medication and leave.	NDTi 2014c	100.00%	Carried forward to committee discussion
61	Advocacy services providing services for African and Caribbean men should work in partnership to enable partners to speak for themselves.	NDTi 2014c	88.89%	Carried forward to committee discussion
62	Advocacy services providing services for African and Caribbean men should support people to make complaints or air grievances.	NDTi 2014c	81.82%	Carried forward to committee discussion
63	Advocacy services providing services for African and Caribbean men should support people to access rights and entitlements.	NDTi 2014c	90.91%	Carried forward to committee discussion
64	Advocacy services should provide interpretation and translation services for African and Caribbean men.	NDTi 2014c	80.00%	Carried forward to committee discussion
65	Advocacy services should provide African and Caribbean men with help on housing and benefit issues.	NDTi 2014c	81.82%	Carried forward to committee discussion
66	Advocacy services should provide support for families of African and Caribbean men using services.	NDTi 2014c	72.73%	Redrafted for round 2
67	Advocacy services should provide support for African and Caribbean men to re-establish social networks, including befriending services.	NDTi 2014c	70.00%	Redrafted for round 2
68	There is a need for cultural sensitivity of services, which should be underpinned by a clear set of principles and standards to provide a framework for a basic standard of competence.	NDTi 2014c	100.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
69	Advocacy has the potential to transform mental health services by increasing choice.	Ridley 2018	83.33%	Carried forward to committee discussion
70	Advocacy has the potential to transform mental health services and support by identification and understanding of diverse mental health needs.	Ridley 2018	83.33%	Carried forward to committee discussion
71	Advocacy has the potential to transform mental health services and support by challenging discrimination and racism.	Ridley 2018	83.33%	Carried forward to committee discussion
72	Advocacy has the potential to transform mental health services and support by promoting access to complementary ways of health and practical help.	Ridley 2018	72.73%	Redrafted for round 2
73	There are possibly wider impacts of advocacy on service cultures, particularly in terms of how staff relate to, and involve service users.	Ridley 2018	83.33%	Carried forward to committee discussion
74	There are possibly wider impacts of advocacy on operational practices, particularly in terms of how staff relate to, and involve service users.	Ridley 2018	83.33%	Carried forward to committee discussion

1 CPA: Care programme approach; IMHA: Independent Mental Health Advocate.

2 **Table 8: Formal consensus round 2 statements and results for scope area: Enabling and supporting effective advocacy**

Statement no.	Statement	References	Percentage agreement	Action taken
1	Advocacy services should help people to identify appropriate organisations that best meet their needs and provide them with a sense of greater control of their life course (such as organisations that provide social activities or provision of access to education or employment).	SERIO 2021	66.67%	Discarded
4	People may be more likely to access and engage with specialist advocacy services that are tailored to supporting specific populations.	SERIO 2021	91.67%	Carried forward to committee discussion
6	Depending on individual circumstances, wishes and communication needs, effective advocacy can be delivered using remote tools or face-to-face.	National Development Team for Inclusion 2020a	90.91%	Carried forward to committee discussion
18	Advocacy organisations providing advocacy services to parents with child protection issues should fully support the parents to ensure that their voices are heard throughout the process and their rights upheld.	Roberts 2012	100.00%	Carried forward to committee discussion

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Statement no.	Statement	References	Percentage agreement	Action taken
23	Effective advocacy will lead to continuous improvements in how health and social care services are planned, delivered, and evaluated.	NDTi 2016a:	81.82%	Carried forward to committee discussion
29	Key local issues need to be identified and local actions planned and carried out accordingly across stakeholders to ensure a more effective role for advocacy in making safeguarding personal.	Lawson 2020	72.73%	Discarded
35	It is important that advocacy providers are viable, for example, by having more than one funding source and being well networked within their locality.	NDTi 2014b	83.33%	Carried forward to committee discussion
57	Advocacy services should provide African and Caribbean men with support to address negative issues, such as drug abuse.	NDTi 2014c	44.44%	Discarded
66	Advocacy services should provide families of African and Caribbean men using services with information about how they can access advocacy support.	NDTi 2014c	75.00%	Discarded
67	Advocacy services should signpost African and Caribbean men to other appropriate services, such as befriending services, that will support them in re-establishing social networks.	NDTi 2014c	54.55%	Discarded
72	Advocacy has the potential to transform mental health services by identifying options available to service users to enable them to access complementary ways of health and practical support.	Ridley 2018	81.82%	Carried forward to committee discussion

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1 Appendix H Expert witness testimony

2 Expert witness testimonial for scope area: What does effective advocacy look 3 like?

4 **Table 9: Expert witness brief and testimonial**

Section A: Developer to complete	
Name:	Doreen Joseph and Karen Newbigging
Role:	DJ: Peer researcher, University of Oxford; Guest lecturer, Queen Marys University, London; advocate and author KN: Independent Researcher; Senior Research Fellow, University of Oxford; Honorary Associate Professor, University of Birmingham; and Senior Research Associate, Centre for Mental Health
Institution/Organisation (where applicable):	As above
Guideline title:	Advocacy services for adults with health and social care needs
Guideline Committee:	Guideline committee meeting 9
Subject of expert testimony:	Ethnicity in relation to advocacy services
Evidence gaps or uncertainties:	Overcoming barriers to accessing advocacy services for people from Black, Asian and Minority Ethnic communities, as well as addressing stigma, discrimination and unconscious bias in advocacy services
<p>The guideline committee for the NICE guideline on Advocacy services for adults with health and social care needs has used various sources to draft recommendations on the topic. Statements, drawn from a call for evidence and evidence highlighted by the committee, have been through a formal consensus process with the committee and developed into recommendations. The guideline committee decided to adapt or adopt a number of existing recommendations relating to advocacy from other NICE guidelines. The committee have also identified relevant gaps, after developing recommendations based on formal consensus and adapting/adopting existing NICE recommendations related to advocacy, that need to be filled by informal consensus.</p> <p>The scope of the guideline has guided the development of recommendations. The scope covers:</p> <p>Identifying those who would benefit from advocacy:</p> <ul style="list-style-type: none"> • Who has a legal right to advocacy? • Who else would benefit from advocacy and how do we identify them? <p>Facilitating advocacy:</p> <ul style="list-style-type: none"> • Improving access to advocacy (including addressing barriers) • Enabling and supporting effective advocacy (for example: time, approach, environment, including virtual and non-face-to-face services) • Information about effective advocacy and signposting to services • Monitoring services and collecting data for quality improvement 	

- Planning and commissioning services for advocacy (including for those who do not have a legal right to advocacy)
- Training and skills for practitioners who work with advocates

Delivering advocacy:

- What does effective advocacy look like?
- Partnership working and relationships with families and carers, commissioners and providers
- Training, skills and support for advocates

An equality impact assessment that was undertaken for the guideline highlighted that people from Black, Asian and Minority Ethnic communities can face disparity in access and discrimination in health and social care services, and are underrepresented in those accessing advocacy services. Stakeholders also raised the issue of the impact of intersectionality (overlapping social identities such as ethnicity, gender, class, sexuality).

The committee highlighted early on in committee meetings that ethnicity was a key area for the guideline to cover. It was felt that advocacy services, as well as mental health services more broadly, had a poor track record when it came to overcoming discrimination within services and disparity in access to advocacy.

A small number of statements or existing recommendations that the committee have looked at have been related to ethnicity. However, there was a paucity of statements or existing recommendations about specific approaches for overcoming barriers to accessing advocacy services for people from Black, Asian and Minority Ethnic communities, as well as addressing stigma, discrimination and unconscious bias in advocacy services.

Although the committee can make recommendations in this area via informal consensus based on their knowledge and experience, the recommendations based on formal consensus and the recommendations adapted/adopted from existing NICE recommendations related to advocacy would potentially be strengthened by expert testimony. Committee members therefore agreed to invite expert witnesses to supplement the recommendations based on formal consensus and the recommendations adapted/adopted from existing NICE recommendations related to advocacy. The committee are looking for the expert witnesses to give testimony about specific approaches for overcoming barriers to accessing advocacy services for people from Black, Asian and Minority Ethnic communities, as well as addressing stigma, discrimination and unconscious bias in advocacy services.

NICE recommendations tend to be quite specific, focusing on a particular action for a particular group or role. The impact that each recommendation will have in terms of changes of practice or resources also need to be considered.

In summary, expert testimony in the following areas would enable the committee to develop or strengthen recommendations, such as those covering:

- Improving culturally appropriate and culturally sensitive advocacy, for example by training or awareness raising among advocacy staff or employing advocates from various backgrounds.
- Partnership working, for example between community and voluntary sector organisations and advocacy services to increase people's access to advocacy services and improve cultural sensitivity of advocacy provision.
- Service delivery considerations, for example by co-location of services

Section B: Expert to complete

Summary testimony:

The context for culturally appropriate advocacy is structural inequalities and systemic racism, which is evidenced by greater social disadvantage and exclusion for people from racialised communities. Inequalities and differential treatment for people from racialised (ie. Black, Asian and Minority Ethnic) communities in a health and social care context include:

- A widening disparity between in maternal mortality between black women and white women, with a fivefold higher maternal mortality rate in 2015-2017 [1];
- Increased prevalence of long-term health conditions, including diabetes and dementia in Black, Asian and other minority ethnic groups with inequalities in access to diagnosis and treatments and end of life care [2];
- Disproportionate mortality rates as a consequence of COVID 19 for all minority ethnic groups during the first wave and a continued higher rate for people from Bangladeshi and Pakistani communities during the second wave [3];
- People from racialised communities are 50% more likely to enter the mental health system via the police; with Black people 4 times more likely to be compulsorily detained under the 1983 Mental Health Act; 10 times more likely to be placed on a Community Treatment Order and experience poor outcomes [4].
- Implicit bias in health service that favour white people [4] and significantly related to:
 - patient-provider interactions
 - treatment decisions
 - treatment adherence
 - patient health outcomes [5, 6]

These inequalities support the case for ensuring that people from racialised communities are able to access appropriate advocacy, as needed. Despite this need being reportedly emphasised, inequalities in access and engagement with advocacy persist [4, 7]. The reasons for these inequalities reflect a lack of appropriate provision for people from racialised communities [8,9,10], which is compounded by ignoring or dismissing racism [11]. It is worth noting that the development of advocacy with the increasing formalisation of provision, as a consequence of legislative developments, favours larger voluntary sector organisations (predominantly white), which often have a superficial understanding of equality and diversity [12], and disadvantages smaller voluntary sector and community organisations rooted in specific ethnic communities. Furthermore, these developments have increased the professionalisation of advocacy, marginalising people with lived experience [13], promoting an individual model of advocacy and sharpening the focus on procedural as opposed to substantive rights [14]. This raises a fundamental question about the purpose of advocacy as rights protection and/or rights promotion as a measure to achieve greater social justice and equality [15].

The evidence base for developing culturally appropriate advocacy is scant and, in part, this reflects limited research on the most effective models for advocacy and the wider systemic biases in research that does not disaggregate data on the basis of ethnicity; excludes people who do not speak English or takes a mainstream approach that does not take account of different lifestyles, idioms of illness, values, preferences regarding treatment and support and desired outcomes [8-0, 16-21].

It is important to be cognisant of this wider context in developing recommendations for the provision of culturally appropriate advocacy and to differentiate aspects subsumed under this terminology, as follows [16]:

- Culturally specific advocacy: advocacy provided to support a specific racial/ethnic population.
- Culturally adapted advocacy: interventions to an advocacy service to help ensure existing practices respond to service users' cultures (e.g. ethnic matching, bilingual advocacy).

- Cultural competence: specialist knowledge, acquired through training, skills development or work experience, of the nuanced interests, needs and lifestyles of service users reflected at an individual and organisational level.

On the basis of the evidence [see for example: 4, 14 -21] , we propose the following:

1. Implementing positive practice to promote equality of access

- The design and provision of advocacy services is to be led by and involve people with lived experience in order to reflect the heterogeneity of meanings and valued outcomes.
- A detailed understanding of the local population by local authority commissioners to ensure that provision is appropriate.
- The development of commissioning models to ensure that smaller community and voluntary sector organisations are not disadvantaged. For example: by directly commissioning Black, Asian and minority ethnic organisations or hub and spoke models to formalise partnerships between larger advocacy providers and relevant community organisations.
- Careful implementation of an opt-out measure for advocacy, in particular contexts, to reflect the UN Convention on the Rights of Persons with Disabilities.
- Advocacy providers to evidence that they are taking appropriate measures in line with the Public Sector Equality Duty, and relevant good practice frameworks (e.g. the Patient Carer Race Equality Framework).
- Training and supervision of health and social care staff to develop their understanding of independent advocacy.

2. Investment in community based advocacy

- Investment in culturally specific advocacy to reflect the local demography.
- Implementing adaptations to existing advocacy practice e.g. through the employment of bilingual advocates, the provision of appropriate materials and the provision of a wider range of advocacy, notably self-advocacy, peer advocacy and group advocacy.
- Mainstream providers to evidence that they are working in partnership with community and voluntary sector organisations to upskill, as necessary, in statutory advocacy.
- Partnership working between community organisations and advocacy providers and with other welfare organisations to support people from racialised communities in addressing structural inequalities.

3. Workforce development

- Ensuring that people from racialised communities are represented in senior leadership and management roles.
- Increasing the number of advocates from racialised communities to enable service users to be offered, as far as is possible, an advocate reflecting their gender, language and culture.
- Supporting staff in mainstream advocacy organisations to improve their cultural competence through training, supervision and mentoring. Training and supervision needs to include an informed understanding of race, culture and ethnicity, and the racialised experience of different communities, how this plays out in the relationship with service providers, and the contribution of social context to health and wellbeing.

4. Accountability for the provision of culturally appropriate advocacy

- Advocacy organisations developing and implementing plans in relation to equality: outlining clear goals and lines of accountability in relation to culturally appropriate services. Regular and ongoing self assessments, good ethnic monitoring, maintaining and understanding of the current demography of service users against the service user population to accurately plan for service implementation and service user involvement.
- Developing a set of indicators to benchmark culturally appropriate advocacy that are sensitive to addressing racialised differences in service access, experiences of advocacy support, and attention to racialised issues at statutory service delivery level.
- Monitoring of the access, uptake and experiences of advocacy by people from racialised communities by advocacy providers, commissioners and the Care Quality Commission to further

develop culturally appropriate advocacy and impose sanctions on racial discrimination in the delivery of advocacy.

- Evidence provided to racialised communities of the commitment to address inequalities in advocacy provision through investment in and supporting community organisations to deliver culturally appropriate advocacy.

References to other work or publications to support your testimony' (if applicable):

- [1] Knight, M., Bunch, K., Kenyon, S., Tuffnell, D. and Kurinczuk, J.J., 2020. A national population-based cohort study to investigate inequalities in maternal mortality in the United Kingdom, 2009-17. *Paediatric and perinatal epidemiology*, 34(4), pp.392-398.
- [2] Shiekh, S.I., Cadogan, S.L., Lin, L.Y., Mathur, R., Smeeth, L. and Warren-Gash, C., 2021. Ethnic Differences in Dementia Risk: A Systematic Review and Meta-Analysis. *Journal of Alzheimer's Disease*, (Preprint), pp.1-19.
- [3] Nafilyan, V., Islam, N., Mathur, R., Ayoubkhani, D., Banerjee, A., Glickman, M., Humberstone, B., Diamond, I. and Khunti, K., 2021. Ethnic differences in COVID-19 mortality during the first two waves of the Coronavirus Pandemic: a nationwide cohort study of 29 million adults in England. *European journal of epidemiology*, pp.1-13.
- [4] Department of Health and Social Care, 2019. Independent Review of the Mental Health Act 1983: supporting documents.
- [5] Hall, W.J., Chapman, M.V., Lee, K.M., Merino, Y.M., Thomas, T.W., Payne, B.K., Eng, E., Day, S.H. and Coyne-Beasley, T., 2015. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *American Journal of Public Health*, 105(12), pp.e60-e76.
- [6] FitzGerald, Chloë, and Samia Hurst. "Implicit bias in healthcare professionals: a systematic review." *BMC Medical Ethics* 18, no. 1 (2017): 1-18.
- [7] Newbigging, K., Ridley, J., McKeown, M., Machin, K. & Poursanidou (2015). "When you haven't got much of a voice": An evaluation of the quality of Independent Mental Health Advocate (IMHA) Services in England. *Health and Social Care in the Community*, 23 (3), pp. 313-324.
- [8] Rai-Atkins, A., Jama, A.A., Wright, N., Scott, V., Perring, C., Craig, G. and Katbamna, S., 2002. Best practice in mental health: Advocacy for African, Caribbean and South Asian communities. York, UK: Joseph Rowntree Foundation.
- [9] Mir, G. and Nocon, A., 2002. Partnerships, advocacy and independence: service principles and the empowerment of minority ethnic people. *Journal of Learning Disabilities*, 6(2), pp.153-162.
- [10] Newbigging, K. McKeown, M. Hunkins-Hutchinson, E. French, B. (2007). *Mtetezi: Mental health advocacy with African and Caribbean Men*. London: Social Care Institute for Excellence.
- [11] Newbigging, K., Rees, J., Ince, R., Mohan, J., Joseph, D., Ashman, M., Norden, B., Dare, C., Bourke, S. and Costello, B., 2020. The contribution of the voluntary sector to mental health crisis care: a mixed-methods study. *Health Services and Delivery Research*, 8(29), pp.1-200.
- [12] Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D. (2012). *The Right to be Heard: Review of the quality of IMHA services*. Report for the Department of Health. Preston: UCLaN.
- [13] Newbigging, K., Ridley, J. and Sadd, J., 2020. Realising the right to equal recognition for disabled people: commissioning statutory advocacy in England. *Disability & Society*, 36(3), pp.420-442.
- [14] Newbigging, K., Ridley, J., McKeown, M., Sadd, J., Machin, K., Cruse, K., De La Haye, S., Able, L. and Poursanidou, K., 2015. *Independent mental health advocacy-the right to be heard: Context, values and good practice*. Jessica Kingsley Publishers.
- [15] Newbigging, K. and Ridley, J., 2018. Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health. *Social Science & Medicine*, 219, pp.36-44.
- [16] Salla, A., Newbigging, K., and Costello, B. (2020). *Culturally appropriate advocacy: a scoping report*. Unpublished report for the Department of Health and Social Care.
- [17] Ridley, J., Newbigging, K. and Street, C., (2018). Mental health advocacy outcomes from service user perspectives. *Mental Health Review Journal*, 23(4), pp.280-292.

- [18] Newbigging, K., McKeown, M., Habte-Mariam, Z., Mullings, D., Charles, J. J., & Holt, K. (2008). Commissioning and Providing Mental Health Advocacy for African and Caribbean Men: A Resource Guide. London: Social Care Institute for Excellence.
<http://www.scie.org.uk/publications/guides/guide21/index.asp>
- [19] Newbigging, K. & McKeown, M. (2007). Mental health advocacy for Black and minority ethnic communities: conceptual and ethical implications for commissioners and practitioners. *Current Opinion in Psychiatry*, 20(6), 588-594.
- [20] Newbigging, K., McKeown, M. & French B. (2013). Mental health advocacy and African and Caribbean men: good practice principles and organizational models for delivery. *Health Expectations*, 16 (1), 80-104.
- [21] El Ansari W, Newbigging K, Roth C, Malik F. (2009). The Role of Advocacy and Interpretation Services in the Delivery of Quality Health Care to Diverse Minority Communities in London, UK. *Health & Social Care in the Community*, 17 (6), 636-646.

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