National Institute for Health and Care Excellence

Final

Advocacy services for adults with health and social care needs

[D] Improving access to advocacy

NICE guideline NG227

Evidence reviews underpinning recommendations 1.4.1 to 1.4.2, 1.4.4 to 1.4.10, 1.4.12, 1.5.5, 1.5.10, 1.8.12 and 1.10.3 in the NICE guideline

November 2022

Final

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Improving access to advocacy

Key theme

- Improving access to advocacy (including addressing barriers)

Introduction

The aim of this review is identify ways of improving access to advocacy.

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 process 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* *For policy or guidance documents, this means, the policies and recommendations apply nationally. For original research, this means the studies have been conducted in the national policy and practice context of our scope, i.e., the English health and social care system
Publication date	2011 onwards
Study design	Primary qualitative or quantitative studies (including unpublished research), excluding case-studies Systematic reviews of qualitative or quantitative studies, excluding case-studies Guidelines or policy documents that are based on qualitative or quantitative evidence, excluding case-studies
Topic areas	Improving access to advocacy (including addressing barriers)

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 appendix A, with further detail 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

Existing recommendations relevant to improving access to advocacy (including addressing barriers) were identified from 3 NICE guidelines ([NG119] Cerebral palsy in adults, [NG189] Safeguarding adults in care homes, [PH50] Domestic violence and abuse: multi-agency working). The audiences for these guidelines included: people with the condition or users of a services and their families and carers; health and social care professionals, practitioners and providers; service managers; commissioners, local authorities and safeguarding adult boards; and other staff who come into contact with people using services (for example, education, voluntary and community sector, and criminal justice staff). Only NG189 specifically listed advocates among their target audiences.

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.

Fourteen documents were identified for this review (Chatfield 2017, Harflett, 2015, Lawson 2017, Lawson 2020, Mercer 2020, National Development Team for Inclusion [NDTi] 2012, NDTi 2016a, NDTi 2020a, NDTi 2020b, Newbigging 2011, Newbigging 2012, Roberts 2012, SERIO 2021,Turner 2012).

Four documents focused on people living with autism and/or people living with learning disabilities, including those who are most isolated (NDTi 2012, Harflett 2015, Roberts 2012, Turner 2012). Three documents focused on providers and commissioners of independent advocacy (Lawson 2017, Lawson 2020, NDTi 2016). Three documents focused on advocacy services (Mercer 2020, NDTi 2020a, NDTi 2020b). One document each focused on people detained under the amended Mental Health Act 1983 (Newbigging 2012); African and Caribbean men using mental health services (Newbigging 2011); critical care unit clinicians, relatives of critical care patients and Independent Mental Capacity Advocates (IMCAs; Chatfield 2017); and Veterans and their families (SERIO 2021).

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 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
Chatfield 2017 Exploratory qualitative study England & Wales	Critical care unit clinicians, relatives of critical care patients, and IMCAs	15 interviews across 2 NHS sites and a survey of IMCA services. Reporting some knowledge of the MCA across both study sites, but that training on MCA was unsatisfactory, with confusion about the role of IMCAs and when

Document	Population	Evidence base
		they should become involved. Overall, suggestion that broader involvement of IMCAs on a regular basis within critical care could be useful
Harflett 2015 Narrative review England	Most isolated people with learning disabilities	Literature review
Lawson 2017 Report England	Those who have duties to commission and arrange advocacy services for safeguarding adults	Report drawing on existing literature (including statutory guidance and core principles for safeguarding) to set out what needs to be done and what needs to be addressed to make safeguarding personal
Lawson 2020 Briefing England	Those who have duties to commission and arrange advocacy services for safeguarding adults	Briefing generated by a series of conversations with 28 advocates from 18 advocacy providers across England, covering 33 local authority areas
Mercer 2020 Scoping review England	Independent advocacy services commissioned to provide advocacy to people accessing support/service through: i) s117 aftercare (under the Mental Health Act) ii) NHS Continuing Healthcare (adults) iii) Children and Young People's Continuing Care iv) Personal Health Budgets v) Personal Wheelchair Budgets	Non-systematic scoping exercise including data from: Freedom of information requests to identify what services were commissioned, by whom and to which groups; advocacy survey for advocates to identify what advocacy providers are delivering; semi-structured telephone interviews with Independent Advocacy providers; review of legislation and guidance to identify current provision and identify gaps
NDTi 2012 Report England	People with learning disabilities and people with autism	Systematic review with content analysis, call for evidence and meetings with experts by experience, family carers and professionals
NDTi 2016 Framework England	Providers and commissioners of independent advocacy	Literature review (no details reported) and consultation with two self-advocacy groups
NDTi 2020a Report on survey findings England & Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 435 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides

Document	Population	Evidence base
		recommendations for government, local authorities, and care providers
NDTi 2020b Report on survey findings Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	Survey of 72 advocates (with expertise across multiple areas of statutory and non-statutory advocacy) reporting data on accessibility and quality of advocacy during the pandemic and the impact on people who are entitled to advocacy; provides recommendations for government, local authorities, and care providers
Newbigging 2011 Systematic literature review and national survey UK (England, Wales, and Northern Ireland)	African and Caribbean men using mental health services	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 Research report England	People detained under the amended Mental Health Act 1983, who were eligible for support from IMHA services, including people with and without capacity and children under the age of 16	Multiple methods (including literature review, 11 focus groups, shadow visits with IMHAs, expert panel review) to obtain information on IMHA services to develop draft quality indicators for IMHA services. Data from 8 case studies (NHS Trust areas) to understand experiences of qualifying service users and the commissioning and delivery of IMHA services and their relationship with mental health services
Roberts 2012 Survey England	People with learning disabilities	3 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies; provides information on, for example, funding and also discusses gaps in advocacy provision and barriers to accessing services
SERIO 2021 Service evaluation England	Veterans and their families	Report of an independent three-year evaluation of The Veterans' Advocacy People, a service targeted at veterans, and their families from each of the service arms, which aims to provide open and flexible advocacy support. Includes qualitative interviews
Turner 2012 Brief report	People with learning disabilities	2 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies (no detailed methods

Document	Population	Evidence base
England		reported); provides advice and suggestions on actions for commissioners and advocacy groups to provide robust evidence on the effectiveness and reach of advocacy services

IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; LGA: Local Government Association; MCA: Mental Capacity Act; NDTi: National Development Team for Inclusion; NHS: National Health Service; s117: section 117

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

A total of 3 existing recommendations related to improving access to advocacy (including addressing barriers) were identified from the 3 NICE guidelines**Error! Reference source not found.**. The committee agreed 1 recommendation should be adapted and 2 recommendations should not be used in this guideline.

See Appendix F for a list of the existing recommendations, a summary of the supporting evidence behind these recommendations, and the decisions made based on the committee's discussion of these recommendations.

The quality of existing NICE guidelines was assessed using the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE II). See the results of the quality assessment in appendix C.

Formal consensus round 1

Three included documents (Lawson, 2017; NDTi, 2012; NDTi, 2016a) were assessed using AGREE II, 3 documents (Harflett, 2015; Mercer, 2020; Newbigging, 2011) were assessed using the Risk of Bias in Systematic reviews (ROBIS) checklist ,and 8 documents (Chatfield, 2017; Lawson, 2020;, NDTi, 2020a; NDTi, 2020b; Newbigging, 2012; Roberts, 2012; SERIO, 2021; Turner, 2012) were assessed using the Critical Appraisal Skills Programme (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 53 statements in round 1 of the formal consensus exercise; responses were received from 11 of 13 committee members. Thirty-two of these statements reached ≥80% agreement in round 1 and were included for the discussion with the committee. Seventeen statements had between 60% and 80% agreement; 15 of these were re-drafted for round 2 and 2 were discarded as the suggestions for revision were covered by existing statements. Four statements had <60% agreement and were discarded.

See appendix G for the statements that were rated by the committee and results of round 1, which are provided in Table 10.

Formal consensus round 2

The committee were presented with 15 statements in round 2 of the formal consensus exercise; responses were received from 10 of 13 committee members. Ten statements reached ≥80% agreement in this round and were included for the discussion with the committee. Four statements had between 60% and 80% agreement and one statement had <60% agreement. Statement 43 was included for the discussion with the committee as comments from the committee related to a minor issue with the population that could be addressed during the discussion of recommendations. The remaining statements were discarded.

See appendix G for the statements that were rated by the committee and results of round 2, which are provided in
BME: Black and Minority Ethnic; IMHA: Independent Mental Health Advocate; MH: mental health

Table 11.

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

Existing NICE guidelines

The quality of the existing NICE guidelines was assessed using AGREE II. Overall, the guidelines are of a very high quality (2 or more domains scored ≥90%) and are recommended for use. Two guidelines scored lower in stakeholder involvement because there were fewer experts by experience included in the committee group compared to other guidelines. In addition, the committee considered whether the recommendation could be generalised to a new context when making a decision about adopting or adapting the recommendations, which is documented in the benefits and harms section and appendix F.

Formal consensus

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.

The quality of 3 documents (Lawson, 2017; NDTi, 2012; NDTi, 2016a) was assessed using the AGREE II instrument. High quality documents were defined as those where any two domains scored ≥ 70%. The 3 documents were not deemed to be high quality. The included documents scored between 16% and 28% for stakeholder involvement and between 4% and 21% for applicability. The documents scored between 8% and 19% for rigour of development and between 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 included documents scored between 22% and 83% for scope and purpose, and between 22% and 56% for clarity of presentation. Generally, the overall aim, specific health questions and target population for the documents were described, but details were sometimes limited. The document did not present recommendations in a clear and concise structure and format.

The quality of 3 documents (Harflett, 2015; Mercer, 2020; Newbigging, 2011) was assessed using the ROBIS checklist for systematic reviews. Two documents (Harflett, 2015; Newbigging, 2011) were judged to have unclear risk of bias because insufficient details were provided to enable a judgement to be made. The remaining document (Mercer, 2020) was judged to have high risk of bias because some eligible studies are likely to have been missed from the scoping exercise and some bias may have been introduced through the data collection, and no risk of bias assessment was completed.

The quality of 8 documents (Chatfield, 2017; Lawson, 2020; NDTi, 2020a; NDTi, 2020b; Newbigging, 2012; Roberts, 2012; SERIO, 2021; Turner, 2012) was assessed using the CASP checklist for qualitative research. One document (Newbigging, 2012) was judged to have minor methodological limitations. One document (Chatfield, 2017) was judged to have moderate methodological limitations because the authors did not adequately consider the relationship between researcher and participants. Six documents (Lawson, 2020; NDTi, 2020a’ NDTi, 2020b; Roberts, 2012; SERIO, 2021; Turner, 2012) were judged to have serious methodological limitations because of insufficient detail relating to participant recruitment, data collection and data analysis. Other concerns related to the lack of adequate consideration for the relationship between researcher and participants, and lack of consideration regarding ethical issues.

Benefits and harms

The committee acknowledged that most of the statements below had been extracted from documents judged to be of lower quality. The committee discussed that although the quality was low, the content of the statements was relevant and important to include. Although there was some variation in the percentage agreement of statements, the majority of committee members agreed with the statements, which chimed with their own knowledge and experience. 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.

Meeting in-person

Statement 7 covered professional visitors, including advocates, being able to meet with people in-person. The committee agreed it was important that advocates are able to meet with people in person, especially in order to facilitate the person’s initial access to advocacy services. In the committee’s experience, an initial in-person meeting could improve access as some people are less willing to use advocacy services if this option isn’t available as a first step into a service. In the committee’s experience, meeting with people in person was routine practice prior to the COVID-19 pandemic, but has become more difficult since the pandemic. They said that motivated by cost savings, many services planned to continue this remote practice even after COVID-19 restrictions lifted. The committee expressed some concern about this, agreeing that this approach to interaction really undermined the advantages of face to face meetings described above.

Blanket restrictions preventing advocates access to people

Statement 8 covered that there should not be universal restrictions that prevent advocates accessing where people are, including care homes and hospitals. The committee agreed to adapt this recommendation to also include prison settings as the committee were aware of advocates also having difficulty in accessing these settings. In the committee's experience, this recommendation is needed as there are concerns that restrictions, such as social distancing and limits on hospital and care home visiting, brought on by COVID-19 might become the new norm. Further, the committee agreed that it seems to have been more difficult for advocates to access such settings during the pandemic than it has been for other professionals and that it was important that people have continued access to advocates so that rights are upheld.

Single and multiple points of access

Statement 22 covered commissioners considering having a single point of access to advocacy services so that individuals do not need to know what type of advocacy they require. The committee agreed that it is important to have a central route into advocacy services, such that referrals for different types of advocacy can be coordinated, in order to maximise access to advocacy. In their experience referrals are often sent back because the right information was not included, which delays and may deter people accessing services. However, the committee agreed that this does not mean there should only be one way to access advocacy services as having only a single point of access could create a barrier and limit empowerment and self-advocacy. On the other hand, the committee agreed that having multiple access points may help to reach seldom-heard groups. Therefore, the committee concluded that it was important for the recommendation to address both these points so that people do not need to go to different places according to which type of advocacy they need and at the same, people should have flexibility in how they access services.

Keeping the same advocate

Statement 25 covered people not having access to advocacy when they no longer qualify for independent mental health advocate (IMHA) services, unless the advocacy service has a strategy for ensuring continuity of access. The committee agreed that the best way to address this would be for people to keep the same advocate when they transition between different types of advocacy as effective advocacy depends on the development of trust and mutual understanding between the advocate and the person using advocacy support. In the committee's experience, this happens in some areas and services, where multi-skilled advocates are available that can provide different types of advocacy, but does not happen everywhere. Therefore, the committee acknowledged that it would not always be possible to keep the same advocate and recommended that systems are in place for handover when needed so that people do not require a new referral and are not lost to services as they 'drop out' out of one advocacy provider. The existing recommendation in enabling and supporting effective advocacy from the NICE guideline on people's experience in adult social care services [NG86] about commissioners and managers in all settings ensuring there is continuity in care was also used to inform this recommendation (see evidence review E).

Regular visits to hospitals by IMHA services

Statement 26 covered the need for regular visits to hospital wards by IMHA services, particularly to identify people who would be unable to instruct them and could potentially miss out on services. Health practitioners should be making referrals in the case of non-instructed advocacy; however, in the committee's experience, this does not routinely happen. Therefore, the committee agreed that having a regular presence of IMHAs on hospital wards is important to help ensure that people are not missing out on their statutory right to advocacy. Further, the committee agreed that advocates having a regular presence on wards could have an important safeguarding effect, in addition to improving access, as it will give them a comprehensive view of people's circumstances and living conditions on the ward. The committee agreed this recommendation was particularly important in light of difficulties accessing services or meeting with individuals face-to-face during the COVID-19 pandemic, as described above.

Offering services to all eligible people

Statement 39 originally covered access to IMHA services being improved by an opt-out system. This was amended in response to comments from the committee to focus on offering services to all eligible people, as opposed to using an opt-out system. However, in light of the expert testimony described in evidence review F, which recommended careful implementation of an opt-out system for advocacy in particular contexts, the committee agreed it was important that everyone who is eligible meets with an advocate and is offered the service. The expert testimony stated that this was an important measure for overcoming barriers to access arising from lack of awareness or understanding and negative attitudes about advocacy. The committee agreed, based on their experience, that referrals are not always made when they should be and that offering advocacy on an opt-out basis has been an effective way of ensuring access to advocacy for those with a statutory entitlement in areas where this has been implemented. The committee agreed it was important that an IMHA is offered to eligible people at the earliest opportunity. In the committees' experience referrals are frequently made too late, which does not give people enough time to arrange advocacy support or meet with their advocates ahead of key meetings or events, resulting in them being unable to fully and effectively participate in decision making. The committee agreed that is was also important to repeat the offer of an IMHA, as in some circumstances people might be too unwell at the point advocacy is initially offered or their circumstances can change, both of which can both lead to people changing their minds about advocacy if they initially declined. However, repeatedly offering an IMHA needs to be done within the context of a regular presence on the ward where the offer of an IMHA can come up conversationally and a person is not being pressurised with repeated offers and information.

Raising awareness of services user groups

Statement 42 highlighted that access to IMHA could be improved by raising awareness of service user groups and supporting peer promotion of services. The committee agreed to amend this statement to focus on raising awareness of services user groups and supporting peer and self-advocacy as it is not within the remit of NICE guidelines to ask peers to promote advocacy services. However, in the committee's experience, people may prefer to seek advocacy from a peer rather than a professional as they may feel that they are better understood by, or more trusting of, people with similar experiences to them. This was also supported by the expert testimony described in evidence review F. Further, self-advocacy has the benefit of developing skills and part of the advocacy ethos is to support independence and, by extension, self-advocacy. The committee also agreed that the use of less formal types of advocacy allows for consideration of wider issues that would not be within the remit of a professional advocate's role.

Ensuring services are being taken up by people with greatest needs

Statement 1 covered advocacy organisations promoting advocacy services and proactively offering support to people who may want to use advocacy services. The committee agreed to reword this statement as advocates cannot be asked to promote themselves, but instead advocacy organisations should have plans as to how to ensure that their services are taken up by people with the greatest need, who may not be able to ask for them. In the committee's experience this is not happening consistently and people might miss out on the support they are entitled to. Having this plan and acting on it would ensure these people do not miss out on this support.

Making information available in a variety of locations

Having made recommendations based on the statements presented as well as the expert testimony, the committee agreed there remained key areas which would benefit from recommendations to ultimately improve access. For instance, they discussed that difficulties in locating information about advocacy services are widely perceived to be a barrier to accessing support. They agreed that this could be addressed by advocacy providers making information available in a variety of different locations online. In the committee's experience people who have previously used advocacy services have reported that they would like other people to be aware of advocacy services. Therefore, ensuring that information is available in multiple places could help to ensure accessibility, improve awareness of advocacy services, and potentially improve equality of access by making it easier to get information to seldom heard groups.

Arranging advocacy where the person themselves in unable to do so

The committee also agreed it would be crucial to address the challenge for people unable to access advocacy despite being entitled to do so. They discussed that people who are unable to ask for an advocate often miss out on advocacy services so to address this they recommended that health and social care practitioners arrange advocacy where the person themselves is unable to ask for an advocate. In the committee's experience this should be happening consistently; however, health and social care professionals frequently do not make this referral.

The use of digital platforms

Statement 9 covered advocacy providers considering using digital platforms when it is genuinely effective. The committee agreed that this statement needed to be strengthened to ensure are actually used, not just considered, when they work and are necessary or preferred by the person. As outlined above, sometimes meeting remotely will be necessary, for example if advocates are unable to access a ward and, based on the committee's experience, some people may prefer to meet with their advocate remotely. Despite the benefits of remote communication the committee also agreed it should only be used if it is likely to be as effective as meeting people in person so that the quality of the service is not compromised. Meeting in person should always be prioritised if this is needed in order to be effective or to ensure privacy. The committee agreed that this recommendation was more relevant in the enabling and supporting effective advocacy and therefore decided to move this recommendation to the area of enabling and supporting effective advocacy.

Sufficient time to build relationships and trust

Statement 49 highlighted that a lack of time can act as a barrier to advocacy services supporting people living with learning disabilities. Although they felt the statement lacked clarity the committee agreed about the importance of advocacy organisations giving people with learning disabilities (or other needs) the time required to build up relationships and trust. They agreed this was the key aspect to the statement and it is where they wanted to focus their recommendation. In the committee's experience effective advocacy is only possible if sufficient time is taken to build relationships and trust with people, otherwise people may be unlikely to share information and what is important to them with their advocate. The committee also agreed that the amount of time it can take to build a trusting relationship with someone can vary greatly based on individual's needs, communication styles, and personalities. Therefore, the committee did not think it was appropriate to limit the recommendation to people living with learning disabilities, as this is just one example of a group where additional time may be needed to build effective relationships. The committee agreed that this recommendation was about how enable effective advocacy and therefore decided to move this recommendation under the area of enabling and supporting effective advocacy (see evidence review E).

Variety of advocacy models to meet the different advocacy needs

Statement 51 highlighted that the lack of appropriate advocacy for people with complex needs acts as a barrier to supporting people living with learning disabilities. The committee agreed this was an important point as it illustrates that people have different advocacy needs, which can be best met by offering a variety of advocacy models. However they also agreed this would apply to all people who may benefit from advocacy, not just people living with learning disabilities. The expert witness testimony (see evidence review F) also highlighted the importance of investing in community based advocacy and a wider range of advocacy types to support the delivery of culturally appropriate advocacy. People are most comfortable with advocates to whom they can relate and have faith in and this tends to lead to more effective advocacy. According to the expert witness testimony, people from racialized communities and those with lived experiences are less represented in mainstream and statutory advocacy services compared with community and voluntary sector organisations. The committee also agreed that peer advocacy and family advocacy should be added to the recommendation as examples of different types of advocacy services that could be made available as, in the committee’s experience, these less formal types of advocacy can often be overlooked. The committee agreed that this recommendation was more about planning and commissioning advocacy and therefore decided to move this recommendation under the area of planning and commissioning (see evidence review H).

Providing training to enhance knowledge of advocacy role

The existing recommendation from the NICE guideline on safeguarding adults in care homes [NG189] stated that all organisations involved in safeguarding should understand the role of advocacy in relation to safeguarding and think about the person’s needs and know when to refer people. Further details about the committee’s decisions to adopt or adapt existing NICE recommendations in the area of improving access to advocacy are given in appendix F. The existing recommendation relates to statement 1 in training other practitioners (see evidence review J) about providing training to all agencies working with advocacy services (including safeguarding adult board members) to enhance knowledge about advocacy role and function. The committee agreed to use the existing recommendation to inform recommendation 1.10.3 in training practitioners (see evidence review J).

Statements that were not used to inform new recommendations

There were a number of statements carried forward to committee discussions that were not used to inform recommendations. Statement 17, which covered the requirement of local and national analysis to examine the extent to which the duty to refer for independent advocacy support is supposed to come into play in safeguarding situations, was not used to inform a recommendation as the committee agreed this would require legal reform which is outside of the scope of NICE guidelines. Similarly, statement 52 was not used to inform a recommendation as the nature of commissioning of health and social care as a whole is outside the scope of NICE guidelines. Statement 34 was not used to inform a recommendation as it outside of the scope of NICE guidelines to ask advocates to promote themselves. Furthermore, the committee agreed that recommendations in the section on information about effective advocacy (see evidence review C) would help ensure people are aware of the services available. Statements 43 and 46 were not used to inform recommendations as it is not within the scope of NICE guidelines to make recommendations about funding or staffing levels. However, the committee agreed that the issues they covered should be addressed by recommendation 1.8.1 about basing commissioning of advocacy services on local needs, in the section on planning and commissioning (see evidence review H). Statement 20, which suggested that advocacy providers should support social workers to make appropriate referrals by responding to feedback about ease of referring, was not used to inform a recommendation as the committee agreed this is likely to already be happening as part of good practice. Statements 11, 12, 15 and 21 were not used to inform recommendations as they did not provide enough detail to inform what action should be taken to improve access. However, the committee agreed that recommendations throughout this section would help to address the general messages made in these statements. Statement 38 was not used to inform a recommendation, as the committee agreed that there was a duty on commissioners to ensure that services are non-discriminatory. The committee acknowledged that equality analysis may be one way of addressing this, but that the requirement to be non-discriminatory is not specific to advocacy and would apply to all health and social care services. Furthermore, the committee were not aware that this duty is being ignored for advocacy services so agreed that the recommendation is not needed.

A large number of statements were not used to inform recommendations as the issues they addressed were already covered by other recommendations. Statements 3, 19, and 24 were not used to inform recommendations as ensuring practitioners understand who is entitled to advocacy and when and how to request advocacy is already covered by recommendation 1.10.1 in training for other practitioners (see evidence review J). Statements 14 and 47 are covered by recommendation 1.2.1 (see evidence review B) about ensuring that advocacy services are available to everyone who needs it. Statement 16 is also covered by the same recommendation, as well as recommendation 1.6.1 in the section on effective advocacy (see evidence review F) about making efforts to reach under-represented and underserved communities. Statement 18 highlighted that the lack of understanding about advocacy contributes to people not always receiving advocacy support in the context of safeguarding. This was not used to inform a recommendation because the committee agreed this would be addressed by recommendation 1.5.15 in the section on enabling and supporting effective advocacy (see evidence review E), recommendations 1.11.11 and 1.11.12 in monitoring services and collecting data (see evidence review K), 1.10.3 in training and skills for practitioners (see evidence review J), and 1.9.2 in training, skills, and support for advocates (see evidence review I). Statements 27 and 29 were not used to inform recommendations as the issue of using interpreters is covered by recommendations 1.5.2 and 1.5.7 in the section on enabling and supporting effective advocacy (see evidence review E), 1.3.4 in information about effective advocacy (see evidence review C) and 1.6.11 in effective advocacy (see evidence review F). Statement 28 is covered by recommendation 1.4.8 about IMHAs having regular visits to wards. Statement 41 is covered in the section on planning and commissioning (see evidence review H) and by recommendation 1.7.10 about advocacy providers working in partnership with other organisations to ensure culturally appropriate advocacy. Statement 23 was not used to inform a recommendation as the issues are covered in the section on training and skills for practitioners (see evidence review J) by recommendation 1.10.1 about training on when and how to request advocacy and in the section on information about effective advocacy (see evidence review C) by recommendation 1.3.3 about how to access independent advocacy. Statement 4 was not used to inform a recommendation as the concept of ensuring face-to-face meetings are made available was covered in the section on effective advocacy (see evidence review F) by recommendation 1.6.1. Statement 10 is covered in effective advocacy (see evidence review F) by recommendation 1.6.1 about delivering face-to-face advocacy. Statement 45 is covered in training and skills and support for advocates (see evidence review I) by recommendation 1.9.1 about supporting a wide range of needs and impairments. Statement 2 was not used to inform recommendations as the principle of not having universal restrictions and regular visits to wards is covered by other recommendations in this section (1.4.3 and 1.4.8 respectively), as described above. Statement 40 was not used to inform recommendations as the concept of making all information available in a variety of formats is covered in the section on information about effective advocacy (see evidence review C) by recommendation 1.3.4. Statements 30 and 36 were not used as the basis for a recommendation because they do not provide a clear action on how to ensure equality of access; however, the committee agreed that this was a core concept made throughout the recommendations in this section of improving access. Furthermore, equality of access should be improved through recommendations in other sections of this guideline, such as the section on enabling and supporting effective advocacy in recommendation 1.5.2 about using interpreters (see evidence review E) and in the section on effective advocacy with recommendation 1.6.1 about making efforts to reach under-represented and disadvantaged populations (see evidence review F). Statement 37 was not used to make a recommendation because needs assessments are covered in the section on planning and commissioning (see evidence review H) by recommendation 1.8.1 about basing the commissioning of advocacy services on an assessment of local need, building on the Joint Strategic Needs Assessment. Statement 6 was not used to inform a recommendation as the statement itself does not indicate what action needs be taken; however, the committee agreed that the actions are covered in the section on training and skills for practitioners (see evidence review J) by recommendation 1.10.1.

Existing recommendations not used in this review

There were two existing NICE recommendations that the committee neither adopted nor adapted for the section on improving access to advocacy. The reasons behind their decision making are given in appendix F.

Cost effectiveness and resource use

During the COVID-19 pandemic many of the initial meetings between an advocate and individuals using the service changed to remote meetings either conducted by telephone or using videoconferencing software. Whilst in-person meetings were the norm before there is concern that for some, such meetings might now be standard practice given it is associated with cost savings through reduced travel costs and advocates time. Moving from these remote meetings back to in-person will be associated with an increase in resource use although it is unlikely to be greater than pre-pandemic. In person meetings may also increase the uptake of advocacy again increasing costs. The committee highlighted that there would be likely cost savings in the long run through greater uptake of advocacy and improvement in the quality of interactions leading to identifying problems earlier, avoiding costly medical interventions such as unplanned admissions to hospital and preventing replication of or inappropriate referrals.

The committee highlighted that whilst in-person meetings were optimal there were situations where remote meetings using digital platforms would still be effective and preferred by the individual. Remote meetings are likely to be less expensive but if the added convenience increases uptake those cost savings will be reduced. There were also a number of recommendations to improve awareness and access to advocacy which would increase the total number of people receiving advocacy. These are compliant with statutory duties for the majority of this group.

The prevention of blanket restrictions on where advocates could visit should not increase resource use beyond those discussed above in regard to in-person meetings recommencing. Most places where advocates would visit would not significantly increase travel or time above other venues. Whilst extra time may be required in visiting prisons to clear security protocols, this population will only represent a small percentage of visits. Again allowing in-person visits may lead to long term cost savings similar to those discussed previously.

Providing a simple process to access to advocacy services will require some resource but this will likely be a shift of existing resources to a fewer number of access points. Cost savings should also be realised through economies of scale of having fewer access points and through a reduction in repeated or inappropriate referrals caused by an overcomplicated process.

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

There will likely be an increase in resource use from regular visitations to hospital wards by IMHA services. Whilst health practitioners should be making referrals in the instance of non-instructed advocacy in many places this does not happen. Whilst it is likely to increase costs there are likely to be savings through improved safeguarding practices and through advocates obtaining a better understanding of peoples' needs. This should allow for better management of needs improving quality of life and preventing costly unplanned hospitalisations.

Making access to IMHA opt-out rather than opt-in will increase the number of meetings between advocates and people using their service, although providing a IMHA to eligible people is a legal requirement. The increase will therefore come from a greater number of people being aware of their right to access IMHAs and through barriers being significantly simplified to access them. This is likely to increase access to those most in need of IMHA services who may have otherwise had difficulty opting-in. Although there is likely to be a significant resource impact to this recommendation in the short term it will lead to improved access to advocacy services by overcoming barriers arising from lack of awareness or understanding and negative attitudes. Opt-out should also significantly speed up referral allowing for more time to prepare for meetings improving their effectiveness and ensuring that views can be expressed effectively. This is likely to reduce costs through more appropriate decision making and preventing waste on inappropriate or sub-optimal health care and also through preventing the need to repeat meetings or reducing their length through better preparation.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.4.1 to 1.4.2, 1.4.4 to 1.4.10, 1.4.12, 1.5.5, 1.5.10, 1.8.12, and 1.10.3. Other evidence supporting these recommendations can be found in the evidence reviews on enabling and supporting (see evidence review E), effective advocacy (see evidence review F), and training practitioners (see evidence review J).

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Existing NICE guidelines

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Formal consensus

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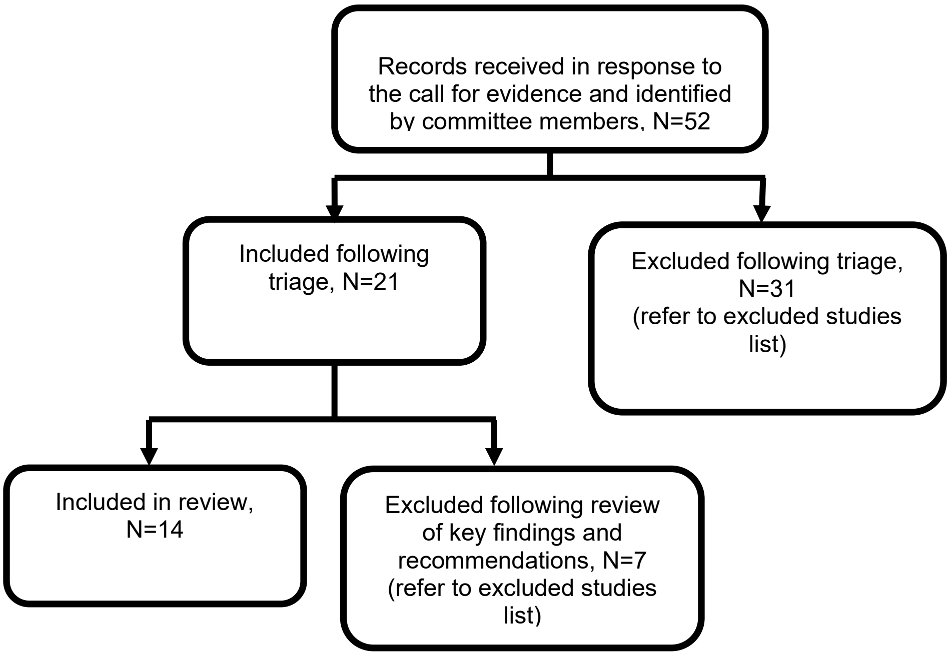
Appendices

Appendix A Study selection for formal consensus process

Study selection for scope area: Improving access to advocacy (including addressing barriers)

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Improving access to advocacy

Table 3: Evidence tables

Study details	Population	Recommendations/key findings	Quality assessment
Full citation 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. **Country/ies where the study was carried out** England and Wales **Study type** Mixed methods (qualitative research: interviews and survey data; open and closed ended questions) **Study dates** Not reported **Source of funding** No sources of funding reported	n=6 critical care units; n=5 relatives of critical care patients; n=4 IMCAs	**Key findings** • It was suggested that IMCAs are “the voice for a patient who isn’t competent at that point in time” (p.3). There was also widespread understanding that IMCAs were employed for incapacitated patients without suitable family members to represent them. • However, from interviews, it was clear that not all eligible patients were being referred to IMCAs. It was not always clear whether clinicians realised they have a statutory obligation to refer to the IMCA services, “there’s quite a lot of confusion around when to actually instruct an IMCA” (p.3). • One NHS Trust believed that IMCAs were mainly involved when end-of-life decisions were being made; the need for an IMCA for a person who	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)** Yes - to explore existing levels of knowledge and awareness of the MCA and understanding of the role of IMCAs in critical care. **2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No)** Yes - how clinicians and IMCAs were recruited is explained (through invitation letter and relatives through critical care unit follow-up clinics across 2 NHS Trusts in England). **5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)** Yes - the methods used were described although saturation of data was not discussed.

Study details	Population	Recommendations/key findings	Quality assessment
		lacks the capacity to make treatment decisions was linked to changing case law in this area.	**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own roles in the formulation of the research questions, or consider their influence on the participants. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** Yes - ethical approval and site specific authorisation was obtained; participants gave consent prior to participation in the study. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Yes - the authors describe the analysis process and sufficient data are presented to support the findings. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings **10. How valuable is the research?** Valuable – highlights that further training is required to ensure greater understanding of advocacy and that vulnerable patients receive services they are entitled to, and there is a need for further investigations into providing a drop in IMCA clinic. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Moderate limitations.

Study details	Population	Recommendations/key findings	Quality assessment
Full citation 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] **Country/ies where the study was carried out** England **Study type** Review of evidence **Study dates** June 2015 **Source of funding** No sources of funding reported	Most isolated people with learning disabilities	**Key findings** • Those with high or complex needs are less likely to have access to advocacy.	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** No information. **1.2 Were the eligibility criteria appropriate for the review question?** Probably no (Insufficient information). **1.3 Were eligibility criteria unambiguous?** Probably no (Insufficient details about eligibility criteria). **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** No information. ***Concerns regarding specification of study eligibility criteria*** Unclear concern (Insufficient information). **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** Probably yes (Used academic search engines but does not specify which ones). **2.2 Were methods additional to database searching used to identify relevant reports?** No information. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
			2.4 Were restrictions based on date, publication format, or language appropriate? No information. **2.5 Were efforts made to minimise errors in selection of studies?** No information. ***Concerns regarding methods used to identify and/or select studies*** Unclear concern (Insufficient information provided). **3.1 Were efforts made to minimise error in data collection?** No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** No. **3.3 Were all relevant study results collected for use in the synthesis?** No information. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** No. **3.5 Were efforts made to minimise error in risk of bias assessment?** Not applicable – study quality was not formally assessed. ***Concerns regarding methods used to collect data and appraise studies*** High concern (No risk of bias assessed). **4.1 Did the synthesis include all studies that it should?** No Information.

Study details	Population	Recommendations/key findings	Quality assessment
			4.2 Were all predefined analyses followed or departures explained? No information. **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?** No information. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information. **4.5 Were the findings robust, e.g. as demonstrated through funnel plot or sensitivity analyses?** No information. **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No information. ***Concerns regarding the synthesis and findings*** Unclear concern (Insufficient information). ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** No. **B. Was the relevance of identified studies to the review's research question appropriately considered?** No. **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes **Risk of bias** – Unclear risk of bias

Study details	Population	Recommendations/key findings	Quality assessment
Full citation Lawson, J. (2017). Making Safeguarding Personal. What might 'good' look like for advocacy? Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.30%20-%20Chip_MSP%20Advocacy_WEB_2.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England **Study type** Report/review **Study dates** 2017 **Source of funding** No sources of funding reported	Those who have duties to commission and arrange advocacy services	**Recommendations** • Commissioners should facilitate easy access to advocacy that is appropriate to the range of people's needs, for example considering a single point of access across different types of guidance (2016) so that the reader can locate examples and details. This means that, at the point of referral, individuals do not need to know what type of advocacy they require.	**Quality assessment using AGREE II** **1) Scope and Purpose** 61% Overall objective and population are described. Health question is not specifically described but alluded to. **2) Stakeholder involvement** 22% Target users are defined but not information on guideline development group and views and preferences from population has been included. **3) Rigour of development** 8% Health benefits when describing recommendations have been considered. No information on systematic methods, criteria selection, strengths and limitations, and methods for formulating recommendations have been provided. Link between recommendations and supporting evidence not clear. No information on external reviewing, and procedure for updating have been provided. **4) Clarity of presentation** 22% Recommendations are not always specific and easily identifiable. No mentioning of different options for management. **5) Applicability** 4% Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource implications, and auditing criteria provided. **6) Editorial independence** 0.0% No funding body and competing interest have been identified.

Study details	Population	Recommendations/key findings	Quality assessment
			Overall rating 29%
Full citation Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding Personal, Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf [Accessed 07/04/2021] **Country/ies where the study was carried out** England **Study type** Qualitative (Focus group discussions) **Study dates** 2020 **Source of funding** No sources of funding reported	Those who have duties to commission and arrange advocacy services	**Key findings** • Suggests further local and national analysis to examine the extent to which duty to refer for independent advocacy support is supposed to come into play in safeguarding situations. • Lack of understanding about advocacy likely contributes to a picture where not everyone who should, receive advocacy support in safeguarding. • Advocacy providers supporting social workers to make appropriate referrals by providing guidance and training and responding to feedback about ease of referring. • Advocates advised that contracts do not always allow adequate time for training.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes – to support strengthening the role of all types of advocacy in safeguarding adults, specifically in Making Safeguarding Personal by generating multi-agency conversations based on the briefing and stimulating local action to address some of the core messages that emerge from this. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Yes – to some extent. Semi-structured focus group discussions on teleconference calls were held with 28 advocates from 18 advocacy providers across England, covering 33 Local Authority areas.

Study details	Population	Recommendations/key findings	Quality assessment
			6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No) No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings. **10. How valuable is the research?** Valuable - the authors discuss issues arising in relation to providing advocacy services in relation to safeguarding adults, and provide suggestions on how to address the key issues. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.
Full citation Mercer, K., Petty, G. (2020). Scoping Exercise Report – An overview of	Independent advocacy services	**Key findings** • Barriers to providing advocacy to people in relation to health-	**Quality assessment using ROBIS** ***Phase two***

Study details	Population	Recommendations/key findings	Quality assessment
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] **Country/ies where the study was carried out** England **Study type** Report of a scoping exercise (including freedom of information requests, advocate survey, semi-structured telephone interviews and desktop review of legislation and guidance) **Study dates** January to March 2020 **Source of funding** Commissioned by NHS England and NHS Improvement	commissioned to provide advocacy to people accessing support/service through: i) s117 aftercare (under the Mental Health Act). ii) NHS CHC (adults). iii) Children and Young People's CC. iv) Personal Health Budgets. v) Personal Wheelchair Budgets.	funded support included not always receiving referrals from healthcare professionals (this left organisations unable to provide support); lack of integration between health and social care which limited provision; the ability to only accept referrals that included a local authority social worker. • Participants highlighted the challenges of NHS CHC processes, including complexity, length, jargon, difficult to understand, and challenges in accessing and navigating the services. • There were reports of the local authority and CCG disagreeing on responsibilities and avoiding decision making. For example, "CHC is incredibly difficult to access – you get health and Local Authority literally fighting across the table". (p.24) **Recommendations** • Establish a statutory right to advocacy for people accessing or wanting to access health funded support to potentially fill the 'gaps' and lead to less episodic and more	**1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** Probably no - There was no evidence of eligibility criteria but objective of the scoping exercise are pre-specified. **1.2 Were the eligibility criteria appropriate for the review question?** No information - Eligibility criteria were not provided. The scoping exercise included a freedom of information request, advocate survey, semi-structured telephone interviews and desktop review of legislation and guidance which appear to be conducted by the authors themselves. **1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the types of study, population, interventions, comparators and outcomes. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information - Restrictions around the studies characteristics are not provided. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** No information - Restrictions applied on the basis of sources of information were not clearly described. ***Concerns regarding specification of study eligibility criteria*** High concern - There were insufficient details regarding study eligibility criteria to judge whether the appropriate studies were included in the scoping exercise. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?**

Study details	Population	Recommendations/key findings	Quality assessment
		holistic advocacy being available.	No information – Searches appear not to have been conducted. **2.2 Were methods additional to database searching used to identify relevant reports?** No information – Additional database searching appears not to have been conducted. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** No information. **2.4 Were restrictions based on date, publication format, or language appropriate?** No information. **2.5 Were efforts made to minimise errors in selection of studies?** No information. ***Concerns regarding methods used to identify and/or select studies*** High concern - There is insufficient information reported however it appears as though some eligible studies are likely to be missing from the scoping exercise. **3.1 Were efforts made to minimise error in data collection?** No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** No. **3.3 Were all relevant study results collected for use in the synthesis?** Probably no – Unclear whether all relevant study results were included.

Study details	Population	Recommendations/key findings	Quality assessment
			3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria? No - Study quality was not formally assessed. **3.5 Were efforts made to minimise error in risk of bias assessment?** Not applicable – study quality was not formally assessed. ***Concerns regarding methods used to collect data and appraise studies*** High concern - Some bias may have been introduced through the data collection and no risk of bias assessment completed. **4.1 Did the synthesis include all studies that it should?** No information. **4.2 Were all predefined analyses followed or departures explained?** No information. **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?** No information. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information. **4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?** No information. **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No - The studies were not explicitly evaluated for quality or risk of bias. ***Concerns regarding the synthesis and findings***

Study details	Population	Recommendations/key findings	Quality assessment
			Unclear concern - There is insufficient information reported to make a judgement on risk of bias. ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** No. **B. Was the relevance of identified studies to the review's research question appropriately considered?** No. **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes. **Risk of bias** – High risk of bias.
Full citation 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] **Country/ies where the study was carried out** England **Study type**	Adults with learning disabilities and adults with autism	**Key findings** • Current gaps in provision of advocacy identified: Lack of non-instructed Independent Mental Health Advocacy, which may be caused by failure to recognise some people with mental health issues also have learning disabilities.	**Quality assessment using AGREE II** **1) Scope and Purpose** 83% Overall objective, population and description of the health are described. **2) Stakeholder involvement** 16% Composition of the committee was alluded to but no specific information provided. Some views from the target audiences were included. Target users of the guideline were not defined. **3) Rigour of development** 19% Systematic methods were attempted but not clearly enough defined. No or little information about criteria for selection, strength and limitations, and methods for formulating recommendations provided. Some health benefits have been considered when making

Study details	Population	Recommendations/key findings	Quality assessment
Mixed Methods (Literature Review and Qualitative Research) **Study dates** February 2012 **Source of funding** No sources of funding reported			recommendations. No explicit links to recommendations, and no procedure for updating guidelines have been included. **4) Clarity of presentation** 33% Recommendations could be clearer and more specific. No different options are presented. Key recommendations are identifiable. **5) Applicability** 8% Descriptions of barriers and tools are vague. No information regarding resource implications and auditing criteria were provided. **6) Editorial independence** 0% No information regarding funding and/or potential conflict of interest were provided. **Overall rating** 36%
Full citation National Development Team for Inclusion (2016a). Advocacy Outcomes Framework: Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type**	Providers, commissioners and users of independent Advocacy	**Key findings** Improve access to advocacy by: • Progress towards providing services to all eligible people. • Increase amount of advocacy to people from seldom heard groups (including but not limited to people with learning disabilities, from BME communities, young people).	**Quality assessment using AGREE II** **1) Scope and Purpose** 22% Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided. **2) Stakeholder involvement** 28% Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear. **3) Rigour of development** 10% Health benefits have seemingly been considered when describing recommendations. No information regarding

Study details	Population	Recommendations/key findings	Quality assessment
Framework **Study dates** 2016 **Source of funding** Esmee Fairbairn Foundation			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. **4) Clarity of presentation** 56% Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to. **5) Applicability** 21% Advice on how to put recommendations into practice is alluded to but not clearly defined. No information facilitators and barriers, potential resource implications, auditing criteria are provided. **6) Editorial independence** 17% Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided. **Overall rating** 34%
Full citation National Development Team for Inclusion (2020). 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]	Advocates (across multiple areas of statutory and non-statutory advocacy)	**Key findings** • Advocates provided examples of increased safeguarding risks (for example, risk of suicide and suicidal thoughts) which were linked to wider restrictions on care and support. Reduced access to advocacy, limitations of remote communication tools,	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to gather information on the accessibility and quality of advocacy and the Covid-19 pandemic's impact on people who are entitled to advocacy, along with the challenges and what was working well in response to the pandemic and the restrictions in place.

Study details	Population	Recommendations/key findings	Quality assessment
Country/ies where the study was carried out England and Wales **Study type** Survey (open and closed ended questions) **Study dates** June 2020 **Source of funding** No sources of funding reported		and lack of privacy during meetings made it harder for advocates to play their role in safeguarding people from harm and abuse. • "We have raised a safeguarding alert for all of the people living in a supported living service, as they were being locked in the house and unable to go out for any reason, including exercise or shopping" (p.14) • Reduced referral rates: many advocates reported frontline local authority workers behaving as if rights to advocacy had been suspended and being told: ○ "we don't have to refer anymore because of the easements." (p.10) • Promotion of both face-to-face advocacy (with measures to assess and reduce risk) and remote advocacy via telephone or video call. • Embedding the actions outlined in the ADASS paper 'Advocacy during Covid-19 and beyond' that set out what local authorities, commissioners, and managers	**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
		could do to make better use of advocacy. • Local authorities must urgently address the knowledge gap of their health and social care providers, the drop in referrals, and the subsequent risk to statutory and human rights. This requires: ○ Clear leadership communication that the Mental Capacity Act continues to apply and the Care Act and Social Services and Wellbeing Act (Wales) remain fully in force unless the authority has formally exercised easements. ○ Action to make sure people's legal rights to advocacy are enforced, including through effective communication with professionals regarding their duty to refer and the active auditing and monitoring of referrals, advocacy uptake, and advocacy reach. ○ Enhanced understanding of human rights and domestic law across the health and social care system, including	Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors provide recommendations relating to responding to future waves of the pandemic and providing social care and support for people with long-term health conditions beyond the coronavirus pandemic. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		targeted training on statutory duties, the Equalities Act, and the Human Rights Act. ○ Increased clarity and communication by health and social care agencies that decisions about restrictive practices and healthcare must be made individually, other than where specifically lawful. • For new arrangements to work in relating to Liberty Protection safeguards, the following must be incorporated: ○ Increased, easy access to independent advocacy to make sure people's rights are protected. • Professional visitors, including advocates, must be able to meet with people in-person. There should not be blanket restrictions that prevent advocates accessing where people are, including care homes and hospitals. If asymptomatic testing is required for advocates to access where someone lives or is staying, this should be easily available.	

Study details	Population	Recommendations/key findings	Quality assessment
		• We must consider how to use digital platforms when it is genuinely effective but also protect the primacy of being able to deliver advocacy in person. **Recommendations** • Shared commitments by advocacy organisations to ensure people's access to effective advocacy. Advocacy organisations have committed to: ○ 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 National Development Team for Inclusion (2020). 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] **Country/ies where the study was carried out** Wales	Advocates (across multiple areas of statutory and non-statutory advocacy)	**Key findings** • 1 in 3 advocates (33%) suggested that the reduction in referrals was in part due to a lack of understanding or awareness of advocacy statutory duties, and that advocacy has become less visible during the pandemic. • "When there is an IMHA presence on the ward, patients approach you directly and also [tell] each other. If	**Quality assessment using CASP qualitative studies checklist** See NDTi 202a.

Study details	Population	Recommendations/key findings	Quality assessment
Study type Survey (open and closed ended questions) **Study dates** June 2020 **Source of funding** Age Cymru		you aren't there, they assume you can't do anything to help. Some staff have assumed you weren't working since you aren't visible on the ward, despite contacting to say otherwise and putting new posters up explaining what is happening.” (p.10)	
Full citation 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. **Country/ies where the study was carried out** UK (England, Wales, and Northern Ireland) **Study type** Systematic literature review and national survey **Study dates** 2011	African and Caribbean men using mental health services	**Key findings** • Focus groups highlighted the difficulties in accessing appropriate help and support for mental health needs, particularly for young men. • The limited evidence available from monitoring suggested that BME advocacy organisations have reasonable uptake of African and Caribbean service users. • However, there was little evidence to suggest proactive efforts to seek out African and Caribbean men although some services did attempt to promote better uptake by directly targeting BME communities.	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** Yes – There were a clear protocol and pre-specification of objectives the review are provided. **1.2 Were the eligibility criteria appropriate for the review question?** Yes – Eligibility criteria seem appropriate for review question. **1.3 Were eligibility criteria unambiguous?** Yes – Eligibility criteria were clearly defined. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** Yes – Restrictions seemed appropriate. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?**

Study details	Population	Recommendations/key findings	Quality assessment
Source of funding SCIE			Yes – Restrictions applied on the basis of sources of information were clearly described. ***Concerns regarding specification of study eligibility criteria*** Low Concern - Considerable effort has been made to clearly specify the review question and objectives, and to pre-specify and justify appropriate and detailed eligibility criteria that have been adhered to during the review. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** Yes – Direct databases are all clearly identified. **2.2 Were methods additional to database searching used to identify relevant reports?** Yes – secondary reference search was undertaken. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** No information. **2.4 Were restrictions based on date, publication format, or language appropriate?** No – Search was restricted to English language publications. **2.5 Were efforts made to minimise errors in selection of studies?** Yes – Two authors independently screened and searched data. ***Concerns regarding methods used to identify and/or select studies***

Study details	Population	Recommendations/key findings	Quality assessment
			Unclear concern – Some information regarding search strategy is missing. **3.1 Were efforts made to minimise error in data collection?** Yes – Two authors independently data extracted. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** Probably yes – Link to full study characteristics provided; however cannot access these. **3.3 Were all relevant study results collected for use in the synthesis?** Probably yes – Unclear whether all relevant study results were included. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** Yes – TAPUPAS standard was used to critically assess included studies. **3.5 Were efforts made to minimise error in risk of bias assessment?** Yes – Two reviewers independently critically assessed included papers and a third reviewer was used where there were discrepancies. ***Concerns regarding methods used to collect data and appraise studies*** Low concern – Insufficient information about study characteristics but risk of bias as assessed accordingly.

Study details	Population	Recommendations/key findings	Quality assessment
			4.1 Did the synthesis include all studies that it should? No information. **4.2 Were all predefined analyses followed or departures explained?** No information. **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?** No information. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information. **4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?** No information. **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No – The studies were evaluated for risk of bias but results were not incorporated into findings/conclusion. ***Concerns regarding the synthesis and findings*** Unclear concern – There is insufficient information reported to make a judgement on risk of bias. ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?**

Study details	Population	Recommendations/key findings	Quality assessment
			Yes **B. Was the relevance of identified studies to the review's research question appropriately considered?** Yes **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes **Risk of bias** – Unclear risk of bias
Full citation 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] **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research (focus groups and interviews), case studies **Study dates** 2010 to 2012	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)	**Key findings** • Specific groups of people who may be under-served by IMHA services include: ○ People from BME communities. ○ People with learning disabilities. ○ Older people, with dementia. ○ People who are hearing impaired or deaf. ○ Children and young people; the proportion of children and young people accessing IMHA services was relatively low. ○ People on CTOs. ○ People placed out of area. • Advocates and mental health service professionals have a role in promoting advocacy, making sure service users and staff know how to contact the	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to people who qualify for these services under the MH Act 1983. To identify the factors that affect the quality of IMHA services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes - how IMHA services and service users were identified is explained, in addition to identification of carers and family members, mental health staff and commissioners.

Study details	Population	Recommendations/key findings	Quality assessment
Source of funding Department of Health		IMHA service and that staff within the organisation have sufficient knowledge of advocacy and their statutory duties to support it. - IMHA's opinions differed about the extent to which they could become involved in issues that went beyond the rights of individuals in terms of the MH Act. When someone no longer qualifies for IMHA services (that is, they are no longer detained under the MH Act), often when discharged, they may not have access to advocacy unless the advocacy service has a strategy for ensuring continuity of access. - Regular visitations to hospital wards by IMHA services, particularly to identify people who would be unable to instruct them and could potentially miss out on services. For example, "We have come across people in hospital, whilst visiting someone else, whom we believe, from what we witness, would really benefit from some advocacy support. However, if we introduce ourselves and explain what we do, the	**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Yes - the methods used were explicitly described and justifications for their use were provided, although saturation of data was not discussed. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** Yes - the authors acknowledged the potential for the quality of the data collection and analysis to be influenced by the researchers. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** Yes - ethical approval was received from the Cambridgeshire Research Ethics Committee and the International School for Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Yes - the authors describe the analysis process and sufficient data are presented to support the findings. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes. **10. How valuable is the research?** Valuable - the authors highlight gaps in the evidence, how the evidence relates to previous research, and implications for practice and policy and future research.

Study details	Population	Recommendations/key findings	Quality assessment
		person may not be able to give clear consent that they would like our help. In these cases we need to have a third party referral to give us a legitimate mandate to act on the persons behalf. We have certainly encouraged mental health staff to make referrals in such cases." [IMHA Manager] (p.76) • Providing access to interpreters who have an understanding of potential cultural issues. • Peer promotion, helped by the IMHA being visible and there is the opportunity for the individual to approach them informally. • IMHA questionnaire responses highlighted variations in access to and uptake of IMHA services, particularly between qualifying patients in urban and rural areas and between those in secure services, acute inpatient care and in the community on CTOs. **Factors identified as influencing access and uptake of IMHA services included:**	**Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Minor limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		• Availability of IMHA services: ○ Minimum provision and other standards for IMHA services agreed nationally. • Understanding the purpose and role of IMHA services. • Promotion by mental health services. • Receptiveness of qualifying patients to IMHA services. • A tangible commitment to equality of access for all. • Practical steps to improve access. • *Practical steps to improve access:* Ways of promoting access and uptake of IMHA services may include: ○ Needs assessment, taking into account factors that could hamper access and uptake (for example, communication, profile of the service, lack of trust and familiarity with the service). ○ Conducting equality analysis to identify whether and how particular groups might be disadvantaged in terms of the current design and provision of services.	

Study details	Population	Recommendations/key findings	Quality assessment
		○ Consider an opt-out rather than opt-in system to overcome gatekeeping. ○ Providing information in a variety of formats to promote an understanding of the role of IMHAs. ○ Ensuring mental health professionals understand their obligations in relation to promoting IMHA services and the purpose and role of these services and revisit the opportunity to make qualifying patients aware of this. ○ Providing access to culturally appropriate forms of IMHA. ○ Providing bilingual advocates (including British Sign Language) or access to trained interpreters if not available. ○ Raising awareness of service user groups and supporting peer promotion of IMHA services. **Recommendations** • Mental health services need to take steps to ensure that all relevant staff understand that access to IMHA services is a	

Study details	Population	Recommendations/key findings	Quality assessment
		right and are aware of the purpose of IMHA. - Quality indicator 9: Access - An opt-out, as opposed to an opt-in, system where IMHA services are routinely offered on detention and discharge is in place. - Easy access to interpreters, for people for whom English is not their first language, or signers for deaf people, where services aren't provided directly by people from those communities. - A proactive approach to address inequalities of access.	
Full citation Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England	A range of people including people living with learning disabilities	**Key findings** - 34 organisations reported funding as a barrier to providing support to people living with learning disabilities. For example, “Lack of consistent and sufficient funding to develop new projects and services and improve what we already do. Really hard to plan when funding is short-lived.” [53] (p.45) - 5 organisations mentioned attitudes as a barrier, either	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)** Yes – to explore the nature and extent of advocacy services for people with learning disabilities in England, how funding changes affect these services, and the impact of advocacy on health and health services for people with learning disabilities. **2. Is a qualitative methodology appropriate? (Yes/Can’t tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No)** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
Study type Survey (open and closed ended questions) and case studies **Study dates** December 2011 and January 2012 **Source of funding** Supported by the Department of Health		towards advocacy or people living with learning disabilities. • 4 organisations mentioned a lack of understanding or knowledge about advocacy as a barrier. • 4 advocacy groups identified a lack of staff as a barrier and this was linked to a lack of resources. For example, “Not enough resources – advocacy should be every vulnerable adult’s statutory right – with enough staff!” [61] (p.46) • 4 organisations mentioned eligibility criteria for services or contract restrictions as a barrier. • Other examples of barriers to supporting people living with learning disabilities included the need for more volunteers (2 organisations) and time (3 organisations). • Responses from commissioners also mentioned the size and location of the service area as a barrier to advocacy provision, a lack of self-advocacy, and a lack of appropriate advocacy for people with complex needs.	**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No)** Yes – how advocacy organisations and commissioners of advocacy services were identified is explained to some extent. **5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)** Can’t tell – limited information on methods of data collection and no other details provided. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)** No – the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)** No – ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)** Can’t tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can’t tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable – the authors provide evidence on gaps in the provision of advocacy services and areas for further research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)**

Study details	Population	Recommendations/key findings	Quality assessment
			Serious limitations.
Full citation 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] **Country/ies where the study was carried out** England **Study type** Survey (open and closed ended questions) and case studies **Study dates** See Roberts 2012 **Source of funding** Supported by the Department of Health	A range of people including people living with learning disabilities	**Key findings** • Although advocacy organisations are not public bodies, they can be commissioned by public bodies and relationships between the two should take equality into consideration. For example, survey responses indicated that parents with learning disabilities and young people in transition may struggle to access advocacy.	**Quality assessment using CASP qualitative studies checklist** See Roberts 2012
Full citation SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return on Investment Analysis, The Advocacy People. Available at:	Military veterans and their families	**Key findings** • The knowledge that The Veterans' Advocacy People was specifically focussed on supporting veterans was important.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes – to assess the impact of advocacy on veterans and their families, and the wider social and financial impact. To enable

Study details	Population	Recommendations/key findings	Quality assessment
https://www.vfrhub.com/wp-content/uploads/2021/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf [Accessed 06/04/2021] **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research and social return on investment analysis **Study dates** 2018 to 2021 **Source of funding** No sources of funding reported		• "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)	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. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell – insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No – the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No – ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)**

Study details	Population	Recommendations/key findings	Quality assessment
			Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings. **10. How valuable is the research?** Valuable – the authors suggest strengths and limitations of the research and potential for unintended outcome consequences, and suggestions for further analysis relating to data monitoring. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

ADASS: Association of Directors of Adult Social Services; AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; BME: Black and minority ethnic; CASP: Critical Appraisal Skills Programme; CHC: Continuing Healthcare; CC: Continuing Care; CCG: clinical commissioning group; CTO: Community Treatment Order; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; MCA: Mental Capacity Act; MH: mental health; NDTi: National Development Team for Inclusion; NHS: National Health Service; ROBIS: Risk of Bias Assessment Tool for Systematic Reviews; s117; section 117; SCIE: Social Care Institute of Excellence; TAPUPAS: transferability, accessibility, propriety, utility, purposivity, accuracy and specificity.

Appendix C Quality Assessment

Quality assessment tables for scope area: Improving access to advocacy

Existing NICE guidelines

Table 4: AGREE II quality assessment of NICE guidelines

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Cerebral palsy in adults (NICE Guideline 119)	2019	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. The views of the target audiences were included in guideline development. The target users	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded	99

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
			of the guideline are clearly defined.	discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the	together in one section. The description of recommendations are summarised as flow charts.	and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.	and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				methodology for this procedure is unavailable.				
Safeguarding adults in care homes (NICE Guideline 189)	2021	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations.	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	97

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		
Domestic violence and abuse: multi-	2014	100 The overall objective of the	72 The guideline development	96 Systematic methods were used to search	100 The recommendati	92 There is some description of	100 The funding body has been	93

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
agency working (Public Health Guideline 50)		guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. There is no report that the target audience (for example, people affected by domestic violence and abuse and their families and carers, or members of the public) were included in guideline development. The target users of the guideline are clearly defined.	for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations,	ons are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendations are summarised as flow charts.	the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these.	stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.		There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; NICE: National Institute for Health and Care Excellence

Formal consensus

Table 5: AGREE II quality assessment of included guidelines

		Domains						
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Lawson 2017	2017	61 Overall objective and population are described. Health question is not specifically described but alluded to.	22 Target users are defined but not information on guideline development group and views and preferences from population has been included.	8 Health benefits when describing recommendations have been considered. No information on systematic methods, criteria selection, strengths and limitations, and methods for formulating recommendations have been provided. Link between recommendations and supporting evidence not clear. No information on external reviewing, and	22 Recommendations are not always specific and easily identifiable. No mentioning of different options for management.	4 Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource implications, and auditing criteria provided.	0 No funding body and competing interest have been identified.	29

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				procedure for updating have been provided.				
NDTi 2012	2012	83 Overall objective, population and description of the health are described.	16 Composition of the committee was alluded to but no specific information provided. Some views from the target audiences were included. Target users of the guideline were not defined.	19 Systematic methods were attempted but not clearly enough defined. No or little information about criteria for selection, strength and limitations, and methods for formulating recommendations provided. Some health benefits have been considered when making recommendations. No explicit links to recommendations, and no procedure for	33 Recommendations could be clearer and more specific. No different options are presented. Key recommendations are identifiable.	8 Descriptions of barriers and tools are vague. No information regarding resource implications and auditing criteria were provided.	0 No information regarding funding and/or potential conflict of interest were provided.	36

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				updating guidelines have been included.				
NDTi 2016a	2016	22 Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided.	28 Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear.	10 Health benefits have seemingly been considered when describing recommendations. No information regarding systematic methods, criteria for selection, strengths and limitations, and methods for formulating recommendations have been provided. Links between recommendations and evidence are	56 Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to.	21 Advice on how to put recommendations into practice is alluded to but not clearly defined. No information facilitators and barriers, potential resource implications, auditing criteria are provided.	17 Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided.	34

Domains								
Guideline reference	Year	Scope and purpose %	Stakeholder involvement %	Rigour of development %	Clarity of presentation %	Applicability %	Editorial Independence %	Overall rating %
				not clear. No information on external reviews and no information on updating has been provided.				

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument;

Table 6: 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
Harflett 2015	2015	Unclear concern	Unclear concern	High concern	Unclear concern	Unclear concern
Mercer 2020	2020	High concern	High concern	High concern	Unclear concern	High concern
Newbigging 2011	2011	Low concern	Unclear concern	Low concern	Unclear concern	Unclear concern

ROBIS: Risk of Bias Assessment Tool for Systematic Reviews

Table 7: 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
Chatfield 2017	2018	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable

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 2020a	2020a	Yes	Yes	Yes	Can’t tell	Can’t tell	No	No	Can’t tell	Yes	Valuable
NDTi 2020b	2020b	Yes	Yes	Yes	Can’t tell	Can’t tell	No	No	Can’t tell	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
Turner 2012	2012	Yes	Yes	Yes	Yes	Can’t tell	No	No	Can’t tell	Yes	Valuable

CASP: Critical Appraisal Skills Programme

Appendix D Excluded studies

Excluded studies for scope area: Improving access to advocacy

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

Table 8: 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.
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)
Healthwatch (2015). Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service. Available at: https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
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 Improving access to advocacy (including addressing barriers)

Study	Reason for Exclusion
National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished.	No key findings or recommendations relevant to Improving access to advocacy (including addressing barriers)
National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished.	No key findings or recommendations relevant to Improving access to advocacy (including addressing barriers)
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 (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 Improving access to advocacy (including addressing barriers)
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
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
Newbigging, K., K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., et al. (2012). The Right to Be Heard: Review of the quality of Independent Mental Health Advocate (IMHA) Services in England, Summary Report	No key findings or recommendations relevant to Improving access to advocacy (including addressing barriers)
Newbigging, K., K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., et al. (2015). Independent Mental Health Advocacy – The Right to Be Heard: Context, Values and Good Practice	Publication is based on book/book chapter.
Older People's Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the	Publication is based on case-studies.

Study	Reason for Exclusion
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]	
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 Improving access to advocacy (including addressing barriers)
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services, easy read version. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/easy-read/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2014). At a glance 67: Understanding Independent Mental Health Advocacy (IMHA) for mental health staff. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence 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 case-studies.
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 case-studies.

Study	Reason for Exclusion
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a briefing for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/briefing/ [Accessed 16/02/2022]	Publication has no case-studies.
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). 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, 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
Social Care Institute for Excellence, University of Central Lancashire (2015). Making a difference: measuring the impact of Independent Mental Health Advocacy (IMHA). Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/impact/ [Accessed 16/02/2022]	Publication is based on case-studies.
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

Study	Reason for Exclusion
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: Improving access to advocacy

No research recommendations were made for this scope area.

Appendix F Existing NICE recommendations

Table 9: Existing NICE recommendations for scope area: Improving access to advocacy

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Health and social care commissioners, health and wellbeing boards and practitioners in specialist domestic and sexual violence services (see Who should take action?) should: • Ensure specialist advice, advocacy and support forms part of a comprehensive referral pathway (see recommendation 4).	**Domestic violence and abuse: multi-agency working [PH50] - (1.12.4)** Evidence Statement 11: Advocacy interventions for victims: There is moderate evidence from ten studies that advocacy services may improve women's access to community resources, reduce rates of IPV, improve safety, decrease depression, reduce various stressors, and improve parenting stress and children's well-being. A cluster-RCT (Taft et al., 2011 [++]) revealed a significant decrease in IPV before adjustment for propensity score for pregnant and postpartum women involved in a community-based mentorship programme. A RCT (Sullivan et al., 2002 [++]) reported improvements in mother's depression and self-esteem and children's well-being following participation in home visitation advocacy services. A before and after study (Howarth et al., 2009 [+]) evaluated the effect of Independent DV advisor services (IDVA), demonstrating improvements in women's safety and a decrease in abuse. A RCT (Bair-Merritt et al., 2010 [+]) found a decrease in IPV rates for mothers involved in a home visitation programme. A cluster RCT (Coker et al., 2012 [+]) observed a decrease in depressive symptoms and suicidal thoughts for rural women receiving advocate services, but found no difference in self-perceived	**Recommendation not used in this guideline** The committee agreed that referral pathways for advocacy services are already in place and that the more crucial issue is ensuring people are aware of and understand these. These issues are covered by recommendations about information and signposting (see evidence review C) and training for practitioners (see evidence review J).	Not applicable

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	mental health or accessing of hot-line services. A cross-sectional study (Kendall et al., 2009 [+]) reported improvements in: perceived safety and safety planning for participants provided with emergency department advocacy counselling services. A RCT (Allen et al., 2004 [+]) revealed improvements in women's access to community resources regardless of presenting need, following post-shelter advocacy services. A before and after study (Poole et al., 2008 [+]) found a decrease in various stressors (partner, housing, mental health, legal and physical health) for women using substances who were accessing shelter services. A before and after study (Price et al., 2008 [+]) found that women receiving support services reported improvements in their safety and quality of life and their children's safety, and caseworkers also reported improvements in women and children's safety. Finally, a qualitative study (Cath Gregory Consulting, 2008 [+]) revealed that a 24 hour helpline service facilitated abused women in understanding abuse and making changes to their lives, and provided links to available supports and services. Evidence Statement 27: Multi-component advocacy interventions: Four studies reviewed by Rizo et al. (2011) [+] evaluated multi-component interventions with advocacy as a primary intervention focus (Blodgett, et al., 2008; Crusto, et al., 2008; McFarlane, et al., 2005a, 2005b). One individually assessed study also evaluated a multi-component		

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	advocacy-based intervention (WhitesideMansell et al., 2009, RCT, [+]). Evidence Statement 28- Multi-component therapy and advocacy interventions: Two studies reviewed by Rizo et al. (2011) [+] evaluated multi-component interventions including therapy and advocacy components (Ernst, et al., 2008; C. M. Sullivan, et al., 2002), in addition to two individually assessed studies (Finkelstein et al., 2005, before and after [+]; Noether et al., 2007, non-RCT [+]).		
Commissioners and service providers should develop pathways that allow adults with cerebral palsy access to a local network of care that includes: - advocacy support	**Cerebral palsy in adults [NG119] - (1.1.3)** Why the committee made the recommendation: The committee also noted that access to services may be limited for adults with cerebral palsy who need practical support and advocacy. There was some evidence that lack of an advocate could disadvantage people, especially when they are admitted to hospital. In addition, some adults with cerebral palsy reported that their family members were expected to act as their carers when they were admitted to hospital. The committee agreed that it should not be assumed that family members should provide personal care in a healthcare setting and that advocacy, and health and personal care, should always be offered to people when they are admitted to hospital.	**Recommendation not used in this guideline** The committee agreed that referral pathways for advocacy services are already in place and that the more crucial issue is ensuring people are aware of and understand these. These issues are covered by recommendations about information and signposting (see evidence review C) and training for practitioners (see evidence review J).	Not applicable
All organisations involved with safeguarding adults in care homes should: - understand the role of advocacy in relation to safeguarding, and that the	**Safeguarding adults in care homes [NG189] - (1.8.11)** Why the committee made the recommendation: The committee used qualitative themes from research evidence on responding to and managing	**Adapted** This recommendation was used to inform recommendation 1.10.3 in training other practitioners.	Providers and commissioners should ensure that staff in organisations working with advocacy services

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
advocate is the only person who acts solely according to instructions from the resident • think about the resident's needs and know when to refer people for advocacy • involve an independent advocate for the resident, when this is required by the Care Act 2014 and Care Act 2014 statutory guidance or the Mental Capacity Act 2005 • ensure that anyone supporting the resident as an informal or independent advocate has been identified in line with the resident's statutory rights to advocacy under the Care Act and the Mental Capacity Act.	safeguarding concerns in care homes, and support and information needs for everyone involved in safeguarding concerns in care homes. The evidence showed that residents benefit when they are involved and kept informed throughout the safeguarding process. The evidence also emphasised the value that residents place on support from family, friends or advocates in helping them achieve their desired outcomes. However, the committee had some concerns about the quality of the data, which had some methodological limitations as well as questionable relevance (it was not always clear whether findings related specifically to care home settings). The committee therefore also used the Making Safeguarding Personal framework and the Care Act 2014. These sources highlight the importance of involving people fully as possible in decisions and giving them the information and support they need to participate. The committee recognised that there should be a clear difference and understanding of the roles of the practitioners and independent advocate involved in safeguarding. Although the practitioner might be acting in the best interest of the person, they may be operating within the constraints of their role. It is only the independent advocate who acts according to instruction from the person.	See the Benefits and harm section of The committee's discussion and interpretation of the evidence in this review for more information.	(including social workers, members of Safeguarding Adult Board members and commissioners of advocacy) have training in the role and function of advocates. This includes understanding that advocates: • help people to get the support they need from services, for example by offering to attend meetings, writing letters and email and making phone calls • support the person to make decisions, for example by providing information about available support services, making sure people understand their options and exploring the potential outcomes of the possible options • represent only the views of the person they are supporting • ensure the person's voice is heard and their

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
			rights are respected in all discussions • aim to empower the person to develop personal agency, self-advocacy and confidence • are independent of any provider service • share information they receive with the person they are supporting • challenge decisions and poor practice • know what to do about safeguarding • have a role in protecting a person's rights and promoting wellbeing • are involved in non-instructed advocacy and what this is.

CB: cognitive behavioural; DV: domestic violence; IDVA: independent domestic violence advisor; IPV: intimate partner violence; NICE: National Institute for Health and Care Excellence; OB/GYN: obstetrician/gynaecologist; RCT: randomised controlled trial

Appendix G Formal consensus

Additional information related to scope area: Improving access to advocacy

Table 10: Formal consensus round 1 statements and results for scope area: Improving access to advocacy

Statement no.	Statement	References	Percentage agreement	Action taken
1	People who want to use advocacy services report it being difficult to ask for help unless it is offered.	SERIO 2021	70.00%	Redrafted for round 2
2	Limitations of remote communication makes it harder for advocates to play their role in safeguarding people from harm and abuse.	National Development Team for Inclusion 2020a	90.00%	Carried forward to committee discussion
3	There is a reduction in referrals partially due to a lack of understanding or awareness of advocacy statutory duties.	National Development Team for Inclusion 2020a, National Development Team for Inclusion 2020b, Chatfield 2017, Mercer 2020	77.78%	Redrafted for round 2
4	There should be promotion of both face-to-face advocacy and remote advocacy.	National Development Team for	90.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
		Inclusion 2020a		
5	There needs to be clear leadership communication that the Mental Capacity act continues to apply and the Care Act and Social Services and Wellbeing Act remain fully in force	National Development Team for Inclusion 2020a	55.56%	Discarded
6	There needs to be action to make sure people's rights to advocacy are enforced (including through effective communication with professionals regarding their duty to refer).	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
7	Professional visitors, including advocates, must be able to meet with people in-person.	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
8	There should not be blanket restrictions that prevent advocates accessing where people are, including care homes and hospitals.	National Development Team for Inclusion 2020a	90.00%	Carried forward to committee discussion
9	We must consider how to use digital platforms when it is genuinely effective.	National Development Team for Inclusion 2020a	90.00%	Carried forward to committee discussion
10	The primacy of being able to deliver advocacy in person should stay protected.	National Developme	80.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
		nt Team for Inclusion 2020a		
11	Advocacy organisations need to be committed to make sure their advocacy services are accessible.	National Development Team for Inclusion 2020a	100.00%	Carried forward to committee discussion
12	There is currently a lack of non-instructed Independent Mental Health Advocacy.	NDTi 2012	75.00%	Redrafted for round 2
13	There is a failure to recognise some people with mental health issues also have learning disabilities.	NDTi 2012	55.56%	Discarded
14	Those with high or complex needs are less likely to have access to advocacy.	Harflett 2015	60.00%	Redrafted for round 2
15	Improve access to advocacy by progressing towards providing services to all eligible people.	NDTi 2016a	100.00%	Carried forward to committee discussion
16	Improve access to advocacy by increasing the amount of advocacy to people from seldom heard groups (including but not limited to people with learning disabilities, from BME communities, children and young people, older people with dementia, people who are hearing impaired, people on community treatment orders, and people places out of area).	NDTi 2016a, Newbigging 2012	100.00%	Carried forward to committee discussion
17	Further local and national analysis is required to examine the extent to which duty to refer for independent advocacy support is supposed to come into play in safeguarding situations.	Lawson 2020	100.00%	Carried forward to committee discussion
18	Lack of understanding about advocacy is likely contributing to a picture where not everyone who should, receives advocacy support in safeguarding.	Lawson 2020	90.00%	Carried forward to committee discussion
19	Advocacy providers should support social workers to make appropriate referrals by providing guidance and training.	Lawson 2020	90.00%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
20	Advocacy providers should support social workers to make appropriate referrals by responding to feedback about ease of referring.	Lawson 2020	90.00%	Carried forward to committee discussion
21	Commissioners should facilitate easy access to advocacy that is appropriate to the range of people's needs.	Lawson 2017	100.00%	Carried forward to committee discussion
22	Commissioners should consider having a single point of access to advocacy services so that individuals do not need to know what type of advocacy they require.	Lawson 2017	81.82%	Carried forward to committee discussion
23	Advocates and mental health service professionals have a role in making sure service users and staff know how to contact the IMHA service.	Newbigging 2012	100.00%	Carried forward to committee discussion
24	Advocates and mental health service professionals need to make sure that staff within the organisation have sufficient knowledge of advocacy and their statutory duties to support it and are aware of the purpose of the IMHA.	Newbigging 2012	100.00%	Carried forward to committee discussion
25	When someone no longer qualifies for IMHA services (that is, they are no longer detained under the MH Act), often when discharged, they may not have access to advocacy unless the advocacy service has a strategy for ensuring continuity of access.	Newbigging 2012	81.82%	Carried forward to committee discussion
26	There is a need for regular visitations to hospital wards by IMHA services, particularly to identify people who would be unable to instruct them and could potentially miss out on services.	Newbigging 2012	90.91%	Carried forward to committee discussion
27	There is a need to provide access to interpreters who have an understanding of potential cultural issues.	Newbigging 2012	90.91%	Carried forward to committee discussion
28	There should be opportunities for the individuals to approach the IMHA informally.	Newbigging 2012	90.91%	Carried forward to committee discussion
29	Access to advocacy should be improved by easing access to interpreters, for people for whom English is not their first language, or signers for deaf people, where services aren't provided directly by people from those communities.	Newbigging 2012	100.00%	Carried forward to committee discussion
30	Access to advocacy should be improved with a proactive approach to address inequalities of access.	Newbigging 2012	90.91%	Carried forward to committee discussion

Statement no.	Statement	References	Percentage agreement	Action taken
31	There is variation in access and uptake of IMHA services, particularly between qualifying patients in urban and rural areas.	Newbigging 2012	44.44%	Discarded
32	There is variation in access and uptake of IMHA services between those in secure services, acute inpatient care and in the community.	Newbigging 2012	77.78%	Discarded
33	Access and uptake of IMHA services is influenced by the availability of IMHA services.	Newbigging 2012	77.78%	Redrafted for round 2
34	Access to advocacy services could be improved by advocates and mental health professionals promoting advocacy.	Newbigging 2012	100.00%	Carried forward to committee discussion
35	Access and uptake of IMHA services is influenced by the receptiveness of qualifying patients to IMHA services.	Newbigging 2012	60.00%	Discarded
36	Access and uptake of IMHA services is influenced by a tangible commitment to equality of access for all.	Newbigging 2012	90.91%	Carried forward to committee discussion
37	Access to IMHA services could be improved by needs assessments (taking into account factors that could hamper access uptake).	Newbigging 2012	90.00%	Carried forward to committee discussion
38	Access to IMHA services could be improved by conducting equality analysis to identify whether and how particular groups might be disadvantaged in terms of the current design and provision of services.	Newbigging 2012	100.00%	Carried forward to committee discussion
39	Access to IMHA services could be improved by an opt-out rather than opt-in system to overcome gatekeeping.	Newbigging 2012	72.73%	Redrafted for round 2
40	Access to IMHA services could be improved by providing information in a variety of formats to promote an understanding of the role of IMHAs.	Newbigging 2012	100.00%	Carried forward to committee discussion
41	Access to IMHA services could be improved by providing access to culturally appropriate forms of IMHA.	Newbigging 2012	100.00%	Carried forward to committee discussion
42	Access to IMHA services could be improved by raising awareness of services user groups and supporting peer promotion of IMHA services.	Newbigging 2012	100.00%	Carried forward to committee discussion
43	Lack of funding is a barrier to providing support to people living with learning disabilities.	Roberts 2012	70.00%	Redrafted for round 2

Statement no.	Statement	References	Percentage agreement	Action taken
44	Attitudes towards advocacy or people living with learning disabilities is a barrier to providing support for people living with learning disabilities.	Roberts 2012	60.00%	Redrafted for round 2
45	Lack of understanding or knowledge is a barrier to providing support for people living with learning disabilities.	Roberts 2012	63.64%	Redrafted for round 2
46	Lack of staff (due to lack of resources) is a barrier to providing support for people living with learning disabilities.	Roberts 2012	70.00%	Redrafted for round 2
47	Eligibility criteria for services or contract restrictions are barriers to providing support for people living with learning disabilities.	Roberts 2012	60.00%	Redrafted for round 2
48	Lack of volunteers acts as a barrier to supporting people living with learning disabilities.	Roberts 2012	40.00%	Discarded
49	Lack of time acts as a barrier to supporting people living with learning disabilities.	Roberts 2012	63.64%	Redrafted for round 2
50	Size and location of the service area acts as a barrier to supporting people living with learning disabilities.	Roberts 2012	62.50%	Redrafted for round 2
51	The lack of appropriate advocacy for people with complex needs acts as a barrier to supporting people living with learning disabilities.	Roberts 2012	77.78%	Redrafted for round 2
52	A lack of integration of health and social care limits provision and acts as a barrier to providing advocacy to people.	Mercer 2020	100.00%	Carried forward to committee discussion
53	Establishing a statutory right for people accessing or wanting to access health funded support would lead to less episodic and more holistic advocacy being available.	Mercer 2020	62.50%	Redrafted for round 2

BME: Black and Minority Ethnic; IMHA: Independent Mental Health Advocate; MH: mental health

Table 11: Formal consensus round 2 statements and results for scope area: Improving access to advocacy (including addressing barriers)

Statement no.	Statement	References	Percentage agreement	Action taken
1	Advocacy organisations should promote advocacy services and proactively offer support to people who may want to use advocacy services but find it difficult to ask for help.	SERIO 2021	100.00%	Carried forward to committee discussion
3	Health and social care providers should ensure professionals have an understanding and awareness of advocacy statutory duties to encourage referrals to advocacy services.	National Development Team for Inclusion 2020a, National Development Team for Inclusion 2020b, Chatfield 2017, Mercer 2020	100.00%	Carried forward to committee discussion
12	Commissioners and advocacy organisations should ensure sufficient non-instructed Independent Mental Health Advocacy is available to everyone who needs it.	NDTi 2012	100.00%	Carried forward to committee discussion
14	Commissioners and advocacy organisations should ensure people with high or complex needs have access to advocacy.	Harflett 2015	100.00%	Carried forward to committee discussion
33	Standardising the amount of IMHA hours required based on the number of people detained under the Mental Health Act would help ensure an appropriate level of funding for IMHA services between local authority areas and improve availability and access.	Newbigging 2012	44.44%	Discarded

Statement no.	Statement	References	Percentage agreement	Action taken
39	IMHA services should be offered to all qualifying patients to ensure they have a choice about using the advocacy service and this should be done on a regular basis.	Newbigging 2012	90.00%	Carried forward to committee discussion
43	Lack of funding is a barrier to providing advocacy support to people living with learning disabilities.	Roberts 2012	77.78%	Carried forward to committee discussion
44	Negative attitudes about people with learning disabilities among employers is a barrier to advocates being able to effectively support people living with learning disabilities in gaining employment.	Roberts 2012	66.67%	Discarded
45	A lack of knowledge or understanding of advocacy is a barrier to providing advocacy support for people living with learning disabilities.	Roberts 2012	100.00%	Carried forward to committee discussion
46	Lack of advocacy staff (due to lack of resources) is a barrier to providing advocacy support for people living with learning disabilities.	Roberts 2012	88.89%	Carried forward to committee discussion
47	Eligibility criteria for services or contract restrictions are barriers to providing advocacy services for people with mild to moderate learning disabilities.	Roberts 2012	100.00%	Carried forward to committee discussion
49	Advocacy organisations should address barriers (such as lack of time) to providing advocacy support to people living with learning disabilities by, for example, working in different ways to give people the time they need to build up relationships and trust.	Roberts 2012	100.00%	Carried forward to committee discussion
50	Advocacy organisations should be aware that size and location of the service area acts as a barrier to providing advocacy support to people living with learning disabilities(e.g., rural areas and large geographical area being covered by one local authority_.	Roberts 2012	62.50%	Discarded
51	Commissioners should try to ensure that an appropriate mix of advocacy services, such as group advocacy, statutory advocacy and non-statutory advocacy, are made available for people living with learning disabilities.	Roberts 2012	100.00%	Carried forward to committee discussion
53	Consideration should be given to establishing a statutory right for people accessing or wanting to access health funded support (such as s117 aftercare, NHS Continuing Healthcare, Children and Young People's Continuing Care, Personal	Mercer 2020	77.78%	Discarded

Statement no.	Statement	References	Percentage agreement	Action taken
	Health Budgets and Personal Wheelchair Budgets) as this may lead to less episodic advocacy provision (that focuses on single issues and starts and stops in line with the requirements of different types of statutory advocacy) and more holistic, person-centred advocacy being available.			

IMHA: Independent Mental Health Advocate; NHS: National Health Service; s117: section 117