National Institute for Health and Care Excellence

Final

# Advocacy services for adults with health and social care needs

## [F] What does effective advocacy look like?

*NICE guideline NG227*

*Evidence reviews underpinning recommendations 1.3.1, 1.5.6, 1.6.1 to 1.6.15, 1.8.12, 1.8.14, 1.10.3, 1.11.1 and 1.11.2 in the NICE guideline*

*November 2022*

*Final*

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# Contents

# What does effective advocacy look like?

## Key theme

- What does effective advocacy look like?

### Introduction

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

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

### Summary of the inclusion criteria

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

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

| | |
|---|---|
| **Country** | UK |
| **Geographical level** | National*<br>*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| **Study design** | Primary qualitative or quantitative studies (including unpublished research), excluding case-studies<br>Systematic reviews of qualitative or quantitative studies, excluding case-studies<br>Guidelines or policy documents that are based on qualitative or quantitative evidence, excluding case-studies |
| **Topic areas** | What does effective advocacy look like? |

### Methods and process

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

Declarations of interest were recorded according to NICE's 2019 conflicts of interest policy (see Register of Interests).

## Effectiveness evidence

### Included studies

#### *Existing NICE guidelines*

No existing NICE recommendations were identified for this scope area.

#### *Formal consensus*

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

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

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

### Expert witness

One important area of inequalities highlighted in the equality impact assessment was 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. The committee highlighted early on in committee meetings that this was a key area for the guideline to cover as advocacy services, as well as mental health services more broadly, have a poor track record when it comes to overcoming discrimination within services and disparity in access to advocacy.

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

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

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

### Excluded studies

#### *Formal consensus*

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

## Summary of included studies

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

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

| Document | Population | Evidence base |
|---|---|---|
| Lawson 2017<br>Report<br>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<br>Briefing<br>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<br>Report of an evidence review<br>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<br>Framework<br>England | Providers and commissioners of independent advocacy | Literature review (no details reported) and consultation with two self-advocacy groups |
| NDTi 2020a<br>Report on survey findings<br>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<br>Report on survey findings<br>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<br>Systematic Review<br>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<br>Mixed methods: literature review, qualitative research (focus groups and interviews), case studies<br>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<br>Survey<br>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<br>Service evaluation<br>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 |

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

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

## Summary of the evidence

### *Existing NICE guidelines*

No existing NICE recommendations were identified for this scope area.

### *Formal consensus round 1*

Two documents (Lawson, 2017; NDTi, 2016a) were assessed using the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE II) tool, 1 document (Newbigging, 2011) was assessed using both the Risk of Bias in Systematic reviews (ROBIS) checklist and the Critical Appraisal Skills Programme (CASP) tool for qualitative research as it included both a systematic literature review and a survey with qualitative components, and 7 included documents (Lawson, 2020; NDTi, 2014b; NDTi, 2020a; NDTi, 2020b; Newbigging, 2012; Roberts, 2012; SERIO, 2021) were assessed using the CASP tool for qualitative research. See the results of the quality assessment in the evidence tables in appendix B and quality assessment tables in appendix C.

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

See appendix G for the statements that were rated by the committee and results of round 1, which are provided in Table 7.

#### *Formal consensus round 2*

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

## Economic evidence

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

## The committee's discussion and interpretation of the evidence

### The outcomes that matter most

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

### The quality of the evidence

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

### *Existing NICE guidelines*

No existing NICE recommendations were identified for this scope area.

### *Formal consensus*

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

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

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

## Benefits and harms

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

### *Communication, confidentiality, and privacy*

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

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

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

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

### *Promoting best practice and consistency*

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

### *Information about local services*

Statement 12 covered the importance of advocacy services ensuring that their services are known about. The committee agreed that increasing awareness about available services is key to improving access but they highlighted that the responsibility for this falls on local authorities rather than individual advocacy services. They therefore used the statement to make a recommendation and they directed it at local authorities. Given that it is a duty set out in the Care Act 2014, for local authorities to make information available about local services they were able to make the recommendation in the strongest terms. The committee also built on this legal duty to say that information about local services should specifically include advocacy services, with the intention that this should improve awareness, signposting and ultimately access to advocacy. The committee agreed to place this recommendation in the section of the guideline about information about effective advocacy and signposting to services (see evidence review C) because it was more relevant to those recommendation than the ones about effective advocacy.

### *Making advocacy services accessible*

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

### *Ensuring advocacy service is person centred*

Statement 14 highlighted the importance of advocacy organisations, for example Independent Mental Health Advocates (IMHAs), ensuring their services are person-centred. There was strong support for this statement with the committee agreeing that delivering a person-centred service is essential to providing effective advocacy. They agreed to use the statement as a basis for two separate recommendations, starting with a list of specific suggestions for ensuring advocacy services are person-centred. The first two suggestions that the committee agreed were similar to those set out in the QPM (2018), so to avoid confusion they agreed to align the wording with the QPM. For one of the other suggestions, the committee drew on statement 30, about offering a choice of delivery for individuals seeking support. In the committee's experience there are a variety of reasons why a person might prefer an advocate of a certain gender, ethnicity, or age. This might not be possible in every situation, however they agreed it is important that advocacy services make every attempt to match an advocate to these preferences to ensure that the person receiving advocacy is comfortable and to help to establish trust with the advocate. The committee agreed that this might not be possible for all organisations, particularly smaller organisations, but this should be done wherever possible. The committee suggested other ways of ensuring a person-centred service on the basis of their own expertise and experience and they agreed they are important across independent advocacy so they did not retain the specific reference in the statement to IMHAs. On the basis of their experience the committee agreed this recommendation, with its list of suggestions, will achieve benefits beyond the effectiveness of the service, as it also informs other professionals and people using services, educating them about what effective advocacy looks like and what can be expected from the service. Stemming from discussions about this recommendation, the committee agreed to add a recommendation that for people assessed as lacking capacity to instruct their advocate, providers need to pay particular attention to ensure that the service is delivered in a person centred way. In part this means involving people with an interest in the person's welfare and it is something the committee agreed they had to emphasise because in their experience involving other appropriate people does not happen consistently.

### *Including people with lived experience*

Statement 19 covered advocacy 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). The committee all agreed with this statement but they thought it should be extended beyond learning disabilities to include a broader representation of people, such as people living with dementia, mental health issues and brain injuries as well as people on the autistic spectrum. They therefore expanded on the statement to recommend the active involvement in advocacy organisations of people with lived experience of health and social care or advocacy. They agreed that the benefit of the recommendation would be ensuring the views of people with lived experience influence the design and development of services, so they are far more relevant and address advocacy needs sensitively and comprehensively (which is particularly relevant for those people who have experienced health inequalities). In the committee's experience this does not happen consistently, and where this does happen, the range of advocacy service users may not be as inclusive as it could be.

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

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

### *Promoting equality through advocacy services*

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

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

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

### *Agreeing on service level outcomes*

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

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

Statement 34 highlighted the importance of advocacy providers offering consistency to people. In the committee's experience, effective advocacy depends on the development of trust and a mutual understanding of the issues that are important to the individual. The committee agreed that this trust and understanding takes time to develop so it is easier if the advocate remains constant for as long as the person needs advocacy. The increased trust and understanding that continuity would likely afford may lead to better outcomes for the individual, thus improving the overall quality of advocacy services. This is not happening consistently and not always possible. The committee agreed that there might be cases where a person does not want the same advocate. Therefore, the committee agreed to reword this statement to improve clarity so that advocacy providers should, where possible and in agreement with the person, keep the same advocate for each person. Statement 44 highlighted the importance of service users and carers being confident that IMHA is independent. There was complete agreement with this and the committee discussed that it is crucially important for people using advocacy and their carers to know they have their advocate's full support and loyalty. The committee thought this was generally relevant to advocacy so they did not include the specific reference to IMHA in the recommendation. They also agreed it would be useful to add specific ways in which advocacy services can demonstrate their independence from other organisations because an obvious separation from other services communicates a clear message about their independence and ultimately gives people greater confidence when using advocacy services. In the committee's experience this does not happen consistently and there needs to be clear protocols in place to ensure advocacy services maintain their independence.

#### *Specialised and multi-skilled advocates*

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

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

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

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

### *Developing cultural competence*

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

### *Training Health and Social Care practitioners*

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

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

The committee agreed with the conclusions drawn from the expert witness testimony and considered the inclusion of culturally appropriate and relevant services as integral to advocacy services. However, some points from the expert witness testimony were not used to support recommendations because the committee agreed that they fell outside the remit of NICE guidelines, such as advocacy providers to evidence that they are taking appropriate measures in line with the Public Sector Equality Duty, and relevant good practice frameworks (for example, the Patient Carer Race Equality Framework); investment in culturally specific advocacy to reflect the local demography; mainstream providers to evidence that they are working in partnership with community and voluntary sector organisations to upskill, as necessary, in statutory advocacy; 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; and 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.

### *Future research recommendation*

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

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

There were a number of statements carried forward to committee discussions that were not used to inform recommendations. The issues addressed in statements 6, 16, 18, 21, 23, 27, 31, 32, 35, 45, 51, 61, 63, 68 and 72 are covered in other recommendations in this guideline. Statements 16, 21, and 31 are covered by recommendation 1.6.2 under this review about advocacy being person centred. Statement 6 is covered by recommendation 1.6.1 in this review about advocacy services being accessible. Statement 35 is covered by recommendation 1.6.9 under this review about advocacy providers maintaining independence. Statement 18 is covered by recommendation 1.10.3 under the area of training practitioners (see evidence review J) about advocates ensuring that people's voices are heard. Statement 23 is covered by recommendations 1.11.6 and 1.11.10 under the area of monitoring services (see evidence review K) about collecting information on the impact of services and about advocacy providers seeking feedback about advocacy support. Statement 27 is covered in the recommendation about improving consistency and advocacy in safeguarding is covered by the Care Act (2014). Statement 32 and 45 are covered in the recommendation about finding out the views, needs, and goals of the person. Statement 26 was not used to inform a recommendation as the recommendations in monitoring provide more detail about what information should be collected. Statement 35 is covered by recommendation 1.7.2 under the area of partnership working (see evidence review G) about advocacy providers being familiar with local support services. Statement 51 is covered by the recommendation about good communication which cross references to existing NICE guidelines. Statement 61 is covered by the recommendation about presenting the persons' needs and preferences. The committee agreed that statement 63 was not just specific to African and Caribbean men and ensuring that people are receiving advocacy when legally entitled to is covered by the recommendation under legal right to advocacy (see evidence review A), recommendation 1.4.14 under improving access (see evidence review D) and recommendation 1.10.1 under training practitioners (see evidence review J). The committee agreed that the need for cultural sensitivity in statement 68 is covered by recommendation 1.6.12 about providing culturally appropriate advocacy but having principles and standards for services was broader than cultural sensitivity which would be a routine part of planning and commissioning services. Statements 50, 52, 53, 54, 56, 58, 60, 62, 63, and 65 were not used to form recommendations as these statements are all part of the job description of an advocate. Statements 4, 11, 15, 17, and 25 were not used to form recommendations as they did not provide enough detail on how to provide effective advocacy. Statements 73 and 74 were not used to inform recommendations as these were statements about the impact of advocacy and did not provide enough detail to inform an action but the wider impact of advocacy services was considered in the recommendations in the monitoring section, such as recommendation 1.11.3 about advocacy providers and commissioners measuring the outcomes that show the impact of advocacy (see evidence review K). Statements 69, 70, and 71 were not used to inform recommendations as advocacy cannot directly transform mental health services or increase choice. Statement 20 was not used to inform recommendations because it did not provide enough detail to say how to achieve good outcomes. Furthermore, other statements already provide this detail. Statement 43 was not used to inform recommendations as it is a statutory requirement that advocates are independent. Statement 49 was not used to inform recommendations because advocacy services are unable to directly affect the overrepresentation of African and Caribbean men in mental health services, therefore this cannot be made into an action. Furthermore, the committee agreed that the recommendations made by this guideline as a whole should help to address the problems this statement highlights, by improving the effectiveness of advocacy resulting in people being listened to properly and potentially minimising inappropriate detention. Statement 55 was not used to inform recommendations as the committee agreed that advocates do not have the power to affect improvements in economic and political power. Statement 59 was not used to inform recommendations because acting as an appropriate adult is not the role of advocate. There is free legal Aid to have a solicitor to represent a person at Mental Health Tribunals, so the added value of an advocate in these situations is not clear. Statement 38 was not used to inform recommendations as this is not something advocates specifically have controlled over and the committee pointed out that a person may have a good sense of wellbeing yet still be in need of advocacy support. Statement 48 was not used to inform recommendations as this is not about advocacy and outside of the scope of this guideline.

**Cost effectiveness and resource use**

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

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

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

Allowing a person-centred approach to advocacy services especially around allowing a choice of advocate may require the need to have a greater number of advocates. Organisations may need to build extra capacity in their services so that advocates have flexibility to work with different people when such a need arises. The committee acknowledge this may not be possible in smaller or medium sized organisations but were keen to highlight that this should be considered if possible. For such organisations there is unlikely to be any resource impact with advocacy resources being reorganised where possible rather than capacity increasing. Person centred care is important for advocacy as well as health and social care generally and the committee thought such an approach in advocacy would improve advocacy meetings reducing the need to replicate meetings or the times decisions are challenged reducing downstream costs. It is also possible it could reduce expensive healthcare interventions such as unplanned admission to hospital. The recommendations are also in line with moves within health and social care towards a more person centred approach to health and care.

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

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

### Other factors the committee took into account

The committee considered the NICE 'Our Principles' in particular principles 9 and 10 when considering cost effectiveness and resource use for recommendations about culturally appropriate advocacy.

### Recommendations supported by this evidence review

This evidence review supports recommendations 1.3.1, 1.5.6, 1.6.1 to 1.6.15, 1.8.12, 1.8.14, 1.10.3, and 1.11.1 to 1.11.2. Other evidence supporting these recommendations can be found in the evidence reviews on partnership working (see evidence review G).

## References – included studies

### Formal consensus

#### Lawson 2017

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]

**Lawson 2020**

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]

**Newbigging 2011**

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

**Newbigging 2012**

Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, 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]

**National Development Team for Inclusion 2014b**

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

**National Development Team for Inclusion 2016a**

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]

**National Development Team for Inclusion 2020a**

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]

**National Development Team for Inclusion 2020b**

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]

**Roberts 2012**

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]

**SERIO 2021**

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

## Other

### Care Act 2014

Care Act, 2014 (c. 23). Available at: https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted [Accessed 21/09/2021]

### Equality Act 2010

Equality Act, 2010 (c.15). Available at: https://www.legislation.gov.uk/ukpga/2010/15 [Accessed 29/04/2021]

### Quality Performance Charter 2018

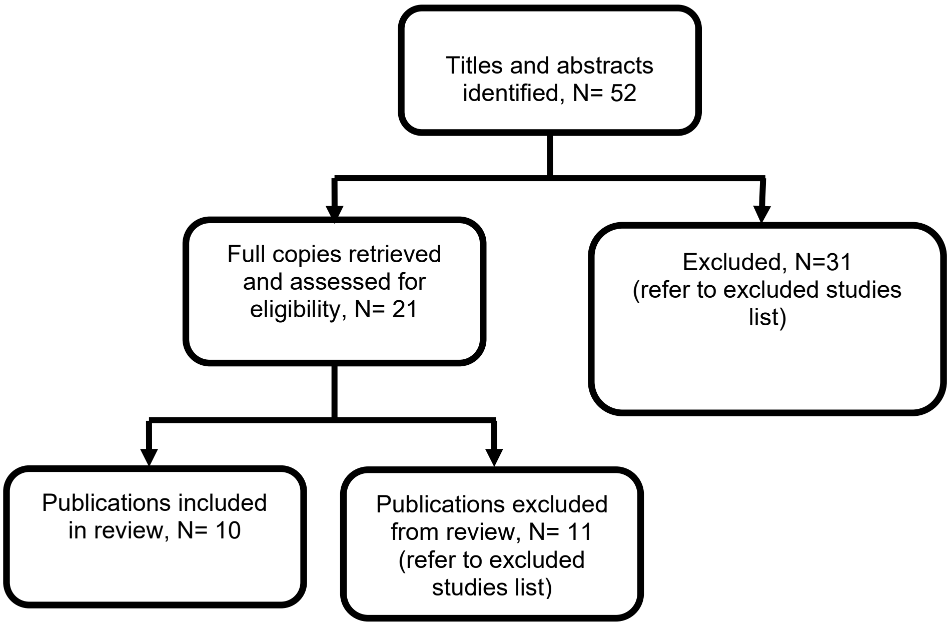
Quality Performance Charter (QPM), 2018. Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf

# Appendices

## Appendix A Study selection for formal consensus process

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

**Figure 1: Study selection flow chart**



# Appendix B Evidence tables

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

### Table 3: Evidence tables

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| **Full citation**<br>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]<br>**Country/ies where the study was carried out**<br>England<br>**Study type**<br>Report/Review<br>**Study dates**<br>2017<br>**Source of funding**<br>No sources of funding reported. | Those who have duties<br>to commission and arrange advocacy services | **Key findings in relation to what does effective advocacy look like? (Delivering Advocacy)**<br>- 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. | **Quality assessment using AGREE II**<br>**1) Scope and Purpose**<br>61%<br>Overall objective and population are described. Health question is not specifically described but alluded to<br>**2) Stakeholder involvement**<br>22%<br>Target users are defined but not information on guideline development group and views and preferences from population has been included.<br>**3) Rigour of development**<br>8%<br>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.<br>**4) Clarity of presentation**<br>22%<br>Recommendations are not always specific and easily identifiable. No mentioning of different options for management. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | **5) Applicability**<br>4%<br>Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource implications, and auditing criteria provided.<br>**6) Editorial independence**<br>0.0%<br>No funding body and competing interest have been identified.<br>**Overall rating**<br>29% |
| **Full citation**<br>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]<br>**Country/ies where the study was carried out**<br>England<br>**Study type**<br>Qualitative (Focus group discussions)<br>**Study dates**<br>2020 | Those who have duties<br>to commission and arrange advocacy services | **Recommendations in relation to what does effective advocacy look like (Delivering advocacy)**<br>• 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:<br>○ national steps that can be taken to enhance consistency of approach and effectiveness.<br>○ key local issues. Planning and carrying out local actions accordingly across stakeholders | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>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.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell - insufficient detail provided on recruitment strategy. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| **Source of funding**<br>No sources of funding reported | | | **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Yes. Semi-structured focus group discussions on teleconference calls were held with 28 advocates from 18 advocacy providers across England, covering 33 Local Authority areas.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No - ethical issues and approval for the study were not discussed.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell – no details provided.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings.<br>**10. How valuable is the research?**<br>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. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | **Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations. |
| **Full citation**<br>National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished<br>**Country/ies where the study was carried out**<br>England<br>**Study type**<br>Briefing Note/Survey<br>**Study dates**<br>2014<br>**Source of funding**<br>No sources of funding reported | People living with disabilities | **Key findings in relation to what does effective advocacy look like (Delivering advocacy)**<br>• Choice of delivery for individuals seeking support determines effectiveness. Important to tailor local delivery to fit local needs.<br>• 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.<br>• Outcomes are identified and recorded (not just for clients but for services too)<br>• 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) | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes – to summarise the findings of the survey to highlight what good advocacy for disabled people should look like.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Can't tell – Survey included over 200 advocacy providers but no more information was included.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell – Insufficient information regarding the survey.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell - insufficient detail provided on recruitment strategy.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell – insufficient detail on data collection<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | • The research identified characteristics reflecting effective, holistic advocacy:<br>○ The importance of advocates having mixed skills-sets to offer support to a diverse range of clients, many with multiple issues<br>○ People living with disabilities being offered and experiencing person-centred support with a choice of different ways of receiving that support. | No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No - ethical issues and approval for the study were not discussed.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell – no details provided.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. Findings are clearly discussed but researchers do not discuss credibility of their findings.<br>**10. How valuable is the research?**<br>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.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations. |
| **Full citation**<br>National Development Team for Inclusion (2016a). Advocacy Outcomes Framework: Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Adv | Providers, commissioners and users of independent Advocacy | **Key findings in relation to what does effective advocacy look like (Delivering advocacy)**<br>• Effective advocacy is/means: | **Quality assessment using AGREE II**<br>1) **Scope and Purpose**<br>22%<br>Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided.<br>2) **Stakeholder involvement** |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| ocacy_framework.pdf [Accessed 06/04/2021]<br>**Country/ies where the study was carried out**<br>England<br>**Study type**<br>Framework<br>**Study dates**<br>2016<br>**Source of funding**<br>Esmee Fairbairn Foundation | | ○ 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.<br>○ Will lead to frequent changes and improvements in how health and social care services are planned, delivered, and evaluated.<br>○ Promoting social inclusion, equality and social justice and critical role in changing how communities are experienced and accessed by its members.<br>○ Measuring what works or does not work is important way of improving impact of advocacy | 28%<br>Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear.<br>**3) Rigour of development**<br>10%<br>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.<br>**4) Clarity of presentation**<br>56%<br>Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to.<br>**5) Applicability**<br>21%<br>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.<br>**6) Editorial independence**<br>17%<br>Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided.<br>**Overall rating**<br>34% |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| **Full citation**<br>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]<br>**Country/ies where the study was carried out**<br>England and Wales<br>**Study type**<br>Survey (open and closed ended questions)<br>**Study dates**<br>June 2020<br>**Source of funding** | Advocates (across multiple areas of statutory and non-statutory advocacy) | **Key findings in relation to what does effective advocacy look like? (Delivering Advocacy)**<br>• 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.<br>○ "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 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)<br>• Advocacy principles for coronavirus and beyond | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>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.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell - insufficient detail provided on recruitment strategy.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell – limited information on methods of data collection and no other details provided.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | - Make sure that people are heard and their rights are respected.<br>- Communicate effectively, and safely meet with people in person.<br>- Effective communication central to advocacy; many advocates support people who need additional support to communicate or who use non-verbal communication techniques.<br>- In addition, confidentiality and privacy are crucial to deliver person-centred advocacy.<br>- Sharing learning, insights, tools and developing joint publications, guidance, and resources, will ensure continued collective effectiveness across the advocacy sector.<br><br>**Recommendations in relation to What does effective advocacy look like? (delivering advocacy)**<br>- Shared commitments by advocacy organisations to ensure people's access to | **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No - ethical issues and approval for the study were not discussed.<br><br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell – no details provided.<br><br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.<br><br>**10. How valuable is the research?**<br>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.<br><br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | effective advocacy. Advocacy organisations have committed to:<br>○ Make sure their advocacy services are known about, accessible, person-centred, and provide effective advocacy whether through remote tools or face to face meetings. | |
| **Full citation**<br>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]<br>**Country/ies where the study was carried out**<br>Wales<br>**Study type**<br>Survey (open and closed ended questions)<br>**Study dates**<br>June 2020 | Advocates (across multiple areas of statutory and non-statutory advocacy) | **Key findings in relation to what does effective advocacy look like? (Delivering Advocacy)**<br>• 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.<br>• 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 to the contrary, that IMHA was | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>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.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell - insufficient detail provided on recruitment strategy. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| **Source of funding**<br>Age Cymru | | suspended by the CA2020…." (p.9) | **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell – limited information on methods of data collection and no other details provided.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No - ethical issues and approval for the study were not discussed.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell – no details provided.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.<br>**10. How valuable is the research?**<br>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.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)** |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | Serious limitations. |
| **Full citation**<br>Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and Caribbean men: Good practice principles and organizational models for delivery. Health Expectations, 16(1), 80-104.<br>**Country where the study was carried out**<br>UK (England, Wales, and Northern Ireland)<br>**Study type**<br>Systematic literature review and national survey<br>**Study dates**<br>2011<br>**Source of funding**<br>Social Care Institute of Excellence (SCIE) | 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. | **Key findings in relation to what does effective advocacy look like (Delivering Advocacy)**<br>• 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.<br>• 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:<br>○ Over representation in mental health services.<br>○ Access to appropriate and sufficient support in the community across statutory and voluntary sectors. | **Quality assessment using ROBIS**<br>***Phase two***<br>**1.1 Did the review adhere to pre-defined objectives and eligibility criteria?**<br>Yes – There were a clear protocol and pre-specification of objectives the review are provided.<br>**1.2 Were the eligibility criteria appropriate for the review question?**<br>Yes – Eligibility criteria seem appropriate for review question<br>**1.3 Were eligibility criteria unambiguous?**<br>Yes – Eligibility criteria were clearly defined<br>**1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?**<br>Yes - Restrictions seemed appropriate<br>**1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?**<br>Yes - Restrictions applied on the basis of sources of information were clearly described.<br>**Concerns regarding specification of study eligibility criteria**<br>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 |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | ○ Good communication to reduce the risks of isolation and exclusion.<br>○ Improved access to housing.<br>○ Support around benefits.<br>○ Enabling issues and complaints about statutory services to be raised.<br>○ Addressing the lack of economic and political power.<br>○ Medication issues.<br>○ Addressing drug abuse.<br>• All organisations described providing, or the potential for providing, the following services for African and Caribbean men:<br>○ Support in meetings with mental health services- ward rounds and CPA meetings.<br>○ Representation at Mental Health Tribunals or as an Appropriate Adult.<br>○ Negotiation with service providers particularly in respect of medication and leave.<br>○ Signposting and referral to other sources of specialist support and support | **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?**<br>Yes – Direct databases are all clearly identified.<br>**2.2 Were methods additional to database searching used to identify relevant reports?**<br>Yes – secondary reference search was undertaken.<br>**2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?**<br>No information<br>**2.4 Were restrictions based on date, publication format, or language appropriate?**<br>No – Search was restricted to English language publications.<br>**2.5 Were efforts made to minimise errors in selection of studies?**<br>Yes – Two authors independently screened and searched data.<br>**Concerns regarding methods used to identify and/or select studies**<br>Unclear concern – Some information regarding search strategy is missing<br>**3.1 Were efforts made to minimise error in data collection?**<br>Yes – 2 authors independently data extracted. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | navigating the mental health system.<br>- Working in partnership to enable partners to speak for themselves.<br>- Supporting people to make complaints or air grievances.<br>- Supporting people to access rights and entitlements.<br>- Interpreting and translating.<br>- Help with housing and benefit issues.<br>- Support for families.<br>- Re-establishing social networks.<br>- Befriending.<br>• 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 | **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?**<br>Probably yes – Link to full study characteristics provided; however cannot access these.<br>**3.3 Were all relevant study results collected for use in the synthesis?**<br>Probably yes – Unclear whether all relevant study results were included<br>**3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?**<br>Yes – TAPUPAS standard was used to critically assess included studies.<br>**3.5 Were efforts made to minimise error in risk of bias assessment?**<br>Yes – Two reviewers independently critically assessed included papers and a third reviewer was used where there were discrepancies.<br>**Concerns regarding methods used to collect data and appraise studies**<br>Low concern – Insufficient information about study characteristics but risk of bias as assessed accordingly.<br>**4.1 Did the synthesis include all studies that it should?**<br>No information<br>**4.2 Were all predefined analyses followed or departures explained?**<br>No information |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?**<br>No information<br>**4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?**<br>No information<br>**4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?**<br>No information<br>**4.6 Were biases in primary studies minimal or addressed in the synthesis?**<br>No - The studies were evaluated for risk of bias but results were not incorporated into findings/conclusion<br>**Concerns regarding the synthesis and findings**<br>Unclear concern - There is insufficient information reported to make a judgement on risk of bias<br>***Phase three***<br>**A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?**<br>Yes<br>**B. Was the relevance of identified studies to the review's research question appropriately considered?**<br>Yes<br>**C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | Yes<br>**Risk of bias** – Unclear risk of bias<br>**Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)**<br>Yes – Aims very clearly defined<br>**2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No)**<br>Yes<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No)**<br>Yes<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No)**<br>Yes – Recruitment strategy clearly defined and deemed appropriate.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)**<br>Yes – Focus groups and national surveys were used.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>Can’t tell – No information provided<br>**7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)** |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | Yes – Ethical issues were considered<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Yes – Thematic analysis was used and clearly defined.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings<br>**10. How valuable is the research?**<br>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.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>No limitations |
| **Full citation**<br>Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, 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](https://www.firah.org/upload/notices3/2012/uclan.pdf) [Accessed 13/05/2021] | Patients detained under the amended Mental Health Act 1983, who are eligible for support from IMHA services (including people with and without capacity | **Recommendations in relation to what does effective advocacy look like (Delivering Advocacy)**<br>• The role of IMHAs in relation to the Safeguarding process needs further investigation and guidance.<br>• Non-instructed advocacy appeared to many to go | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>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. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| **Country/ies where the study was carried out**<br>England<br>**Study type**<br>Mixed methods: literature review, qualitative research (focus groups and interviews), case studies<br>**Study dates**<br>2010 to 2012<br>**Source of funding**<br>Department of Health | and children under the age of 16 years) | 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.<br>• 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 they've been listened to and | **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>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.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Yes - the methods used were explicitly described and justifications for their use were provided, although saturation of data was not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>Yes - the authors acknowledged the potential for the quality of the data collection and analysis to be influenced by the researchers.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>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. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | understood by services." [IMHA] (p.192)<br>• Increasing service users' confidence.<br>• Increasing service users' sense of wellbeing.<br>• Providing support and a sense of there being someone on the side of the service user.<br>• Providing information to increase understanding and awareness, for example on rights and treatment.<br>• Assisting service users to regain a sense of personal agency and recovery.<br>• Supportive, empowering approach.<br>• Providing an important safeguarding function.<br>• IMHA Service Characteristics<br>• Quality indicator 13 – Independence<br>○ IMHA services are independent organisations from statutory mental health service provision.<br>○ Mental health service users and their carers are confident that the IMHA | **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Yes - the authors describe the analysis process and sufficient data are presented to support the findings.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes.<br>**10. How valuable is the research?**<br>Valuable - the authors highlight gaps in the evidence, how the evidence relates to previous research, and implications for practice and policy and future research.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Minor limitations. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | service is independent from statutory provision.<br>- Quality indicator 14 – Person-centred focus<br>  - 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. | |
| **Full citation**<br>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]<br>**Country/ies where the study was carried out**<br>England<br>**Study type** | A range of people including people living with learning disabilities | **Key findings in relation to what does effective advocacy look like? (delivering advocacy)**<br>- 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:<br>- Supporting parents with learning disabilities, including child protection issues (8 organisations). Fully including people with learning disabilities within the advocacy organisations (sometimes as | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>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.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| Survey (open and closed ended questions) and case studies<br>**Study dates**<br>December 2011 and January 2012<br>**Source of funding**<br>Supported by the Department of Health. | | 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).<br>- 1-1 case advocacy, including crisis advocacy (7 organisations). | **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Yes - how advocacy organisations and commissioners of advocacy services were identified is explained to some extent.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell – limited information on methods of data collection and no other details provided.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No - ethical issues and approval for the study were not discussed.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell – no details provided.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.<br>**10. How valuable is the research?** |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| | | | Valuable - the authors provide evidence on gaps in the provision of advocacy services and areas for further research.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations. |
| **Full citation**<br>SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return on Investment Analysis, The Advocacy People. Available at: [https://www.vfrhub.com/wp-content/uploads/221/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf](https://www.vfrhub.com/wp-content/uploads/221/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf) [Accessed 06/04/2021]<br>**Country/ies where the study was carried out**<br>England<br>**Study type**<br>Mixed methods: literature review, qualitative research and social return on investment analysis<br>**Study dates**<br>2018 to 2021 | Military veterans and their families | **Key findings in relation to what does effective advocacy look like (Delivering Advocacy)**<br>• Benefits for many clients in terms of onward referral to, 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.<br>○ “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 | **Quality assessment using CASP qualitative studies checklist**<br>**1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)**<br>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.<br>**2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No)**<br>Yes.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No)**<br>Yes.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No)**<br>Can't tell - insufficient detail provided on recruitment strategy.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)**<br>Can’t tell – limited information on methods of data collection. |

| Study details | Population | Recommendations/key findings | Quality assessment |
|---|---|---|---|
| **Source of funding**<br>No sources of funding reported. | | health, physical health, etc." (p.21)<br>• The knowledge that The Veterans' Advocacy People was specifically focussed on supporting veterans was important.<br>○ "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) | **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No - ethical issues and approval for the study were not discussed.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell – no details provided.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings.<br>**10. How valuable is the research?**<br>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.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations. |

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

# Appendix C Quality Assessment

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

### Formal consensus

**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% |

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

**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 |

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

**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 |

*CASP: Critical Appraisal Skills Programme*

# Appendix D Excluded studies

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

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

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. Nursing in Critical Care, 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. Health Expectations, 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? |
| 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 | Publication is based on case-studies |

| Study | Reason for Exclusion |
|---|---|
| .co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022] | |
| Kilinç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. Disability and Rehabilitation, 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 |
| 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? |

| Study | Reason for Exclusion |
|---|---|
| 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 |
| Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, 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, | Publication has no evidence base |

| Study | Reason for Exclusion |
|---|---|
| easy read version. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/easy-read/ [Accessed 16/02/2022] | |
| 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 |
| 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: | Publication is based on case-studies |

| Study | Reason for Exclusion |
|---|---|
| https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/impact/ [Accessed 16/02/2022] | |
| 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. Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-_2012-01.pdf [Accessed 06/04/2021] | No key findings or recommendations relevant to What does effective advocacy look like? |
| 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 |

### Excluded economic studies

No economic evidence was considered for this scope area.

# Appendix E Research recommendations – full details

## Research recommendations for scope area: What does effective advocacy look like?

No research recommendations were made for this scope area.

# Appendix F Existing NICE recommendations

No existing NICE recommendations were identified for this scope area.

# Appendix G Formal consensus

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

**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 | 100.00% | Carried forward to committee discussion |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| | | Inclusion 2020a | | |
| 8 | Delivering person-centred advocacy requires confidentiality and  privacy. | National Development Team for Inclusion 2020a | 100.00% | Carried forward to committee discussion |
| 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 | 100.00% | Carried forward to committee discussion |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| | | Inclusion 2020a | | |
| 14 | Advocacy organisations, for example IMHAs, need to make sure that their services are person-centred. | National Development Team for Inclusion 2020a, Newbigging 2012 | 100.00% | Carried forward to committee discussion |
| 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 |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| 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 |
| 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 |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| 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 |
| 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 statuary 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 |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| 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 |
| 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 |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| 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 |
| 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 |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| 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 |

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

**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 |
| 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 |

| Statement no. | Statement | References | Percentage agreement | Action taken |
|---|---|---|---|---|
| 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 |

# Appendix H Expert witness testimony

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

### 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<br>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 |
| 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.<br>The scope of the guideline has guided the development of recommendations. The scope covers:<br>**Identifying those who would benefit from advocacy:**<br>• Who has a legal right to advocacy?<br>• Who else would benefit from advocacy and how do we identify them?<br>**Facilitating advocacy:**<br>• Improving access to advocacy (including addressing barriers)<br>• Enabling and supporting effective advocacy (for example: time, approach, environment, including virtual and non-face-to-face services)<br>• Information about effective advocacy and signposting to services<br>• Monitoring services and collecting data for quality improvement<br>• Planning and commissioning services for advocacy (including for those who do not have a legal right to advocacy)<br>• Training and skills for practitioners who work with advocates<br>**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 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.

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